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Focus: *Loss and Bereavement*

GUEST EDITORIAL

Broadening Perspectives in Knowledge about Grieving

Betty Davies

In my clinical work and in my research with grieving families I have repeatedly heard stories about what happened at the time of the death of a loved one — and nearly always the story includes a reference to the nurse, whether the death of the loved one occurred in hospital or at home.

Family members may not always remember the nurse's name, but they do remember the nurse's actions. They remember how the nurse responded to their mother's wish for fresh air by figuring out how to open the window; how the nurse took the time to answer the questions of their elderly father who didn't understand why his dying wife's feet were so cold; how the nurse prayed with them until the chaplain arrived; how the nurse cried with them; how the nurse gently gave them some idea of the path ahead — what they could expect to happen next; how the nurse phoned every week "just to see how we were doing," and located a grief support group for them. Years after the death, families remember such nursing actions with fondness and gratitude.

They also remember the nurse whose actions were not so helpful. They remember the nurse who rushed from the room, "abandoning" them to their sorrow and leaving their questions unanswered; the nurse who asked them to hurry with their goodbyes so the hospital room could be readied for another patient; the nurse who attempted to console them with empty platitudes; the nurse who did not have the

time to listen to their story. Years after the death, these families, too, remember — but with resentment and anger.

We have learned much about loss and grieving over the years; what is lacking in the field, however, is systematic study of the impact of alternative approaches to supporting those who are grieving, and ways of telling when people need ongoing professional help and when they do not.

The concepts of loss and bereavement are integral to nursing. No matter what field of practice nurses choose, they will encounter individuals who are grieving — for confrontation with loss and bereavement is by no means limited to palliative care. No one can take away the pain of bereavement, but nurses can do much to facilitate optimal grieving, and they could do much more — if only they knew how.

Research into loss and bereavement provides an avenue for learning more about optimizing the difference that nurses can make. Research provides a vehicle for knowing more about the grieving process itself, the factors that influence bereavement and grieving, and nursing practices that can help, rather than hinder, the coping efforts of those in our care. This issue of the *Canadian Journal of Nursing Research* includes a variety of papers that address each of these major realms of knowledge.

Jeanne Quint Benoliel, a respected pioneer in the death and dying movement, shows us how the study of loss and bereavement has developed historically, pointing out that nurse researchers and clinicians have made significant contributions to this field of knowledge. Benoliel writes that the late 20th century has spawned a proliferation of people living with multiple losses, such as those with AIDS and their caregivers and those who suffer from violence, famine, and other forms of cruelty beyond the imagination of privileged North Americans. Kelli Stajduhar's study focuses on one of those groups, detailing the loss and bereavement experiences of family caregivers of persons with HIV/AIDS. Benoliel advises us to expand our research horizons beyond the traditional focus on individuals and families, to take in the larger human community.

Alicia Skinner Cook, on the other hand, encourages us to broaden our perspective as researchers by looking inward. She points to the necessity for us to understand the role of "self" in research. Skinner Cook discusses four sources of bias in bereavement research and offers strategies for minimizing such bias. She highlights the need for personal reflection and exploration of motives, beliefs, assumptions, and

stereotypes — including those that are products of our socialization as nurses. Helen Brown's paper is one response to Skinner Cook's challenge. Moving seamlessly back and forth between personal narrative and theory, Brown shares her own reflections and offers insights into the loss experience of mothers following the death of their newborn baby. She poignantly illustrates how one mode of inquiry, phenomenological reflection, can serve as a path to self-understanding.

In their comprehensive review of literature on predictors of bereavement outcomes following the cancer death of a family member, Priscilla Koop and Vicki Strang indicate that care offered during the terminal phase of illness has a great effect on those who are left behind. Stajduhar's findings also show that professional caregivers, particularly nurses, have a significant impact on the bereavement outcome of family caregivers. Both of these studies report on the value of support to grieving individuals.

Shirley Murphy, using randomized clinical trial methodology, also documents the value of social support in bereavement outcome. Her findings derive from an analysis of outcome measures in parents whose children, aged 12–28, met sudden, violent death and who participated in a structured intervention program for the bereaved. Murphy's work provides a rare example of the kinds of investigation that are now needed if we are to broaden our perspective on helping. The findings of her examination show that bereavement outcome is influenced by several factors, such as gender differences — which are also highlighted in Koop and Strang's literature review.

Finally, Ruth Grant Kalischuk's review of Thomas Attig's *How We Grieve: Relearning the World* points out that Attig, too, broadens our perspective, by making an important distinction between grief and the grieving process and thereby challenging long-held assumptions about the nature of grief.

Together, these papers form a worthy contribution to the study of loss and bereavement and provide direction for us in better understanding and informing nursing practice. It is my hope that these papers will serve to broaden the perspectives of both researchers in the field and clinicians who care for those who suffer loss.

Several years have passed since Dr. Laurie Gottlieb, Editor-in-Chief, first invited me to be the guest editor for an issue of the *Canadian Journal of Nursing Research* devoted to loss and bereavement, and I am very pleased that the project has finally come to fruition. I am grateful to Laurie for giving me this opportunity and for the high calibre of direc-

tion in the editorial process she has provided me. I wish to thank the contributing authors for their submissions and their responses, as well as those authors whose manuscripts could not be included because of space limitations. Fortunately, some of those manuscripts will be published in subsequent issues of the journal. I also extend my appreciation to the reviewers, whose insightful comments and constructive criticisms reflected diligent attention to each manuscript. During the time it took to complete this issue, three Managing Editors guided the process (I hope it had nothing to do with this particular issue!). To each of them (Jill Martis, Joanna Toti, and Anne Renaud) I offer my thanks for their support and excellent organizational skills in facilitating the editorial process.

Betty Davies, R.N., Ph.D., is Professor and Graduate (Doctoral) Program Advisor, School of Nursing, University of British Columbia, Vancouver, and holds an Investigator Award with the British Columbia Institute for Child and Family Health.

Point de vue : perte et deuil

COLLABORATION SPÉCIALE

Élargir les perspectives sur la connaissance du deuil

Betty Davies

Dans ma pratique clinique et ma recherche avec les familles en deuil, j'ai entendu à maintes reprises des histoires à propos de ce qui s'est passé lors du décès d'un être cher, et celles-ci font pratiquement toujours référence à l'infirmière, peu importe si le décès a eu lieu à l'hôpital ou à la maison.

Les membres d'une famille en deuil ne se rappellent peut-être pas toujours le nom de l'infirmière, mais ils se souviennent de ses actes. Ils se rappellent la façon dont l'infirmière a répondu au désir de leur mère d'avoir de l'air frais en trouvant le moyen d'ouvrir la fenêtre; comment l'infirmière a pris le temps de répondre aux questions de leur père âgé qui ne comprenait pas pourquoi les pieds de sa conjointe mourante étaient si froids; comment l'infirmière a prié avec eux jusqu'à l'arrivée de l'aumônier; comment l'infirmière a pleuré avec eux; comment l'infirmière a fait preuve de délicatesse en leur donnant une idée des événements à venir, de ce à quoi ils devaient s'attendre; comment l'infirmière téléphonait toutes les semaines, « simplement pour voir comment ils allaient »; et comment elle leur a trouvé un groupe de soutien. Plusieurs années après le décès de l'être cher, les familles se souviennent avec gratitude et affection de tels gestes.

Les familles se souviennent également de l'infirmière dont les actes n'étaient pas d'un aussi grand secours. Ils se rappellent l'infirmière qui les a fait sortir précipitamment de la chambre, les « abandonnant » à leur chagrin et laissant leurs questions sans réponses; l'infirmière qui leur demandé d'accélérer leurs adieux afin que la chambre d'hôpital

puisse être préparée pour recevoir un autre patient ; l'infirmière qui tentait de les consoler avec des platitudes ; l'infirmière qui n'avait pas le temps d'écouter leur histoire. Plusieurs années après le décès de leur proche, ces familles aussi se souviennent, mais avec colère et ressentiment.

Nous avons appris beaucoup de choses à propos de la perte et du deuil au cours des années. Toutefois, ce qui manque encore dans ce domaine, c'est l'étude systématique de l'impact des approches parallèles pour soutenir les personnes en deuil et des façons d'identifier les gens qui nécessitent un suivi professionnel.

Les concepts de perte et de deuil sont une partie intégrante des soins infirmiers. Peu importe le champ de pratique choisi par les infirmières, celles-ci vont croiser des individus en deuil puisque la confrontation avec la perte et le deuil n'est nullement exclusive aux soins palliatifs. Personne n'est en mesure d'éliminer la douleur du deuil, mais les infirmières peuvent faire beaucoup pour faciliter sa résolution optimale, et elles pourraient en faire encore plus si seulement elles savaient comment procéder.

La recherche sur la perte et le deuil permet d'enrichir nos connaissances à propos des moyens à mettre en oeuvre, afin d'optimiser la différence que peuvent faire les infirmières. La recherche fournit un véhicule pour en apprendre davantage au sujet du processus de deuil lui-même, des facteurs qui l'influencent et des pratiques infirmières susceptibles d'aider, plutôt qu'entraver, les efforts d'adaptation de ceux et celles dont nous prenons soin. Les différents articles publiés dans ce numéro de la Revue canadienne de recherche en sciences infirmières abordent chacun de ces domaines de connaissance majeurs.

Jeanne Quint Benoliel, une pionnière estimée des études sur la mort, nous décrit comment l'étude de la perte et du deuil s'est développée au cours de l'histoire, en attirant notre attention sur les contributions significatives des chercheuses et chercheurs, ainsi que des praticiennes et praticiens en soins infirmiers, à ce champ de connaissance. Benoliel souligne que la fin du vingtième siècle a vu proliférer le nombre de personnes souffrant de multiples pertes, telles les personnes atteintes du VIH-sida et ceux et celles leur prodiguant des soins, ainsi que les victimes de violence, de famine et d'autres formes de cruauté inimaginables pour les Nord-Américains privilégiés. C'est justement à un de ces groupes que s'attarde Kelli Stajduhar dans son étude détaillée des expériences de perte et de deuil chez les personnes prodiguant des soins à un proche atteint du VIH-sida. Benoliel, elle, nous recommande d'élargir nos horizons de recherche au delà du point de vue

traditionnel sur les individus et les familles pour y inclure la communauté humaine dans son ensemble.

À l'inverse, Alicia Skinner Cook nous encourage à enrichir notre point de vue comme chercheuses et chercheurs à travers l'introspection. Elle insiste sur la nécessité pour nous de comprendre le rôle du « moi » dans la recherche. Skinner Cook examine quatre sources de préjugés dans la recherche sur le deuil et propose des stratégies pour les minimiser. Elle met en relief l'importance de l'introspection et de l'exploration des motivations, des croyances, des *a priori* et des stéréotypes, y compris ceux qui sont le produit de notre socialisation en tant qu'infirmières. Une des réponses possibles au défi proposé par Skinner Cook nous est offerte dans l'article d'Helen Brown, qui évolue constamment entre le récit personnel et la théorie pour nous faire part de ses réflexions personnelles et nous introduire à l'expérience de perte vécue par les mères suite au décès de leur nouveau-né. Elle illustre de manière poignante, comment un mode de questionnement tel que la réflexion phénoménologique peut servir d'avenue à la compréhension de soi.

Dans leur revue détaillée de la littérature consacrée aux prédicteurs des conséquences du deuil chez les familles de personnes décédées du cancer, Priscilla Koop et Vicki Strang révèlent que les soins prodigués durant la phase terminale de la maladie ont beaucoup d'influence sur ceux qui restent. Les conclusions de Stajduhar montrent également que le personnel soignant professionnel, en particulier les infirmières et les infirmiers, exerce un impact significatif sur les résultats du deuil de personnes ayant pris soin d'un proche. Les deux études soulignent l'importance d'offrir un soutien aux individus en deuil.

Shirley Murphy documente, elle aussi, l'influence du soutien social sur l'issue du deuil en ayant recours à la méthodologie de l'essai clinique aléatoire. Les conclusions de son étude sont tirées d'une analyse des résultats d'un programme d'intervention structuré pour les personnes endeuillées auquel ont participé des parents ayant vécu la mort soudaine et violente d'un enfant âgé de 12 à 28 ans. Le travail de Murphy est un des rares exemples du type d'investigations qui sont présentement nécessaires à l'élargissement de notre perspective sur l'aide offerte aux personnes en deuil. Les résultats de son étude indiquent que le deuil est influencé par plusieurs facteurs tels que la différence de comportements entre les sexes, qui est également mise en lumière dans la revue de littérature de Koop et Strang.

Finalement, le compte rendu de Ruth Grant Kalischuk, dans l'ouvrage de Thomas Attig, *How We Grieve : Relearning the World*, montre que cet auteur contribue aussi à enrichir notre perspective en faisant

une distinction importante entre le deuil lui-même et son processus, remettant ainsi en question des *a priori* de longue date à propos de la nature du deuil.

Ensemble, ces articles représentent une contribution importante à l'étude de la perte et du deuil et nous fournissent une orientation pour mieux comprendre et informer la pratique infirmière. Je souhaite qu'ils serviront à élargir les horizons à la fois des chercheuses et des chercheurs dans le domaine et des praticiennes et praticiens qui prennent soin de ceux et celles qui subissent une perte.

De nombreuses années se sont écoulées depuis que Dre Laurie Gottlieb, la rédactrice en chef de la Revue canadienne de recherche en sciences infirmières, m'a invitée à diriger un numéro de la revue consacré à la perte et au deuil, et je suis très heureuse que le projet se réalise enfin. Je suis aussi reconnaissante envers Laurie de m'avoir offert une telle occasion, tout en me fournissant un encadrement de haut calibre au cours du processus éditorial. Je tiens à remercier les auteur(e)s participant au numéro pour avoir répondu à mon invitation en soumettant un article, ainsi que les auteur(e)s dont le manuscrit n'a pu être publié en raison de contraintes d'espace. Heureusement, certains de ces manuscrits seront publiés dans des numéros ultérieurs de la revue. Je voudrais également exprimer ma gratitude à l'égard des évaluatrices et des évaluateurs dont les commentaires éclairants et les critiques constructives reflétaient l'attention qu'ils et elles ont accordée à chaque manuscrit. Au cours de la réalisation du projet, trois rédactrices adjointes ont guidé le processus. (J'espère que cela n'avait rien à voir avec ce numéro en particulier!) J'offre mes remerciements à chacune d'elles (Jill Martis, Joana Toti et Anne Renaud) pour leur appui et leurs excellentes compétences organisationnelles, lesquelles ont facilité le processus éditorial.

Betty Davies, i.a., Ph. D., est professeure et directrice d'études de troisième cycle au School of Nursing, de la University of British Columbia, à Vancouver, et a reçu un Prix d'excellence en recherche du British Columbia Institute for Child and Family Health.

Discourse

Loss and Bereavement: Perspectives, Theories, Challenges

Jeanne Quint Benoliel

Loss is a common experience in human existence. Major loss stimulates both personal and social responses, often of high intensity, as was observed throughout the world after the tragic accidental death of Princess Diana in 1997. Knowledge of loss and grief has been reflected in poetry, paintings, novels, myths, and plays across the centuries of recorded history. Understanding the complex influence of loss on human adaptations and collective responses has come about in the 20th century through scientific approaches to the creation of knowledge.

Historical Overview

Origins of Studies on Loss

The first systematic study on loss is credited to the psychoanalyst Freud (1957), who proposed that grief is a process in which loss is resolved through hypercathexis followed by gradual decathexis related to internalized bonds of attachment. Eliot identified the need for studies on family grief (1930) as well as for a social psychology of bereavement (1933). Lindemann's (1944) psychiatric study of acute-grief responses of survivors of a deadly nightclub fire served as a stimulus for the development of research and theory by investigators in many fields.

Research on loss and bereavement was closely associated with the emergence of the "death" movement in the 1950s and 1960s. Perspectives on mourning as a process of adaptation were found in the writings of Irion (1954) and Jackson (1957) in the field of pastoral psychology. Marris (1958) described the bereavement responses of women

Jeanne Quint Benoliel, D.N.Sc., F.A.A.N., is Professor Emeritus of Psychosocial and Community Health, School of Nursing, University of Washington, Seattle.

to the death of their spouse, and Parkes (1964) outlined the effects of bereavement on widows' mental and physical health. On the subject of catastrophic loss, Lifton (1963) wrote of the numbing effects of mass atomic death on the survivors of Hiroshima. Interest in the study of death led to systematic research in many disciplines, the emergence of interdisciplinary journals and organizations, and the development of death education for both lay persons and professionals (Pine, 1977).

Viewpoints and Theories

Observation of the loss experiences of children led to clinical studies and, in turn, theories to explain the contribution of loss to human development. Proponents of psychoanalytic theory focused on reactions to loss and separation as tied to psychic conflicts in childhood (Peretz, 1970). Proponents of attachment theory (Bowlby, 1973, 1980) perceived grief as an adaptive response that takes account of present as well as past meanings of loss, and environmental as well as intrapsychic influences. Both perspectives provided the bases for subsequent studies on loss and bereavement in children and adolescents.

Knowledge of bereavement in adult life was stimulated by Parkes's (1972) studies, which included identification of predictor variables for estimating bereavement outcomes after the loss of a spouse (Parkes & Weiss, 1983). In a comprehensive review of research on loss, grief, and bereavement, Raphael (1983) found that the phenomena had been studied from many theoretical perspectives. She reported that studies focused on growing old, surviving disaster, and caregiving, in addition to death losses experienced by children, adolescents, and adults.

The proliferation of studies on loss and death in many fields brought new terminology to describe and explain the observations. Adding to the language of loss were concepts of anticipatory grief (Schoenberg, Carr, Kutscher, Peretz, & Goldberg, 1974), grief work (Worden, 1982), cultural variations in bereavement (Rosenblatt, Walsh, & Jackson, 1976), complicated mourning (Rando, 1992-93), disenfranchised grief (Doka, 1989), and transcendence of loss (Weenolsen, 1988). Research served to broaden our understanding of bereavement to include special meanings of parental grief (Klass, 1988), sibling bereavement in adolescents (Balk, 1990, 1996; Davies, 1991), and the effects of parental death on child adjustment (Worden & Silverman, 1996). By the 1990s, differences in viewpoint on the processes and outcomes of bereavement were stimulating debate in the literature on myths and misconceptions associated with loss and grief (Stroebe, van den Bout, & Schut, 1994; Wortman & Silver, 1989).

Programs and Interventions

A basic component of the hospice, begun in the 1960s to provide humane care to the dying, was bereavement services for survivors (Corr & Corr, 1983; Stoddard, 1978). The clinical needs of people struggling with various losses contributed to the development of grief counselling and grief therapy (Worden, 1982).

Crisis-intervention programs and teams had origins in Caplan's (1964) thinking on preventive psychiatry. Suicide-prevention programs were established in many communities, and crisis teams were assembled to manage disaster situations. Mutual-help groups sprang up in response to growing needs for assistance with bereavement. Among these were the Widow-to-Widow program initiated by Silverman (1980, 1986) and Compassionate Friends, an organization for bereaved parents (Klass, 1988). In the 1990s, guidelines were developed to help schools to set up bereavement services for students and staff (Stephenson, 1994).

Literature on how to assist bereaved persons and groups has grown extensively over the past two decades. This literature includes guidelines for clinical caregivers (Rando, 1984), proposals for helping children (Wass & Corr, 1984), strategies for assisting adolescents (Corr & Balk, 1996), and proposals to guide work with specific populations such as persons with AIDS and their survivors (Nord, 1996) and the bereaved elderly (Caserta & Lund, 1992).

Loss from a Nursing Perspective

Perspectives and Programs

Nursing literature is rich in anecdotal accounts of loss and bereavement, which are often accompanied by proposals for clinical interventions. Research on terminal illness contributed to perspectives on personal loss, group loss, multiple loss (Benoliel, 1971, 1985a), professional loss associated with clinical practice (Benoliel, 1974), and guidelines for nursing practice (Benoliel, 1985b).

Bereavement research added perspectives on parental health and adaptation to the loss of a child (Miles, 1985; Williams & Nikolaisen, 1982), sources of guilt in parental bereavement (Johnson-Soderberg, 1981; Miles & Demi, 1983–84), family influences on sibling bereavement (Davies, 1988, 1991), and the salience of ongoing attachment in adolescent sibling bereavement (Hogan & Balk, 1990; Hogan & DeSantis, 1992). From research on widowhood came insights on grief resolution (Saunders, 1981), adjustment processes (Demi, 1984a), and health and

coping among elderly widows (Gass, 1987; Heath, 1990). Studies in the 1990s have added perspectives on the search for meaning in loss (Steeves, 1996), grief among older women whose husbands died in hospice care (Jacob, 1996), loss associated with family caregiving in AIDS (Brown & Powell-Cope, 1995), and bereavement tasks of families (Steeves & Kahn, 1994).

Guided by clinical interests, nurses have helped to initiate assistance programs for various populations of bereaved persons. These programs include hospice services for children (Davies & Eng, 1995), a community-based bereavement network (Kirschling & Osmont, 1992–93), bereavement interventions in hospital emergency departments (Coolican & Pearce, 1995; Mian, 1990), and family bereavement services in pediatric oncology (Johnson, Rincon, Gober, & Rexin, 1993; Ruden, 1996). Nurses have also participated in the evaluation of support programs for parents (Heiney, Ruffin, & Goon-Johnson, 1995) and hospice bereavement services (Longman, 1993).

Models and Theories

The search for outcome predictors was pioneered by Vachon and colleagues in their studies of conjugal bereavement (Vachon, Rogers, et al., 1982). More recently, Kristjanson and colleagues sought predictors of family functioning subsequent to the palliative-care experience (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Tests of theory-based interventions were conducted by Vachon, Lyall, Rogers, Freedman-Letofsky, and Freeman (1980), who studied the effects of social support on adaptation among widows, and by Murphy and colleagues, who developed and tested a preventive intervention for bereaved parents after vehicle-related deaths of adolescent/adult children (Murphy, 1996; Murphy, Aroian, & Baugher 1989; Murphy, Baugher, et al., 1996).

Bereavement models in the 1980s were multidimensional and process-oriented (Demi, 1984b; Dimond, 1981; Murphy, 1983). Research evidence provided the base for models of parental bereavement guilt (Miles & Demi, 1983–84), caring in early pregnancy loss (Swanson-Kauffman, 1986), recovery from disaster loss (Murphy, 1989), a theory on adolescent sibling bereavement (Hogan & DeSantis, 1996), and an experiential theory of bereavement that encompassed the concept of personal growth (Hogan, Morse, & Tason, 1996). Developed to guide practice as well as research, this body of intellectual work by nurses reflects a range of clinical situations of which loss and bereavement are salient components.

Current and Future Challenges

As acceptance of loss and bereavement as serious human problems increased, so too did the numbers of people facing serious losses — many without the support of traditional family and kinship systems. The rapid pace of social and technological change has fostered environments in which human beings are vulnerable to the lethal effects of nuclear technology, virulent microorganisms, illegal drug use, and public and private violence (Benoliel, 1997). Around the world people are living with loss brought about by such human pursuits as warfare, terrorism, racism, genocide, and environmental contamination — which Leviton (1991) refers to as “horrendous death.”

The changed world of the late 20th century has brought with it a proliferation of groups living with multiple losses. These groups include refugees, the frail elderly, people with AIDS and their survivors, and persons disabled by injury and chronic mental and physical illness. This latter group is expected to grow in the next century. By World Health Organization projections, the leading causes of disease burden for the year 2020 are ischemic heart disease, unipolar major depression, and road accidents (Murray & Lopez, 1996).

In developed countries, bereavement services were slow to develop because they did not fit well with the organizing framework of disease and treatment. Funding for hospice and palliative care did not come easily, and the implementation of many of these services relied heavily on volunteers. Bereavement care has had low priority in the ranking of health-care needs and has relied on the good will of sensitive providers and the availability of resources from privately funded organizations. Private groups like the Red Cross have fulfilled basic needs and provided crisis services in situations of catastrophic loss affecting masses of people. Such crises, however, require help beyond that which can be provided by established agencies.

Nurses have been major players in confronting the challenges of loss and bereavement over the past 50 years. Meeting the new challenges of the 21st century will require them to move beyond the traditional ways of thinking about loss and grief — that is, as individual and family matters. Development of national and international programs geared to the human needs of large numbers of people will require new perspectives on caregiving and new forms of leadership in interdisciplinary efforts to help bereaved persons in all parts of the world.

References

- Balk, D.E. (1990). The self-concept of bereaved adolescents: Sibling death and its aftermath. *Journal of Adolescent Research*, 5, 112–132.
- Balk, D.E. (1996). Models for understanding adolescent coping with bereavement. *Death Studies*, 20, 367–387.
- Benoliel, J.Q. (1971). Assessments of loss and grief. *Journal of Thanatology*, 1, 182–194.
- Benoliel, J.Q. (1974). Anticipatory grief in physicians and nurses. In B. Schoenberg, A.C. Carr, A.H. Kutscher, D. Peretz, & I.K. Goldberg (Eds.), *Anticipatory grief* (pp. 218–228). New York: Columbia University Press.
- Benoliel, J.Q. (1985a). Loss and adaptation: Circumstances, contingencies, and consequences. *Death Studies*, 9, 217–233.
- Benoliel, J.Q. (1985b). Loss and terminal illness. *Nursing Clinics of North America*, 20, 439–448.
- Benoliel, J.Q. (1997). Death, technology, and gender in postmodern American society. In S. Strack (Ed.), *Death and the quest for meaning* (pp. 31–56). Northvale, NJ: Jason Aronson.
- Bowlby, J. (1973). *Separation*. New York: Basic.
- Bowlby, J. (1980). *Loss*. New York: Basic.
- Brown, M.A., & Powell-Cope, G. (1995). Themes of loss and dying in caring for a family member with AIDS. *Research in Nursing and Health*, 16, 179–191.
- Caplan, G. (1964). *Principles of preventive psychiatry*. New York: Basic.
- Caserta, M.S., & Lund, D.A. (1992). Bereavement stress and coping among old people: Expectations versus the actual experience. *Omega*, 25, 33–45.
- Coolican, M.B., & Pearce, T. (1995). After care bereavement program. *Critical Care Nursing Clinics of North America*, 7, 519–527.
- Corr, C., & Corr, D. (Eds.). (1983). *Hospice care principles and practice*. New York: Springer.
- Corr, C.A., & Balk, D.E. (Eds.). (1996). *Handbook of adolescent death and bereavement*. New York: Springer.
- Davies, B. (1988). The family environment in bereaved families and its relationship to surviving sibling behavior. *Children's Health Care*, 17, 22–31.
- Davies, B. (1991). Long-term outcomes of adolescent sibling bereavement. *Journal of Adolescent Research*, 6, 83–96.
- Davies, B., & Eng, B. (1995). Challenges in developing a children's hospice. In D.W. Adams & E.J. Deveau (Eds.), *Beyond the innocence of childhood: Helping children and adolescents cope with life-threatening illness and dying* (pp. 317–333). Amityville, NY: Baywood.
- Demi, A.S. (1984a). Social adjustment of widows after a sudden death: Suicide and nonsuicide survivors. *Death Education*, 8(Suppl.), 91–111.

- Demi, A.S. (1984b). Hospice bereavement programs: Trends and issues. In S.H. Schraff (Ed.), *Hospice: The nursing perspective* (pp. 131–151). New York: National League for Nursing.
- Dimond, M. (1981). Bereavement and the elderly: A critical review with implications for nursing practice and research. *Journal of Advanced Nursing*, 6, 461–470.
- Doka, K. (Ed.). (1989). *Disenfranchised grief: Recognizing hidden sorrows*. Lexington, MA: Lexington Books.
- Eliot, T.D. (1930). The adjustive behavior of bereaved families: A new field for social research. *Social Forces*, 8, 543–549.
- Eliot, T.D. (1933). A step toward the social psychology of bereavement. *Journal of Abnormal and Social Psychology*, 27, 380–390.
- Freud, S. (1957). Mourning and melancholia. In J. Strachey (Ed. and Trans.), *The standard edition of the complete works of Sigmund Freud* (Vol. 14) (pp. 243–258). London: Hogarth (original work published in 1917).
- Gass, K.A. (1987). The health of conjugally bereaved older widows: The roles of appraisal, coping and resources. *Research in Nursing and Health*, 10, 139–147.
- Heath, K. (1990). Relationship of hope, coping styles, concurrent losses, and setting to grief resolution in the elderly widow(er). *Research in Nursing and Health*, 13, 109–117.
- Heiney, S.P., Ruffin, T., & Goon-Johnson, K. (1995). The effects of a support group on selected psychosocial outcomes of bereaved parents whose child died from cancer. *Journal of Pediatric Oncology Nursing*, 12(2), 51–58.
- Hogan, N., & DeSantis, L. (1996). Basic constructs of a theory of adolescent sibling bereavement. In D. Klass, P.R. Silverman, & S.L. Nickman (Eds.), *Continuing bonds: New understandings of grief* (pp. 235–254). Washington: Taylor & Francis.
- Hogan, N., Morse, J.M., & Tason, M.C. (1996). Toward an experiential theory of bereavement. *Omega*, 33, 45–65.
- Hogan, N.S., & Balk, D.E. (1990). Adolescent reactions to sibling death: Perceptions of mothers, fathers, and teenagers. *Nursing Research*, 39, 103–106.
- Hogan, N.S., & DeSantis, L. (1992). Adolescent sibling bereavement: An ongoing attachment. *Qualitative Health Research*, 2, 159–177.
- Irion, P.E. (1954). *The funeral and the mourners*. Nashville: Abingdon Press.
- Jackson, E.N. (1957). *Understanding grief*. Nashville: Abingdon Press.
- Jacob, S.R. (1996). The grief experience of older women whose husbands had hospice care. *Journal of Advanced Nursing*, 24, 280–286.
- Johnson, L.C., Rincon, B., Gober, C., & Rexin, D. (1993). The development of a comprehensive bereavement program to assist families experiencing pediatric loss. *Journal of Pediatric Nursing*, 8(3), 142–146.
- Johnson-Soderberg, S. (1981). Grief themes. *Advances in Nursing Science*, 3(4), 15–26.

- Kirschling, J.M., & Osmont, K. (1992-93). Bereavement network: A community-based group. *Omega*, 26, 119-127.
- Klass, D. (1988). *Parental grief: Solace and resolution*. New York: Springer.
- Kristjanson, L.J., Sloan, J.A., Dudgeon, D., & Adaskin, E. (1996). Family members' perceptions of palliative cancer care: Predictors of family functioning and family members' health. *Journal of Palliative Care*, 12(4), 10-20.
- Leviton, D. (1991). *Horrendous death: Health and well-being*. New York: Hemisphere.
- Lifton, R.J. (1963). Psychological effects of the atomic bomb in Hiroshima. *Daedalus*, 92, 462-497.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Longman, A.J. (1993). Effectiveness of a hospice community bereavement program. *Omega*, 27, 165-175.
- Marris, P. (1958). *Widows and their families*. London: Routledge.
- Mian, P. (1990). Sudden bereavement: Nursing interventions in the E.D. *Critical Care Nurse*, 10, 30-41.
- Miles, M.S. (1985). Emotional symptoms and physical health in bereaved parents. *Nursing Research*, 34, 76-81.
- Miles, M.S., & Demi, A.S. (1983-84). Sources of guilt in bereaved parents: Toward the development of a theory of bereavement guilt. *Omega*, 14, 299-314.
- Murphy, S.A. (1983). Theoretical perspectives on bereavement. In P.L. Chinn (Ed.), *Nursing theory development* (pp. 191-206). Rockville, MD: Aspen.
- Murphy, S.A. (1989). An exploratory model of recovery from disaster loss. *Research in Nursing and Health*, 12, 67-76.
- Murphy, S.A. (1996). Parent bereavement stress and preventive intervention following the violent deaths of adolescent or young adult children. *Death Studies*, 20, 441-452.
- Murphy, S.A., Aroian, K.J., & Baugher, R. (1989). The development of a theory-based preventive intervention for bereaved parents following the vehicle-related deaths of their adolescent or young adult children. *Journal of Traumatic Stress*, 2, 321-336.
- Murphy, S.A., Baugher, R., Lohan, J., Scheideman, J., Heerwagen, J., Johnson, L.C., Tillery, L., & Grover, M.C. (1996). Parents' evaluation of a preventive intervention following the sudden violent deaths of their children. *Death Studies*, 20, 453-468.
- Murray, C.J.L., & Lopez, D. (1996). *Summary: The global burden of disease*. Cambridge, MA: Harvard University Press on behalf of WHO and the World Bank.
- Nord, D. (1996). Issues and implications in the counseling of survivors of multiple AIDS-related loss. *Death Studies*, 20, 389-413.
- Parkes, C.M. (1964). The effects of bereavement on physical and mental health: A study of the case records of widows. *British Medical Journal*, 2, 274-279.

- Parkes, C.M. (1972). *Bereavement: Studies of grief in adult life*. New York: International Universities Press.
- Parkes, C.M., & Weiss, R. (1983). *Recovery from bereavement*. New York: Basic.
- Peretz, D. (1970). Development, object-relationships, and loss. In B. Schoenberg, A.C. Carr, D. Peretz, & A.H. Kutscher (Eds.), *Loss and grief: Psychological management in medical practice* (pp. 3-19). New York: Columbia University Press.
- Pine, V.R. (1977). A socio-historical portrait of death education. *Death Education*, 1, 57-84.
- Rando, T.A. (1984). *Grief, dying and death: Clinical interventions for caregivers*. Champaign, IL: Research Press.
- Rando, T.A. (1992-93). The increasing incidence of complicated grief. *Omega*, 26, 43-59.
- Raphael, B. (1983). *Anatomy of bereavement*. New York: Basic.
- Rosenblatt, P.C., Walsh, P.C., & Jackson, D. (1976). *Grief and mourning in cross cultural perspective*. New Haven, CT: Human Relations Area Files Press.
- Ruden, B.M. (1996). Bereavement followup: An opportunity to extend nursing care. *Journal of Pediatric Oncology*, 13, 219-225.
- Saunders, J.M. (1981). A process of bereavement resolution: Uncoupled identity. *Western Journal of Nursing Research*, 3, 319-322.
- Schoenberg, B., Carr, A.C., Kutscher, A.H., Peretz, D., & Goldberg, I.K. (Eds.). (1974). *Anticipatory grief*. New York: Columbia University Press.
- Silverman, P.R. (1980). *Mutual help: Organization and development*. Beverly Hills, CA: Sage.
- Silverman, P.R. (1986). *Widow to widow*. New York: Springer.
- Steeves, R.H. (1996). Loss, grief, and the search for meaning. *Oncology Nursing Forum*, 23, 897-903.
- Steeves, R.H., & Kahn, D.L. (1994). Family perspectives: Tasks of bereavement. *Quality of Life — A Nursing Challenge*, 3(3), 48-53.
- Stephenson, R.G. (1994). *What will we do? Preparing a school community to cope with crises*. Amityville, NY: Baywood.
- Stoddard, S. (1978). *The hospice movement*. New York: Random House.
- Stroebe, M., van den Bout, J., & Schut, H. (1994). Myths and misconceptions about bereavement: The opening of a debate. *Omega*, 29, 187-203.
- Swanson-Kauffman, K.M. (1986). Caring in the instance of unexpected early pregnancy loss. *Topics in Clinical Nursing*, 8(2), 37-46.
- Vachon, M.L.S., Lyall, W.A.L., Rogers, J., Freedman-Letofsky, K., & Freeman, S.J.J. (1980). A controlled study of self-help interventions for widows. *American Journal of Psychiatry*, 137, 1380-1384.
- Vachon, M.L.S., Rogers, J., Lyall, W.A., Lancee, W.J., Sheldon, A.R., & Freeman, S.J.J. (1982). Predictors and correlates of adaptation to conjugal bereavement. *American Journal of Psychiatry*, 139, 998-1002.

- Wass, H., & Corr, C. (Eds.). (1984). *Helping children cope with death* (2nd ed.). Washington: Hemisphere.
- Weenolsen, P. (1988). *Transcendence of loss over the life span*. New York: Hemisphere.
- Williams, R.A., & Nikolaisen, S.M. (1982). Sudden Infant Death Syndrome: Parents' perceptions and responses to the death of their infant. *Research in Nursing and Health*, 5, 55-61.
- Worden, J.W. (1982). *Grief counseling and grief therapy*. New York: Springer.
- Worden, J.W., & Silverman, P.R. (1996). Parental death and the adjustment of school-age children. *Omega*, 33, 91-102.
- Wortman, C.B., & Silver, R.C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57, 349-357.

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Tanner's Story: A Phenomenologic Stance towards Newborn Death

Helen J. Brown

Un point de vue phénoménologique sera exploré ici comme perspective de développement d'une connaissance personnelle de la pratique des soins infirmiers offerts aux familles vivant la perte d'un nouveau-né. L'expérience de l'auteure vis-à-vis de la mort du nouveau-né est analysée à l'aide des thèmes existentiels de van Manen. La validation de la maternité est le thème essentiel qui émerge d'une analyse fondée sur les thèmes existentiels du monde vécu de van Manen. La pensée phénoménologique est présentée comme une voie vers la compréhension de soi et la réflexion pouvant informer la connaissance personnelle de la pratique des soins infirmiers et les relations que nous entretenons avec les familles.

A phenomenologic stance is explored as a perspective from which to develop personal knowledge for nursing with families experiencing perinatal loss. The author's experience of newborn death is analyzed using van Manen's existential themes. An essential theme — validating motherhood — emerges from an analysis based on van Manen's lifeworld existential themes. Phenomenologic reflection is presented as a path to self-understanding and reflection, which may inform personal knowledge for nursing practice and the relationships nurses nurture with families.

It was a long, quiet journey home with my sister. My numbness momentarily gave way to the shock and reality that I was going home without my newborn son. As this day ended I knew that it would be permanently composed in my memory along with a number of other powerful experiences. Of these experiences some were positive, such as giving birth to my beautiful boy, and some were devastating, such as when I generated the courage to say goodbye as Tanner took his last breath snuggled between my husband and me, in our ever so brief "family bed."

It is a challenge to see into another person's life with real clarity and understanding, yet in nursing we accompany people through their health and healing experiences and seek to understand and create knowledge related to the meaning of those experiences. As professionals grounded in humanistic philosophy (Parse, 1987; Paterson & Zderad, 1988; Watson, 1985), nurses care for people who have suffered

Helen J. Brown is a faculty member specializing in perinatal, pediatric, and neonatal nursing, British Columbia Institute of Technology, Burnaby, British Columbia.

perinatal loss, an experience that is unique to childbearing women and their families. A true understanding of perinatal loss supports what Lauterbach and Becker (1996) describe as the ultimate aim of nursing, to be "a human caring art and science to assist persons and society in becoming more fully human" (p. 57). The search for meaning in newborn death is inseparable from the experiences of life and death that are woven seamlessly into our lives.

Purpose

There has been considerable discourse, in the development of nursing knowledge, on appropriate ways of knowing (Gortner, 1990; Schultz & Meleis, 1988; White, 1995). A postpositivistic philosophy of knowledge development in nursing supports interpretive understandings of personal experience and introspective analyses of subjective realities. In this context, both self-understanding and reflection have the potential to inform nursing knowledge and the relationships with families that the profession nurtures.

The purpose of this paper is to provide a way of thinking about the contribution of personal knowledge to nursing practice, one that emerges from an existential analysis of the newborn-death experience. I will propose that reflection and self-understanding from a phenomenologic stance can provide insights and understandings for nurses caring for families experiencing perinatal loss. My personal experience of newborn death is the lens through which I will interpret van Manen's (1990) existential themes.

Perspective: A Phenomenologic Stance

The primary thesis of this paper is that a phenomenologic stance, as a particular perspective from which to explore the meaning of loss, can inform personal knowledge for nursing practice through self-understanding and reflection on lived experiences. A phenomenologic way of being, or a process of phenomenologic reflection, has the potential to sensitize nurses to the relationship between personhood, self-understanding, personal experience — as a way of knowing, or knowledge in experience — and nursing practice. In particular, a phenomenologic stance combined with narrative as the primary scheme by which human existence is rendered meaningful (Polkinghorne, 1988) can be a lens through which to view the development of nursing knowledge.

As a method of human science research, phenomenology calls into question how we live as human beings (van Manen, 1990). In nursing,

this form of inquiry focuses most frequently on the research method, to generate knowledge for practice. I believe that approaches to inquiry can be broadened to include analysis of and reflection on personal experience, to help human beings understand the unique nature of human thoughts, behaviours, and ways of being in the world. Rather than attempt to understand what it is like to live within the respondent's world, we might seek opportunities for self-understanding, using phenomenologic reflection as a way of acquiring personal knowledge.

A Phenomenologic Stance: A Narrative of Newborn Death

The purpose of phenomenologic reflection is to capture essential meaning (van Manen, 1990). My interpretation of the experience of newborn death will be based on four lifeworld existential themes, as guides to phenomenologic reflection: *lived space*, *lived body*, *lived time*, and *lived human relation* (van Manen). These world-of-lived-experience existential themes probably pervade the lifeworld of all human beings, regardless of their historical, cultural, or social situatedness. In order to come to an understanding of the meaning of my son's death, I will address fundamental insights related to these four themes.

Lived Space

Lived space is felt space (van Manen, 1990). The theme of lived space, as the way in which I experience the world, encourages me to reflect on the special care nursery (SCN), the ocean, my home, and the places of my day-to-day existence. My lived space became the setting for the events surrounding Tanner's birth and those surrounding his inexplicable severe hypoxic insult. The delivery room became a place where words described and framed Tanner's precarious existence. My being thrust into the SCN lived space, as a care receiver rather than as a care provider, contributed to my existing internal chaos and confusion about accepting Tanner's short life. This space eventually shifted to the beach, where we had chosen to take Tanner for his last few moments of life. After we left the health-care setting behind, our house became the lived space, where the evidence of our hopes and dreams was visible and tangible in the room we had prepared for Tanner. I have hesitated to change the lived space of Tanner's room, since it validates his existence in our life and is full of treasures and the gifts that were given to us.

My day-to-day space is "safe" places where I nestle with family and friends as life continues in a new, unanticipated direction. My lived space (that is, my day-to-day life) feels empty. I find my most profound

comfort in the shared space of healing with my husband. We describe our felt space — our day-to-day experience of grief following our son's death — as similar to sailing in a storm: the waves wash over you and startle you, and just when you are beginning to recover from the assault another wave comes. There is no pattern. One is never sure when that rogue wave is going to come and leave your boat a crumpled mass of debris. It has been a continual challenge to find the calm seas between the storms that leave us a crumpled mass of emotional debris.

My day-to-day space offers me limited opportunity to refer to my son, since he is not physically present. My journey of healing has been a continual search for a space where I can find validation for my pregnancy, labour, and birth, and for Tanner's short life. The search for this space shaped the weeks following his death and is integral to the experience of suspended time.

Lived Time

Lived time is subjective time, as opposed to clock time, which is objective time (van Manen, 1990). Our experience of time is not often the subject of reflection, but when we are awaiting vacation it seems to pass slowly and when we are on vacation it seems to pass quickly. I experienced time as a whole new dimension following Tanner's death. Time was suspended, as if the familiar measures of morning, afternoon, evening, and night-time were intangible and incomprehensible. The hours and minutes of watching Tanner's final struggle for breath, and the moment of passing his body to his grandparents to take to the funeral home, where they would part with his physical being, seem timeless. The time spent with family forms a comforting image in my memory, yet I cannot discern how we actually passed those days.

For me, questions have arisen related to the experience of lived time: Must one live 80 years in order to have a meaningful life? Can the value of life be measured based on our limited understanding of time? This dimension of our experience inspired us to create memories in a limited amount of time, by taking pictures, visiting the ocean, saving a lock of hair, making plaster moulds of our son's hands and feet. These memories will enable us to share Tanner's spirit with others for an unlimited amount of time.

Pregnancy represented my journey through time from conception to delivery: 37 weeks of intense attachment and fear. My nursing practice made me fully aware that this journey can be hazardous and that healthy babyhood cannot always be expected. Despite my fear, our son

was, in the words of my mother, "incorporated into every dimension of his parents' lives and was celebrated, as Chinese babies are, from the time of conception." This celebration of my pregnancy has enriched Tanner's short life by helping me to value the cherished moments we shared and will continue to share as a family.

Lived Body

Lived body refers to the phenomenological fact that we are always bodily in the world (van Manen, 1990). The embodied experiences of pregnancy and the postpartum period caused me to reflect, as I sought to understand the healing of my body following emergency forceps delivery and the ensuing bodily changes that signified both motherhood and nonmotherhood. The changes that my body underwent as it returned to its nonpregnant state seemed to me almost a betrayal — I wanted to stay within a mother's world to validate Tanner's existence. I constantly searched for meaning in the irony of a changing body. I had a strong desire to return to my pregnant body, Tanner nestled safely inside. I still proudly display my linea nigra — the embodiment of his existence. The chant "no belly, no baby; no belly, no baby" rang in my head those first few weeks at home. I believe this was my way of understanding the reality of being suspended between two worlds, motherhood and nonmotherhood. I belonged in neither world at that point; I had lived through pregnancy and birth but my mothering experience was suspended, because my baby was not with me in body.

After I arrived home, midst the warmth of my family, my physical healing became a tangible focus for the challenge of providing immediate remedies: food, water, exercise, sleep, the warmth of the sun, the beauty around us. The inevitable emotional pain, which was at times impossible, was embodied in restlessness, inertia, loss of appetite, and a feeling of overwhelming heaviness. My instinct and drive for health have been my guides through this dense fog of sadness and loss. For me, my mother's words, "Thank you for letting me care for your body," embody grief as experienced within my family relationship.

Three weeks after Tanner died I found myself attending a postnatal fitness class that, reflection and understanding tell me, validated my motherhood. All the mothers had their babies with them as they moved through the exercise routines. The reaction of many people was that seeing all those new mothers and babies must have been "pure torture" for me. When my family expressed a desire to protect me from this potentially hurtful experience, my response was: "I am a mother. I just don't have Tanner here with me. He is embodied by my memories of

him." Attending this class as a postpartum mother allowed me to validate motherhood by acknowledging the physical experience and bodily changes that surrounded Tanner's entry into our lives.

Lived Human Relation

Lived human relation is the relationships we maintain in the interpersonal space we share with others (van Manen, 1990). For me there is no more profound emptiness than that of the shared parenthood that emerged as suspended time and lived human relation; I was suspended between the world of parenthood and the world of nonparenthood. My husband and I feel emptiness when we try to understand our experiencing two of life's most powerful events, birth and death, in the same moment. All the anticipation and preparation for the change from couple to family of three ended abruptly — death 24 hours after birth. Our lives are forever changed because we are parents, the world looks different to us because we are parents, and we are vulnerable simply by being in the world as parents.

The central presence of my older sister, her husband, and their four-month-old son during Tanner's life is forever etched in my heart and soul. They shared tears, hard decisions, cuddles on the beach, and, most of all, their spirit, guiding us along the path we most feared to tread. Their own loss experience is integrally linked to ours, since we shared many hopes and dreams for Tanner's presence in our collective lives. This shared pain and vulnerability helped to lift the heavy weight of grief. My younger sister appeared almost instantly to spend time holding, admiring, and making memories of her own. She slept beside us the only night my husband, Tanner, and I would share as a family. I felt stronger as she lay beside me, ready in a moment to cry with us and admire our little boy as he lay so very still.

My understanding of Tanner's life and death is informed in significant part by my relationships with my family and the meaning that family members take from the experience. In the words of my sister:

I hope your souls, individual and collective, are finding some warmth somewhere too. Little Tanner is everywhere, inside each of us, in different ways, all the time. What an intense influence for one so little and pure. I couldn't love you more than I do — and yet each day I love you more.

If experience can be reflected upon through lived space, lived body, lived time, and lived human relation, then I find the most profound meaning in my lived human relation with my partner in parenthood.

If to love someone is to feel their pain so intensely that your whole body groans in anguish when they are hurting, then I have truly found my soulmate. My pain is almost tolerable, but his is unbearable, and my healing is intimately connected to our shared comfort, inner peace, and life ahead.

An Essential Theme: Validating Motherhood

According to van Manen (1990), to determine the universal or essential quality of a theme is to discover aspects or qualities of a phenomenon without which it could not exist. It is my belief that without the essential theme of validating motherhood, the phenomenon of life and death of my newborn son has no fundamental meaning. Van Manen describes an essential theme, such as validating motherhood, as "knots in the web of our experiences, around which certain lived experiences are spun and thus lived through as a meaningful whole" (p. 90).

Further illumination on the theme of validating motherhood is offered by its location in the literature on perinatal loss: categories that emerge in the literature help one interpret the theme — the categories are integral to one another because they are associated with a search for meaning in newborn death.

Loss of the World of Motherhood

In the weeks and months following Tanner's death, the existential feeling of being abandoned in a world between motherhood and non-motherhood was the overarching theme in my day-to-day existence. Losing the world of motherhood drives my journey towards healing. I want to reclaim this world despite the irony of being in it without a baby. In my day-to-day world I so often want to say to the people I encounter, "I am a mother; please ask me about my baby." In addition, the thought of having another child helps me to gravitate back to the world of motherhood.

Lauterbach's (1993) phenomenological study explored the essences of the meanings in mothers' experiences of perinatal death of a wished-for baby. I find comfort in Lauterbach's work because I recognize my search to validate motherhood in the mothers' descriptions of existential abandonment by their baby. They describe "a profound feeling of isolation, of Being-a-mother in another world, and the loss of the world of mothering that follows death of a particular, wished-for baby" (p. 157). The women tell of their loss of both motherhood and its accompanying personal and social role. By reviewing the essential themes and

narratives in this study, I was able to verify and support my theme of validating motherhood. Extending this work, through further analysis of my narrative of newborn death based on Lauterbach's results, may provide opportunities to reflect with greater understanding of the experience of perinatal loss as an essential theme.

Symbolic Meaning of Loss

Theorists and researchers suggest that the meaning ascribed to the reality of loss, more than anything else, indicates how people feel about their loss. Toder's (1986) research with grieving parents examined the symbolic meaning of the loss of a child. My thematic approach could be considered a way of understanding the symbolic meaning of experiencing newborn death. In describing the symbolic meanings of the loss of a child, Toder alludes to a loss of identity: "...a sudden realization that the way you have been perceiving and defining yourself is no longer available or functional. It suggests that the old way no longer fits but that it has been stripped away before a new way of being has been developed" (p. 65). Women have expressed the need for caregivers who know what pregnancy means to them as individuals (Swanson-Kauffman, 1986). It is in this sense that my loss of identity as a mother, and the symbolic meaning of that loss, underlie my efforts to reclaim the world of motherhood.

It is my belief that the present work, because it focuses on the death of a first baby, introduces another dimension to the theme of loss of identity. Since Tanner was my first baby, my awareness of his existence represented a journey *towards* motherhood. Lederman (1984) describes such a journey in primigravid women as a progressive shift in their thinking away from the self-unit towards the mother-infant unit. During pregnancy we prepare for motherhood by imagining ourselves as a mother and contemplating our life as a woman with a child (Rubin, 1984). Motherhood was an "imagined identity" during my pregnancy. I believe the theme of validating motherhood following Tanner's death is bound to the notion that maternal identity is not completely formed until the infant is born and has an identity (Colman, 1983; Rubin). The moments for confirming Tanner's identity and my identity as his mother were finite, and it is a difficult process to grieve for an identity that existed so briefly and that was primarily an imagined one. My husband describes this imagined identity as a motion picture playing over and over in his mind prior to Tanner's birth and after his death. The journey to reclaim the world of motherhood is also a quest to capture what could have been and our identity as parents.

Birth and Death: Disorientation to Orientation

Davidson (1977) describes women's movement, following neonatal death, from disorientation to orientation. This process, which is inextricably linked to the woman's perceptual confirmation of her loss, is crucial to her reorientation after the death of her baby. I found disorientation to be pervasive, as my body returned to its pre-pregnant state even while I wanted to remain pregnant: orientation to the reality of newborn death was tangible in the suppression of breast-milk production, physical healing following emergency forceps delivery, and living with the experience of acute grief overlaid with an array of postpartum hormonal fluctuations. The movements between birth and death, disorientation and orientation, as described by Davidson, are another dimension of the experience of newborn death, a dimension that transcends time, space, body, and lived relations.

A Context of Personal Meaning

The theme of validating motherhood, in the present study, must be seen in a context of personal meaning. Swanson-Kauffman (1986) and Lemmer (1991) suggest, based on their studies with bereaved parents, that loss must be seen in a context of personal meaning that emerges through empathetic, caring, personal interactions with caregivers. Lemmer found that mothers' perceptions of noncaring following perinatal loss focused on nurses' failure to acknowledge the loss and the unique contexts of personal meaning associated with their experience of loss. An essential theme of validating motherhood is located within a particular context of personal meaning that recognizes the uniqueness of each experience of grief and loss.

Implications

Phenomenologic reflection is, consistent with van Manen's (1990) existential lifeworld themes, a way of developing personal knowledge for nursing with families experiencing the death of a newborn. Reflecting on an essential theme can help to interpret perinatal loss in a meaningful way, and thus inform the personal knowledge that is required in nursing. In other words, the *process* of phenomenologic reflection might inform nursing practice with families experiencing loss, in addition to the specific theme of validating motherhood. Furthermore, a process of reflection and self-understanding can serve to facilitate an understanding of broader contexts of human experience in caring for families experiencing perinatal loss.

However, families' experiences of newborn death can and do vary. Personal experience and reflection cannot be applied to the experience of all families, regardless of social context. For example, to assume that all women need to validate motherhood following newborn death would indicate a blindness to the diversity of women's experience; to do so would direct nursing action towards outcomes that might not represent the realities of individual women.

The following passage demonstrates the power of story-telling and the search for meaning in newborn death, while also speaking to the lived human relation of one family:

Tanner began in love and lived and died surrounded by love. In the time since his death we have felt the pervasive presence of love in all its diversity. Love has been shown by those determined to walk with us, when we are not very good company, and in their eager, gentle listening to the story even when they already know it. Love is felt in the words of comfort humbly offered, chosen, and spoken in love, and in the willingness to see and hear the pictures of Tanner's beauty.

All of these form a part of learning that says "life is fragile and precious. Children, grandchildren, lovers, partners, spouses, brothers-and sisters-in-law, and friends near and far are to be treasured and told that they are loved and valued." Tanner's immediate family is woven closer than ever. Perhaps all of us, because of Tanner, will love more extravagantly, cherish more fully, snuggle more closely, celebrate life and love more abundantly. We cherish him; he will be with us always.

References

- Colman, L.L. (1983). Psychology of pregnancy. In L. Sonstegard et al. (Eds.), *Women's health II: Childbearing* (pp. 3-16). New York: Grune & Stratton.
- Davidson, G.W. (1977). Death of a wished for child: A case study. *Death Education*, 1, 265-275.
- Gortner, S.R. (1990). Nursing values and science: Toward a science philosophy. *Image: Journal of Nursing Scholarship*, 7, 134-137.
- Lauterbach, S.S. (1993). In another world: A phenomenological perspective and discovery of meaning in mothers' experience with death of a wished-for baby: Doing phenomenology. In P.L. Munhall & C. Oiler Boyd (Eds.), *Nursing research: A qualitative perspective* (pp. 133-179). New York: National League for Nursing Press.
- Lauterbach, S.S., & Becker, P.H. (1996). Caring for self: Becoming a self-reflective nurse. *Holistic Nursing Practice*, 10, 57-68.
- Lederman, R.P. (1984). *Psychosocial adaptations in pregnancy* (2nd ed). New York: Springer.

- Lemmer, S.M. (1991). Parental perceptions of caring following perinatal bereavement. *Western Journal of Nursing Research*, 13(4), 475–493.
- Parse, R.R. (1987). Man-living-health theory of nursing. In R.R. Parse (Ed.), *Nursing science: Major paradigms, theories, and critiques* (pp. 159–180). Philadelphia: Saunders.
- Paterson, J., & Zderad, L. (1988). *Humanistic Nursing*. New York: National League for Nursing.
- Polkinghorne, D.E. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.
- Rubin, R. (1984). *Maternal identity and the maternal experience*. New York: Springer.
- Schultz, P.R., & Meleis, A.I. (1988). Nursing epistemology: Traditions, insights, questions. *Image: Journal of Nursing Scholarship*, 20, 217–221.
- Swanson-Kauffman, K. (1986). Caring in the instance of unexpected early pregnancy loss. *Topics in Clinical Nursing*, 8, 37–46.
- Toder, F. (1986). *When your child is gone: Learning to live again*. Sacramento: Capitol Publishing.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Watson, J. (1985). *Nursing: The philosophy and science of caring*. Boulder: Colorado Associated University Press.
- White, J. (1995). Patterns of knowing: Review, critique, and update. *Advances in Nursing Science*, 17(4), 73–76.

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Predictors of Bereavement Outcomes in Families of Patients with Cancer: A Literature Review

Priscilla M. Koop and Vicki Strang

Le but de cet article est d'examiner la littérature consacrée aux prédicteurs des conséquences du deuil chez les familles ayant prodigué des soins à un proche décédé du cancer. Cette littérature a été divisée selon des thèmes communs de prédicteurs, soit les caractéristiques de la personne décédée, les caractéristiques de la personne endeuillée, les comparaisons entre les personnes endeuillées et des groupes de personnes non endeuillées, le bien-être de la personne endeuillée avant le décès, les relations interpersonnelles antérieures, les caractéristiques de la maladie, les caractéristiques de l'expérience de soins et les caractéristiques des soins donnés lors de la phase terminale.

Un certain nombre de comportements récurrents permettent d'identifier les personnes courant un risque plus élevé de mal s'ajuster au cours du deuil. Il est manifeste que les hommes et les femmes expriment leur chagrin quelque peu différemment. Cependant, il reste encore à déterminer qui, des hommes ou des femmes, coure le plus grand risque d'un mauvais ajustement. Des preuves empiriques suggèrent qu'un statut socio-économique inférieur et les barrières linguistiques interfèrent avec l'ajustement au cours du deuil. Fournir des services adaptés aux besoins particuliers des différentes communautés culturelles est important si l'on veut aider les patients recevant des soins palliatifs et les membres de leur famille à faire les ajustements requis. La nécessité de prendre pleinement conscience de l'imminence du décès et de planifier avec attention le moment et le lieu de la mort est apparente dans la littérature. La présence régulière et fréquente de soignants professionnels rehausse le degré de satisfaction à l'endroit des soins offerts en milieu familial. Les résultats divergents des études indiquent la nécessité d'explorer davantage les questions sous-jacentes qui expliquent ces contradictions. Les personnes plus âgées qui ont pris soin d'un proche semblent avoir certains avantages par rapport aux plus jeunes au moment du deuil, mais cette conclusion ne se retrouve pas dans les résultats de toutes les études. Les problèmes méthodologiques rencontrés incluent la taille réduite des échantillons et de grandes variations entre les conséquences particulières des deuils étudiés.

The purpose of this paper is to review the literature on predictors of bereavement outcomes in family caregivers of persons who have died of cancer. The literature has been divided into common themes of predictors: characteristics of the deceased person, characteristics of the bereaved person, comparisons of bereaved and non-bereaved persons, well-being of the bereaved person prior to the death, prior interpersonal relationships,

Priscilla M. Koop, R.N., Ph.D., is Assistant Professor, Faculty of Nursing, University of Alberta, and Nurse Scientist, Cross Cancer Institute, Edmonton. Vicki Strang, R.N., Ph.D., is Associate Professor, Faculty of Nursing, University of Alberta, Edmonton.

characteristics of the illness, characteristics of the caregiving experience, and characteristics of terminal care. A number of recurring patterns point the way to identifying persons who may be at increased risk for poor adjustment during bereavement. It is apparent that men and women express their grief somewhat differently. Whether men or women are at greater risk for poor adjustment, however, remains to be determined. There is some empirical evidence to suggest that lower socioeconomic status and linguistic barriers interfere with adjustment during bereavement. There is a dearth of culturally relevant services to help palliative-care patients and their family members make the required adjustments. The literature makes apparent the need for open awareness of the impending death and for careful and thoughtful planning for where and how the death ought to occur. The regular and frequent presence of professional caregivers contributes to family caregivers' satisfaction with care. Discrepant findings point to the need to explore the issues that underlie them. Older bereaved caregivers appear to have some advantages over younger ones, but this finding is not universally found in the results of these studies. Methodological problems include small sample sizes and large variations in the particular bereavement outcomes studied.

It has been estimated that by the year 2000 cancer will surpass heart disease as the primary cause of death in North America (Greenwald & Sondek, 1986). Approximately 75% of cancer patients will inevitably require some form of palliative care (Diehl, 1994). According to the World Health Organization, the principles of palliative care include the availability of a support system to help the family cope during the patient's illness as well as during the period of bereavement (World Health Organization Expert Committee, 1990). Thus the focus of palliative care goes beyond the patient to include the family.

Family members as well as the patient experience the trajectory of cancer, and following the death of the patient the family members carry the memories of their experiences into the bereavement stage. Thus palliative care not only relieves the suffering of the patient and the family during the terminal phase of the illness, but also helps to ease the suffering of family members after the patient's death.

The purpose of this paper is to review the literature on predictors of bereavement outcomes following the death of a family member from cancer, focusing in particular on the identification and examination of those characteristics of caregiving during the terminal phase that affect bereavement outcomes.

Selection of the Literature

To be included in the review, a paper had to focus on outcomes following the cancer death of a family member *and* say something about pre-bereavement conditions and variables that would allow predictive statements to be made. Furthermore, the paper had to describe empirical work published since 1980. Only papers written in English were

included in the review. The majority of the patients in the study had to have died of cancer and its respondents had to have had a close, committed relationship with the deceased person. This limitation, while somewhat arbitrary, allows us to draw conclusions about "family" relationships that might go beyond blood or legal ties but are committed and caring ones nonetheless. If qualitative papers met these criteria they were included, along with studies that had used quantitative methods. The papers that describe qualitative method hold a special place in this analysis because they add to our understanding in a way that even a very high correlation coefficient fails to accomplish.

The literature will be reviewed according to categories of predictors: characteristics of the deceased person, characteristics of the bereaved person, comparisons of bereaved and non-bereaved persons, well-being of the bereaved person prior to the death, prior interpersonal relationships, characteristics of the illness, characteristics of the caregiving experience, and characteristics of terminal care.

Characteristics of the Deceased Person

Only two studies were found to focus on specific characteristics of the deceased person as affecting bereavement outcomes. Hoekstra-Weebers, Littlewood, Boon, Postma, and Humphrey (1991) focused on the age of the deceased child, while Shanfield, Benjamin, and Swain (1984) focused on gender. Neither study has been replicated, nor were studies found that explore the nature of the relationships between these demographic variables and bereavement outcomes.

Hoekstra-Weebers et al. (1991), in a Dutch study, examined the age of the deceased child as a potential predictor of grief responses. They compared the parental coping styles and psychological well-being of parents who had lost younger children (age 3–9) and parents who had lost older children (age 13–19). Parents of younger children were found to be more likely to use a problem-focused coping style. This study included 33 parents of 19 bereaved children. It did not acknowledge the potential for non-independence of data from the mothers and the fathers. Shanfield et al. (1984) found the gender of the deceased adult child to be a factor in parents' post-bereavement anger scores as well as in the closeness of family relationships during the bereavement period. Both scores were elevated when the deceased child was a daughter. Further research might determine whether these findings can be replicated, and could also explore the relationships between characteristics of the deceased person and bereavement outcomes.

Characteristics of the Bereaved Person

A number of studies focused on a range of characteristics of the bereaved persons and the outcomes associated with bereavement. Gender is among the most commonly studied predictors of bereavement outcomes. Some studies found that females tended to score higher on measures of distress, whether they were parents of deceased adult children (Shanfield et al., 1984), young-adult children of deceased parents (Galloway, 1990), or spouses (Gilbar & Dagan, 1995). Other researchers, however, found no association between gender and depression during the bereavement period (Kurtz, Kurtz, Given, & Given, 1997; McHorney & Mor, 1988), emotional distress (Houts, Lipton, Harvey, Simmonds, & Bartholomew, 1989; Yancey, Greger, & Coburn, 1990), or satisfaction with care (Beck-Friis & Strang, 1993).

Gilbar and Dagan (1995) explored possible reasons for their findings of gender-based differences in a study with Israeli widows and widowers. Among their explanations were the potential for reduced caregiving stress associated with lower expectations among male caregivers, financial problems that might result from a husband's prolonged illness, and the loneliness experienced by older women who have become highly dependent on their husbands.

Cook (1983) examined the influence of gender on spousal relationships in the year following the death of a child from cancer or a blood disorder. This study featured both qualitative and quantitative aspects. Cook found important differences as well as similarities in the ways in which fathers and mothers grieved for their child and articulated their grief. The quantitative data confirmed the qualitative findings. Mothers were found to be significantly more likely to experience difficulties at anniversaries and on special days, and more likely to report distance in the marital relationship, but less likely to report that they and their spouses were able to comfort each other.

The extent to which the conflicting findings regarding gender are a result of cultural or cohort differences in the experiences or expressions of grief, or a result of pre-bereavement relationships or other variables, remains to be determined. The role of gender in bereavement outcomes is not likely to go away, and we will benefit from the debate.

Age is commonly tested as a predictor in bereaved or potentially bereaved groups. The results to date are contradictory and bear further exploration. Beck-Friis and Strang (1993) found an association between advanced age of bereaved spouse and greater satisfaction with care, and Houts et al. (1989) found that younger bereaved spouses were

likely to experience greater distress during bereavement. However, Jurk, Ekert, and Jones (1981), in an Australian study of parents of children who had died of cancer, found older parental age to be associated with greater family dysfunction during the bereavement period. Kurtz et al. (1997) did not find age to be a significant predictor of depression during the bereavement period. McHorney and Mor (1988), in a study of 1,447 bereaved caregivers, found that caregivers under age 65 were 1.8 times more likely to be depressed during bereavement. Vachon et al. (1982) found younger age of bereaved widows ($n=162$) to be associated with lower scores on a general-health questionnaire.

Socioeconomic variables have also been studied as potential predictors of bereavement outcomes. Jurk et al. (1981) found lower educational achievement to be related to greater family dysfunction after the loss of a child to cancer. This finding is supported by that of McHorney and Mor (1988): caregivers who had not completed high school were found to be 1.9 times more likely to experience post-bereavement depression than those who had completed some post-secondary education. Similarly, Vachon et al. (1982) found that lower socioeconomic status predicted higher distress scores among widows at two months post-death.

Cultural and linguistic characteristics of bereaved persons can potentially affect grief resolution. Access to informal support systems can be limited for those whose cultural group is limited, and formal support services for bereaved persons are of limited benefit in the face of linguistic and cultural barriers. Only the Vachon et al. (1982) study included ethnicity as a potential predictor of bereavement outcomes. It found that having a primary language other than English or being Jewish were associated with higher distress scores in bereaved widows at one month post-death.

One of the few studies to focus on measures specifically designed to predict bereavement outcomes was that of Robinson, Nuamah, Lev, and McCorkle (1995), who adapted the Parkes and Weiss (1983) Bereavement Risk Index (BRI) for identifying spouses at risk for psychological distress. Eight items, each using an ordinal scale, focus on age, occupation, length of preparation for the patient's death, clinging or pining, anger, self-reproach, availability of family support, and clinician's overall prediction of the respondent's bereavement outcome. Robinson et al. found that low-risk and high-risk groups (based on BRI scores) demonstrated similar patterns of change in their distress scores over the course of the study. The high-risk group scored significantly higher on somatization, interpersonal sensitivity, depression, and

anxiety than the low-risk group at all time points except the 25-month point.

Comparisons of Bereaved and Non-Bereaved Persons

A number of studies compared bereavement outcomes to norms for non-bereaved populations as well as to scores of psychiatric patients. Researchers have been particularly interested in measures of physical and emotional health. Widely discrepant measures and varying methods of operationalizing variables account for a number of the conflicting results of these studies.

Family members of deceased children (Moore, Gilliss, & Martinson, 1988), offspring of deceased parents (Shanfield et al., 1984), and bereaved family members in general (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996) were found to score low on a number of measures of psychological health when compared to normative scores from a non-bereaved population.

Birenbaum, Robinson, Phillips, Stewart, and McCown (1989–90) found that the siblings of children who had died of cancer exhibited more behavioural problems and scored lower on measures of social competence than children who had not been bereaved. In contrast, Siegel, Karus, and Raveis (1996) found that while children whose parent had died of cancer scored higher than matched controls on measures of depression and anxiety prior to the death, their scores on both variables were not statistically different from those of matched controls at seven to 12 months after the death.

Birenbaum, Stewart, and Phillips (1996) found that parents of children who had died of cancer were not significantly less healthy than a normative sample of adults and that they concluded their health was not adversely affected by the death of their child. Hoekstra-Weebers et al. (1991), however, found bereaved parents to be less emotionally expressive when compared to normative data for The Netherlands. The authors speculate that everyday occurrences may no longer be sufficient to elicit an emotional response for parents who have experienced the death of a child.

There is growing interest in the effects of stressful events, such as bereavement, on immune function. Irwin, Daniels, Smith, Bloom, and Weiner (1987) compared Natural Killer (NK) cell activity and depression scores in widows ($n=10$) and age-matched control women ($n=8$) with healthy husbands. They also compared the NK activity and

depressive symptoms in women ($n=6$) before and one month after the death of their husbands from cancer. Bereaved women had lower NK activity and higher depression scores than the controls. In the longitudinal study, neither mean NK activity nor mean depression scores differed significantly from before the death to bereavement. However, for respondents whose depressive symptoms increased during this time, NK activity was found to be likely to decrease. These findings suggest that immune responses may be related to depression rather than to the process of bereavement itself.

Well-Being of the Bereaved Person Prior to the Death

There is increasing evidence to suggest that the greatest predictor of well-being during bereavement is well-being prior to the death. In general, these studies suggest that caregivers be especially vigilant regarding poor bereavement outcomes when family members are unwell prior to the death. Kristjanson et al. (1996) studied 64 family members of advanced-cancer patients before and after the death. They found the strongest predictor of health (using the symptoms-of-stress scale) during the bereavement period to be the health score during the terminal phase of the illness. In a similar vein, Houts et al. (1989) found that bereaved spouses who had been in distress just prior to the death experienced greater distress during bereavement, and Jurk et al. (1981) found previous social and psychological disturbances to be predictive of family dysfunction in the bereavement period. Kurtz et al. (1997), in a study with family caregivers of cancer patients, found two critical factors associated with increased post-bereavement depression: decreased caregiver optimism and high levels of pre-bereavement depression. Furthermore, these two factors predicted whether or not the depression would lessen during the bereavement period.

McHorney and Mor (1988) analyzed data from the National Hospice Study and found poor prior physical and mental health to be predictive of post-bereavement depression. Their study included 1,754 bereaved caregivers for whom they had complete data, including interview data from the bereavement period. They found the odds of experiencing post-bereavement depression to be twice as great in caregivers who had been depressed prior to the death. Shanfield et al. (1984) found no significant differences in parents' health complaints before and after the cancer death of an adult child, and Vachon et al. (1982) found prior poor health to be predictive of greater post-bereavement distress.

Awareness of Impending Death

Interest in the potential value of anticipatory grief has generated studies of links between awareness of the impending death and bereavement outcomes. Houts et al. (1989) found that bereaved spouses who had avoided thinking about the possibility of the death were likely to experience higher levels of distress during bereavement than spouses who had thought about the death. In the study by Jurk et al. (1981) the children had not generally been informed of their impending death. The investigators found that when the bereaved parents perceived that their child knew s/he was dying there was a significantly higher incidence of family dysfunction in the bereavement period. These studies would support the value of open awareness for healthy grieving.

Prior Interpersonal Relationships

There is considerable interest in the effects of prior interpersonal relationships on the bereavement process. Kissane, Bloch, and McKenzie (1997) studied bereavement with 670 family members of 115 adults who had died of cancer. They found family coping to be the most consistent correlate of the bereavement outcomes (grief, distress, depression, and social adjustment). Another important interpersonal characteristic appears to be social support during the terminal phase of the illness. Kurtz et al. (1997) found family caregivers who reported higher levels of social support from friends during the terminal period to be at higher risk for depression during the bereavement period. This finding seems to be contrary to expectations. The authors relate it to other findings (Kurtz, Given, Kurtz, & Given, 1994; Sankar, 1991; Vachon et al., 1977) that as the terminal illness progresses members of the social network gradually disappear, leaving the caregiver to manage alone. Perhaps the variable of interest is not the amount of social support, but the degree of change over time. If the support system dwindles during the terminal phase of cancer it may not be available during bereavement. Given the value of social support in general, this issue bears further exploration. McHorney and Mor (1988) also found that social support was not significantly related to post-bereavement depression. They did find the odds of experiencing post-bereavement depression to be 1.4 times greater for caregivers who reported family tension than for those who did not. Yancey et al. (1990), however, found social support from family and friends to be positively associated with post-bereavement function. Their study included family members and friends who had had some "involvement" (physical care, emotional support, and/or

instrumental support) with the deceased person during the week prior to death. The depth of involvement was not defined.

In her study with siblings of children who had died of cancer, Davies (1988) examined the degree to which the closeness of the sibling relationship prior to the death influenced behavioural responses during bereavement. The interview data suggested that social withdrawal during the bereavement period was related to the closeness of the sibling relationships. The quantitative results, although not statistically significant, supported these findings. Shanfield et al. (1984) found that bereaved parents who perceived closeness during the illness of their adult child were more likely to feel that the loss of the child had been the most painful experience of their lives and were less likely to feel guilt or sense that business had been left unfinished. These findings are confirmed by those of McHorney and Mor (1988): for spouses the odds of being depressed are 1.5 times greater than for bereaved offspring and 3.6 times greater than for persons who have lost secondary kin or a non-family member. However, spouses did not differ significantly in their odds of being depressed when compared to bereaved parents or siblings. Jurk et al. (1981) found poor family communication and lack of support within the family by one of the parents to be associated with family dysfunction during the bereavement period. These findings suggest that the closeness of the relationship is an important predictor of bereavement outcomes.

Fakhoury, McCarthy, and Addington-Hall (1996), in a large British study with bereaved family caregivers, found the presence of living children to be associated with greater satisfaction with care delivered by district nurses. Houts et al. (1989) found living alone to be predictive of emotional distress following spousal bereavement.

Characteristics of the Illness

Researchers are recognizing the benefits of a good caregiving experience for bereavement outcomes. Caregiving experience moves beyond the characteristics of patient and caregiver to include the contributions of professional caregivers to the quality of the experience for family members. Another important aspect is the perceived value of the caregiving role.

A number of researchers looked at the effects of the cancer trajectory on bereavement outcomes. Of particular interest is the effect of duration of illness on the grieving process. Beck-Friis and Strang (1993), in a study with 87 primary caregivers of patients who had died of

cancer, found the length of time from diagnosis to death to be unrelated to satisfaction with care. However, they found a greater length of time (> 60 days) in terminal care to be associated with greater satisfaction. All patients had been part of a hospital-based home-care program and died at home. These findings suggest that family members need time to adjust to programs of care and to the personnel who deliver the care. Fakhoury et al. (1996) found caregivers whose deceased family member had experienced lengthy functional limitations, but short durations of incontinence and respiratory symptoms, to be more satisfied with their general practitioner (GP). McHorney and Mor (1988), like Beck-Friis and Strang, found length of illness to be unrelated to post-bereavement depression in family caregivers of cancer patients. However, Shanfield et al. (1984), in a study with parents of adult children who had died of cancer, found a relationship between length of illness and frustration with the patient. Steele (1990) found an illness of less than six months to be associated with increased social isolation, anger, and hostility, as well as greater dependency, among bereaved caregivers.

Characteristics of the Caregiving Experience

Fakhoury et al. (1996), in their large study ($n=1,858$), found that caregivers who perceived their role as rewarding and had not required additional help in caring at home were more likely to be satisfied with the district nurse and the GP. On the other hand, caregivers who had found home-based caregiving a burden reported greater satisfaction with the hospital physicians.

Häggmark, Theorell, and Ek (1987) conducted a quasi-experimental study to evaluate the results of increased participation in care of cancer patients by family members. They interviewed family caregivers over the course of the illness and at one and two months following the death. The experimental treatment consisted of an invitation to participate in the care of the family member while in hospital as well as to meet regularly with staff. Caregivers in the experimental group had increased the number of their own activities at one month following the death, which suggests that participation in caregiving activities facilitates recovery from the experience.

Kurtz et al. (1997) found no relationship between perceived esteem associated with caregiving and post-bereavement depression. McHorney and Mor (1988), however, found that caregivers who expressed dissatisfaction with their caregiving abilities were twice as likely to experience post-bereavement depression as caregivers who

did not. These findings are supported by those of Shanfield et al. (1984), who found that bereaved parents who reported frustration with their adult child during the illness had higher scores on obsessive-compulsiveness and hostility.

Stetz and Hanson (1992) conducted a longitudinal study of perceptions of the caregiving experience and found that these changed somewhat after the death. During the illness experience, the top three perceived demands on caregivers were ranked as managing physical care, managing household finances, and standing by. Retrospectively, standing by was ranked first, followed by managing physical care and alterations in the caregiver's well-being. These findings suggest that while nurses should be aware of the demands placed on family caregivers, they should keep in mind that these perceptions might change following the death. Significantly, caregivers wished, in retrospect, that they had sought out more resources to help them in their caregiving experience. Further research might explore the degree to which fatigue prevents caregivers from recognizing the need for rest. Perhaps only in retrospect, after the death has occurred and they have had time to sleep and reflect, do caregivers realize how fatigued they were. Another possible reason for the finding is that caregivers see the death as too imminent to justify their taking a respite; as a result, when the death occurs they find themselves too fatigued to fulfil the social responsibilities that accompany bereavement.

Levy (1991) reported on the development of a measure of anticipatory grief. He found a correlation between anticipatory grief and depression and subjective stress, and suggested that anticipatory grief might not be as helpful to positive bereavement outcomes as had previously been thought.

Characteristics of Terminal Care

A number of studies compared the care of cancer patients in hospital versus at home, and in specialized (palliative-care, hospice) units versus in general medical in-patient units. Many of these studies focused on the satisfaction of family caregivers. Generally, caregivers of patients cared for in hospices were found to be more satisfied than caregivers of patients cared for elsewhere (Cameron & Parkes, 1983; Dawson, 1991; Godkin, Krant, & Doster, 1983-84; Steele, 1990). Furthermore, Dawson found overall satisfaction with the program of care to be very positively correlated with the psychosocial support of the nurse and with the satisfactory fulfilment of basic needs.

Fakhoury et al. (1996), in their survey of 1,858 bereaved caregivers in 20 health-care districts in England, used a range of service and non-service variables as predictors in measuring satisfaction with the district nurse, the GP, and hospital physicians. Service variables produced higher odds ratios than non-service variables. Among the service variables that predicted greater satisfaction with the district nurse were: higher frequency of home visits, contacting other services, helping at night, and visiting the bereaved caregiver. Satisfaction with the GP was predicted by higher frequency of visits and telling the caregiver about the diagnosis. Caregivers were more likely to be satisfied with hospital physicians if they thought the deceased person had been given a choice about treatment and had been allowed sufficient privacy while in hospital and if they thought the doctor had treated the patient's respiratory symptoms. In addition, if the patient had died at home, caregivers were more likely to have reported satisfaction with the district nurse. Similarly, Yancey et al. (1990) found that survivors of cancer patients reported higher levels of perceived social support from nurses and greater satisfaction with care when the deceased person had participated in a hospice program than when the patient had been cared for in hospital.

Ferrell (1985) used the Grief Experience Inventory (GEI) to examine the place of death as predictive of grief experiences, including feelings, symptoms, and behaviours associated with grief. Her study with spouses of cancer patients who had died at home ($n=22$) and in hospital ($n=38$) found that the home-based spouses experienced less guilt, ruminated less, and experienced less depersonalization during bereavement. Scores on other clinical scales (despair, anger, social isolation, loss of control, somatization, and death anxiety) were not significantly different for the two groups of respondents. Similarly, Steele (1990) found home deaths to be associated with lower scores on denial, guilt, and rumination, as well as on social isolation and death anxiety. These findings suggest that home-based deaths can have beneficial bereavement outcomes for family caregivers. They also suggest that caregivers whose loved one dies in an institutional setting might experience a sense of failure, which can complicate the bereavement process. Nurses who provide care to patients with advanced cancer might do well to explore this issue with family members.

Lauer, Mulhern, Bohne, and Camitta (1985) and Lauer, Mulhern, Schell, and Camitta (1989) studied the effects of home and hospital death on the adjustment of siblings and parents. In both studies, multiple family members participated and no accounting for non-independence was explicated. Both reports suggest that home deaths are asso-

ciated with positive outcomes, including stronger family relationships and fewer psychological and interpersonal problems. The siblings of patients who died at home (Lauer et al., 1985) reported that they had been involved in their care and had been kept informed, whereas the siblings of those who died in hospital felt useless in terms of their involvement with the ill child and ill prepared for the death.

These findings are not supported by those of Houts et al. (1989), who found home death to be associated with greater distress among bereaved spouses. In this study with 112 respondents, distress scores were calculated by summing the scores of the three measures used: CES-D, selected questions from the GEI, and respondents' self-reports of their distress concerning the death. Thus the distress score is likely a somewhat different measurement of attributes of distress (e.g., depression) than that of the GEI alone. Furthermore, the respondents in both the Ferrell (1985) study and the Steele (1990) study had arranged for a home death. Since the children studied by Lauer et al. (1985) had been part of a home-care program, one might assume that a home death was favoured in those cases as well, although this is not explicitly stated in their findings. Houts et al. do not state whether the deaths studied in their investigation occurred as planned. Also, we do not know the degree to which the services in the two studies were comparable. Kurtz et al. (1997) did not find a relationship between the setting of death and post-death depression. These findings would suggest that caregivers are likely to experience less distress when the death has occurred as planned.

Methodological Concerns

A major and recurring methodological problem in the research on palliative care and bereavement outcomes is small sample size, resulting in limited ability to find meaningful relationships among variables of interest. The primary reason for small sample size is perceived vulnerability in family members of terminally ill or recently deceased persons. Also, both clinicians and family members often act as gatekeepers, preventing access to patients as potential respondents. Protector of vulnerable subjects is a role that clinicians and family members take seriously, as they should. The vulnerability of bereaved persons must also be acknowledged and respected. However, there are times when patients and family members might welcome the opportunity to participate in research. Protecting potential respondents from intrusion must be balanced by offering them an opportunity to participate in studies that are conducted in an ethical and compassionate manner.

Another way to solve the problem of small sample sizes is to develop research networks. Investigators can increase sample size by broadening the base of clinical settings from which they accrue respondents. Networks can be developed informally across settings or across a country. An excellent example of cross-Canada networking is the Sociobehavioural Network developed by the National Cancer Institute (Advisory Committee, 1994).

Another recurring issue for researchers relates to the collection of data from multiple family members. Collecting information from more than one family member allows for richness of the data. However, precautions must be taken for the sake of statistical analysis, because data collected from one family member cannot be assumed to be independent of that collected from another. This problem of non-independence can be handled in a number of ways. Moore et al. (1988) collected data from bereaved mothers and fathers but analyzed the two sets of data separately. Davies (1988) reported separately for data collected from single siblings and data representing multiple family members. Birenbaum et al. (1996) tested their data for non-independence and then analyzed appropriately. Siegel et al. (1996) weighted the scores to account for multiple family participants. Each of these methods is appropriate and each facilitates valid statistical analysis of the data.

Differences in predictors, outcome variables, and measures used make it difficult to compare results. This problem, which is a common one in psychosocial research, is caused by many factors, several of which are intertwined. Researchers who conduct studies into palliative care and bereavement outcomes represent a variety of disciplines, each with its own way of approaching psychosocial phenomena. The concepts being examined are complex and often multidimensional, requiring multiple measures within a single study, which in turn requires that the measures be valid, reliable, and short, so that respondents with limited time and energy can answer questions without becoming unduly fatigued. These problems are balanced, however, by the richness that accrues from research projects conducted in this way. It is of paramount importance that researchers build on each other's work and use scales that are valid and reliable and that fit conceptually with the variables of interest.

Conclusion

A number of recurring patterns point the way to identifying persons who may be at increased risk for poor adjustment during bereavement.

It is apparent that men and women express their grief somewhat differently and that women generally report greater distress. Whether either gender is at greater risk for poor adjustment, however, remains to be determined. Age is one area in which findings conflict, depending on the particular bereavement outcome measured and the age range included in the study. There is some empirical evidence to suggest that lower socioeconomic status and linguistic barriers interfere with adjustment during bereavement. There is a need for culturally relevant services in helping palliative-care patients and their family members make the required adjustments.

A recurring theme in the literature on palliative care and associated bereavement outcomes is the need for open awareness of the impending death and for careful and thoughtful planning of the location and circumstances of the death. The presence of professional caregivers contributes to the satisfaction of family caregivers with the care being provided. This professional presence is especially important for patients being cared for in their own home.

Discrepant findings point to the need for further exploration of the issues that lie at the source of these discrepancies. Older bereaved caregivers appear to have some advantages over younger ones, but this finding is not universal to the results of these studies. Perhaps some sort of curvilinear relationship exists between age and bereavement outcomes. Older bereaved caregivers may also fare better on some variables and worse on others. Some of the specific outcomes investigated vary from study to study.

Methodological problems point to the need for strategies to accrue samples large enough to allow for meaningful interpretation of results. Two such strategies were suggested in the studies reviewed. Although the diversity of variables and their measures renders it difficult to compare findings, it makes for a richness that in the long run might benefit the development of a strong knowledge base.

References

- Advisory Committee on Cancer Control, National Cancer Institute of Canada. (1994). Bridging research to action: A framework and decision-making process for cancer control. *Canadian Medical Association Journal*, 151(8), 1141-1146.
- Beck-Friis, B., & Strang, P. (1993). The family in hospital-based home care with special reference to terminally ill cancer patients. *Journal of Palliative Care*, 9(1), 5-13.

- Birenbaum, L.K., Robinson, M.A., Phillips, D.S., Stewart, B.J., & McCown, D.W. (1989-90). The response of children to the dying and death of a sibling. *Omega*, 20(3), 213-228.
- Birenbaum, L.K., Stewart, B.J., & Phillips, D.S. (1996). Health status of bereaved parents. *Nursing Research*, 45(2), 105-109.
- Cameron, J., & Parkes, C.M. (1983). Terminal care: Evaluation of effects on surviving family of care before and after bereavement. *Postgraduate Medical Journal*, 59, 73-78.
- Cook, J.A. (1983). A death in the family: Parental bereavement in the first year. *Suicide and Life-Threatening Behavior*, 13(1), 42-61.
- Davies, B. (1988). The family environment in bereaved families and its relationship to surviving sibling behavior. *Children's Health Care*, 17(1), 22-31.
- Dawson, N.J. (1991). Need satisfaction in terminal care settings. *Social Science and Medicine*, 32(1), 83-87.
- Diehl, V. (1994). Controversies in terminal cancer care. *Supportive Care in Cancer*, 2(2), 82-87.
- Fakhoury, W., McCarthy, M., & Addington-Hall, J. (1996). Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Social Science and Medicine*, 42(5), 721-731.
- Ferrell, B.R. (1985). Cancer deaths and bereavement outcomes. Home versus hospital. *American Journal of Hospice Care*, 2(4), 18-23.
- Galloway, S.C. (1990). Young adults' reactions to the death of a parent. *Oncology Nursing Forum*, 17(6), 899-904.
- Gilbar, O., & Dagan, A. (1995). Coping with loss: Differences between widows and widowers of deceased cancer patients. *Omega*, 31(3), 207-220.
- Godkin, M.A., Krant, M.J., & Doster, N.J. (1983-84). The impact of hospice care on families. *International Journal of Psychiatry in Medicine*, 13(2), 153-165.
- Greenwald, P., & Sondek, E. (Eds.). (1986). Cancer control objectives for the nation. *National Cancer Institute Monograph*, 1985-2000.
- Häggmark, C., Theorell, T., & Ek, B. (1987). Coping and social activity patterns among relatives of cancer patients. *Social Science and Medicine*, 25(9), 1021-1025.
- Hoekstra-Weebers, J.E.H.M., Littlewood, J.L., Boon, C.M.J., Postma, A., & Humphrey, G.B. (1991). A comparison of parental coping styles following the death of adolescent and preadolescent children. *Death Studies*, 15, 565-575.
- Houts, P.S., Lipton, A., Harvey, H.A., Simmonds, M.A., & Bartholomew, M.J. (1989). Predictors of grief among spouses of deceased cancer patients. *Journal of Psychosocial Oncology*, 7(3), 113-126.
- Irwin, M., Daniels, M., Smith, T.L., Bloom, E., & Weiner, H. (1987). Impaired Natural Killer cell activity during bereavement. *Brain, Behavior, and Immunity*, 1, 98-104.

- Jurk, I.H., Ekert, H., & Jones, J. (1981). Family responses and mechanisms of adjustment following death of children with cancer. *Australian Paediatric Journal*, 17, 85-88.
- Kissane, D.W., Bloch, S., & McKenzie, D.P. (1997). Family coping and bereavement outcome. *Palliative Medicine*, 11(3), 191-201.
- Kristjanson, L.J., Sloan, J.A., Dudgeon, D., & Adaskin, E. (1996). Family members' perceptions of palliative cancer care: Predictors of family functioning and family members' health. *Journal of Palliative Care*, 12(4), 10-20.
- Kurtz, M.E., Given, B.A., Kurtz, J.C., & Given, C.W. (1994). Interaction of age, symptoms and survival status on physical and mental health of cancer patients and their families. *Cancer*, 74(7), 1-8.
- Kurtz, M.E., Kurtz, J.C., Given, C.W., & Given, B. (1997). Predictors of post-bereavement depressive symptomology among family caregivers of cancer patients. *Supportive Care Cancer*, 5, 53-60.
- Lauer, M.E., Mulhern, J.K., Bohne, J.B., & Camitta, B.M. (1985). Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. *Cancer Nursing*, 8, 21-27.
- Lauer, M.E., Mulhern, R.K., Schell, M.J., & Camitta, B.M. (1989). Long-term follow-up of parental adjustment following a child's death at home or hospital. *Cancer*, 63, 988-994.
- Levy, L.H. (1991). Anticipatory grief: Its measurement and proposed reconceptualization. *Hospice Journal*, 7(4), 1-28.
- McHorney, C.A., & Mor, V. (1988). Predictors of bereavement depression and its health services consequences. *Medical Care*, 26(9), 882-893.
- Moore, I.M., Gilliss, C.L., & Martinson, I. (1988). Psychosomatic symptoms in parents 2 years after the death of a child with cancer. *Nursing Research*, 37(2), 104-107.
- Parkes, C.M., & Weiss, R.S. (1983). *Recovery from bereavement*. New York: Basic.
- Robinson, L.A., Nuamah, I.F., Lev, E., & McCorkle, R. (1995). A prospective longitudinal investigation of spousal bereavement examining Parkes and Weiss' Bereavement Risk Index. *Journal of Palliative Care*, 4, 5-13.
- Sankar, A. (1991). Ritual and dying: A cultural analysis of social support for caregivers. *Gerontologist*, 31(1), 43-50.
- Shanfield, S.B., Benjamin, A.H., & Swain, B.J. (1984). Parents' reactions to the death of an adult child from cancer. *American Journal of Psychiatry*, 141(9), 1092-1094.
- Siegel, K., Karus, D., & Raveis, V.H. (1996). Adjustment of children facing the death of a parent due to cancer. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35(4), 442-450.
- Steele, L.L. (1990). The death surround: Factors influencing the grief experience of survivors. *Oncology Nursing Forum*, 17(2), 235-241.
- Stetz, K.M., & Hanson, W.K. (1992). Alterations in perceptions of caregiving demands in advanced cancer during and after the experience. *Hospice Journal*, 83, 21-34.

- Vachon, M.L., Freedman, K., Formo, A., Rogers, J., Lyall, W., & Freeman, S. (1977). The final illness in cancer: The widow's perspective. *Canadian Medical Association Journal*, 117, 1151-1153.
- Vachon, M.L.S., Rogers, J., Lyall, A., Lancee, W.J., Sheldon, A.R., & Freeman, S.J.J. (1982). Predictors and correlates of adaptation to conjugal bereavement. *American Journal of Psychiatry*, 139(8), 998-1002.
- World Health Organization Expert Committee. (1990). *Cancer pain relief and palliative care: Report of a WHO expert committee*. Technical Report Series 804. Geneva: World Health Organization.
- Yancey, D., Greger, H.A., & Coburn, P. (1990). Determinants of grief resolution in cancer death. *Journal of Palliative Care*, 6(4), 24-31.

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All correspondence should be addressed to Priscilla M. Koop, Faculty of Nursing, 3rd floor, CSB, University of Alberta, Edmonton, AB T6G 2G3.

A Bereavement Intervention for Parents Following the Sudden, Violent Deaths of Their 12-28-Year-Old Children: Description and Applications to Clinical Practice

Shirley A. Murphy

Ce rapport décrit le processus associé à la conduite d'un essai clinique de type longitudinal impliquant un échantillonnage aléatoire de parents affligés par la mort violente d'un enfant âgé entre 12 et 28 ans. Le deuxième objectif de ce rapport est d'appliquer des éléments sélectionnés de l'étude à la pratique clinique.

Les participants à l'étude étaient des parents endeuillés dont les enfants étaient décédés deux à sept mois auparavant, à la suite d'un accident, d'un homicide ou d'un suicide. Les parents ont été identifiés à l'aide du certificat de décès de leur enfant. Des 261 parents recrutés et répartis aléatoirement au sein de situations de contrôle et d'intervention, 171 étaient des mères et 90 étaient des pères. Parmi les conclusions les plus importantes, l'étude démontre qu'il existe des différences au niveau du stress fondamental et de la réaction au traitement, ces différences étant liées à l'appartenance au sexe, et ce indépendamment de toute participation au programme d'intervention. Peu importe les groupes auxquels étaient attitrés les sujets ou la période de mesure, les mères affichaient une détresse mentale plus élevée, des signes de traumatisme plus abondants, une plus grande perte de capacité d'adaptation, un état de santé plus détérioré et un taux de satisfaction conjugale inférieur, en comparaison aux pères participants. Parmi les mères, 85 % s'inscrivaient dans les critères fondamentaux caractérisant un état de détresse mentale (deux à sept mois suivant le décès), 81 % s'inscrivaient dans les mêmes critères immédiatement après le traitement (cinq à dix mois après la mort) et 67 % répondaient aux critères six mois plus tard (onze à seize mois après le décès). En ce qui a trait aux pères, 63 % s'inscrivaient dans les critères fondamentaux caractérisant un état de détresse mentale, 71 % répondaient aux mêmes critères immédiatement après le traitement et 69 % répondaient aux critères six mois plus tard. Les recommandations issues de l'étude comprennent la planification du programme, le recrutement et le maintien de la participation, la sélection et l'orientation des participants, le format du programme et l'évaluation.

This report describes a randomized clinical trial with a longitudinal design involving parents bereaved by the violent deaths of their 12-28-year-old children, with a view to applying selected components of the study to clinical practice. Parents of children who died in the previous two to seven months by accident, homicide, or suicide were identified through the death certificates of the children. Of the 261 parents recruited and randomized to intervention and control conditions, 171 were mothers and 90 were fathers.

Shirley A. Murphy, R.N., Ph.D., F.A.A.N., is Professor, Department of Psychosocial and Community Health, School of Nursing, University of Washington, Seattle.

Among the most important findings were: gender differences in both baseline distress and treatment response; and a very slow rate of reduction in distress over time, irrespective of participation in the intervention. Regardless of study group assignment and measurement period, mothers reported higher mental distress, more evidence of trauma, poorer loss accommodation, poorer physical health, and less marital satisfaction than did fathers. Among mothers, 85% met mental distress caseness criteria at baseline (2 to 7 months post-death), 81% met the criteria immediately following the treatment (5 to 10 months post-death), and 67% met the criteria six months later (11 to 16 months post-death). For fathers, 63% met mental distress caseness criteria at baseline, 71% met the criteria immediately post-treatment, and 69% met criteria six months later. Recommendations concern program planning, recruiting and retaining participants, screening and orientation of participants, program format, and evaluation.

In 1992 alone, over 40,000 Americans between 12 and 28 years of age died by accident, homicide, or suicide. These three causes of violent death account for 80% of all deaths among U.S. youth and young adults, with motor vehicle accidents (MVA) accounting for nearly 50% (U.S. Bureau of the Census, 1995). Statistics for Canadian youth differ markedly: accidents are the fifth leading cause of death, suicides the eighth; however, homicides are apparently categorized under "all other causes" (Health Statistics Division, Canada, 1994).

Parents of young people who die violently are an understudied and "at risk" population. Although studies have *identified* challenges faced by bereaved parents, such as prolonged grief, difficulty eating and sleeping, strain in the marital relationship, and overprotection of other children (Cook, 1983, 1988; Lehman, Wortman, & Williams, 1987; Schwab, 1990), few have included control groups, none have collected extensive amounts of data over time, and none have focused on parents bereaved by the violent deaths of adolescent and young-adult children. The current report has two primary purposes: to describe a randomized clinical trial conducted with parents following the violent deaths of their 12–28-year-old children; and to make recommendations concerning parent-bereavement programs in the community based on the results of the study.

Negative Consequences of a Child's Violent Death for Parents

Pervasiveness of problems. When a young person dies violently, the suddenness and irrevocability of the death, and the disbelief that one's child has died before one, causes the parents intense suffering. Investigators consistently report that the violent death of a child is the most negative life event one can experience, affecting all domains of personal and social functioning, including affect, cognition, health, and legal and economic status (Amick-McMullan, Kilpatrick, Veronen, &

Smith, 1989; Lehman et al., 1987; Rando, 1986; Rynearson & McCreery, 1993; Trolley, 1993; Van Dongen, 1991).

Each of the three modes of death studied can result in mental distress, trauma, delayed loss accommodation, poor physical health, and role strain. In a controlled study (Lehman et al., 1987), parents bereaved by the accidental death of their child reported depression, physical illness, absenteeism from work, inadequate support from their social networks, and divorce rates that were eight times those of matched controls. A recent study with parents following the sudden death of their children found significantly decreased T-suppressor cells, significantly increased T-helper cells, and depression, compared to control parents (Spratt & Denney, 1991).

Persistence of problems. The problems associated with coping with violent death appear to occur immediately and to persist for a long time (Amick-McMullan et al., 1989; Lehman et al., 1987; Lord, 1987; Rinear, 1988). Lehman et al. reported statistically significant differences between bereaved and control-group parents up to seven years after the death in the areas of self-esteem, depression, marital and parental performance, and employment stability. In addition, bereaved parents continued to report feelings of grief, resentment, rage, guilt, blaming others, being stigmatized, and inability to find meaning in the sudden, violent death. Finally, some parents face civil and criminal trials that last several years, resulting in economic hardship and lack of closure (Lehman, Ellard, & Wortman, 1986; Lehman et al., 1987; Trolley, 1993). Thus the evidence overwhelmingly suggests that losses are not resolved but merely accommodated, and that parents' lives are permanently changed. Both the pervasiveness and the persistence of the problems suggest that some parents need supplemental support.

Types and Functions of Social Support During Bereavement

Network-centred support. A central assumption of social-support theory is that close personal relationships, particularly those involving kin, protect individuals against the impact of stressful life events (Cohen & Wills, 1985; Gottlieb, 1988; Thoits, 1986, 1995; Wellman & Wortley, 1990). It has also been proposed that both confidantes and acquaintances are necessary to the bereavement process, to ensure a cadre of non-judgemental listeners should family members and close friends tire of hearing the same story repeated over and over (Pennebaker & O'Heeron, 1984; Perrine, 1993; Wellman & Wortley).

Peer-centred support. Silverman (1980) suggests that mutual-support groups might be a better source of support than confidantes and kin. Mutual support provides a milieu for identification with others who have similar knowledge and experience, for expression of mutual concerns, and for the emotional support that is said to contribute to the processes of loss accommodation (Bahrey, McCallum, & Piper, 1991; Silverman, 1980; Thoits, 1986; Yalom & Vinogradov, 1988). Feedback based on group consensus makes a more powerful impression than suggestions or advice offered by individuals (Gottlieb, 1988). The Compassionate Friends (TCF) is the only known U.S. organization devoted to parent bereavement. However, its bereavement groups meet only once a month, and all parents, regardless of how their child died or the age of the child at the time of death, attend the same meeting. Survivors of Suicide (SOS) and Victims of Violent Crime also convene only monthly.

Thoits (1986) has contributed to our understanding of *how* support works, through her conceptualization of social support as comprising two types of coping assistance: problem-focused and emotion-focused. Problem-focused support consists of direct actions to alter circumstances deemed threatening, or alter the meaning of a situation by offering information or advice that might motivate one to adapt. A problem-focused intervention provides information and training in the coping skills that pertain to specific stressors. Emotion-focused support consists of actions or thoughts to control negative feelings, alter mood, and cause one to feel respected and loved (Thoits, 1986). An emotion-focused intervention creates a safe environment for disclosure and validation of feelings associated with an event and its consequences.

Major Factors Affecting Parental Bereavement Outcomes

Three causal processes linked the children's violent death to the dependent variables and provided a rationale for the design of the bereavement program. These were: the suddenness and violent nature of the death, the age of the deceased at the time of death, and insufficient social support. According to Bloom (1981), causal processes become the intended targets for change.

The experience of sudden, violent death interferes with cognition, perception, and the expression of emotion. Some parents witness the violent death of their child, but parents typically learn of the death from others. The hanging of one's child, or the severely burned or maimed body of one's child, provoke images that are inescapable and that can

lead to great difficulty accommodating the loss (Amick-McMullan et al., 1989; McIntosh, 1993; Rinear, 1988).

Assumptive world theory (Janoff-Bulman & Frieze, 1983) postulates that we generally view the world as benevolent and meaningful and the self as worthy. The sudden, violent death of a child brings about the abrupt disintegration of our inner world, rendering the self helpless and weak in a malevolent, meaningless world. The coping task is to construct a new assumptive world consisting of the personal and relational change needed to prevent breakdown in partner communication, poor coping response, and loss of self-esteem and self-efficacy. This task might be particularly drawn out and difficult because of the tension between emotion and cognition. Denial and numbing represent efforts to avoid dealing with the event, whereas intrusion and re-experiencing represent efforts to confront it. Persistently talking about the event allows survivors to revise it in ways that make it more tolerable and to impose order on experience. Cognitive reframing and assimilation might help to reduce the number of intrusive thoughts and images.

In addition to shattering assumptions about an orderly and predictable world, stigmatizing aspects of the violent death of a child interfere with a parent's mental/emotional status. These stigmatizing aspects include suicide, high-risk behaviours such as speeding, driving while intoxicated, neglecting to use safety devices, and joining gangs. Parents might perceive that they are being blamed for the death, which can lead to disruptions in sleep, thought processes, and sense of well-being (Calhoun, Selby, & Abernathy, 1984; Ness & Pfeffer, 1990).

The youth of the deceased at the time of death makes it difficult to find meaning in the death. Shanfield and Swain (1984) found several significant predictors of poor bereavement in parents, such as the child living at home at the time of the death. Bereaved parents frequently believe they should have prevented the death.

Family life cycle theory (Carter & McGoldrick, 1988) suggests that mid-life parents and their children are at crucial stages in their development. Parents are redefining marital/parenting roles, trying to attain career goals, and, sometimes, caring for aging parents. Youth are defining their identities and struggling to achieve emotional and economic independence. Parents' inability to find meaning early in the bereavement process may lead to mental distress, role strain, poor health, and delayed loss accommodation, in which case both problem-focused and emotion-focused dimensions of support are needed to reduce negative consequences.

Insufficient social support can lead to a sense of alienation. Parents' social networks do not always provide adequate support during the lengthy bereavement period (Jacobsen, 1986; Lehman et al., 1987; Piper, McCallum, & Azim, 1992). Network links, including colleagues and superiors, might have unrealistic expectations of the bereaved. For example, Janoff-Bulman and Frieze (1983) and Wortman and Lehman (1983) posit that one's initial reaction to another's plight is to recognize one's own vulnerability — "this could happen to me." The personalizing of another's situation, particularly when one perceives it as within the realm of possibility for oneself, is apparently so compelling that it can engender feelings of insecurity, vulnerability, helplessness, and anxiety. To relieve these feelings, one might blame or avoid the victim, or discount the event. Because social support is an interactive process, the result might be unintentional negative effects on the bereaved, such as being avoided or being given hurtful messages. Thus some parents might require supplemental support.

In summary, causal processes linking the violent death of a child and potential negative outcomes were the basis of a hypothesis tested as part of the first aim of the study: to determine the immediate and short-term effects of a two-dimensional preventive intervention provided two to seven months post-death. The second aim of the study was to identify factors associated with a lessening of mental distress, progressive resolution of loss, decreasing number of disruptions in health-maintenance behaviours, and improved role functioning. The third aim of the study was to determine the value of the program from the viewpoint of the participants, by assessing their responses.

Method

Design

A multi-site randomized cohort study was conducted over a three-year period. Post-treatment follow-up took place immediately following, six months following, and 18 months following the program.

Participants and Procedures

Inclusion criteria. Criteria for inclusion in the study were as follows: The deceased child had to have died, unmarried, between the ages of 12 and 28, by accident, homicide, or suicide within 72 hours of the initial traumatic insult and two to seven months preceding the intervention. The parent (biological, step- or adoptive) of the deceased child

had to agree to be randomized to either the experimental or the control group and had to reside within a three-county area, in order to attend weekly sessions for the purpose of data collection.

Identification and recruitment strategies. Death certificates on file at Medical Examiner's offices in two northwestern U.S. states were used to identify parents of the deceased youth. Approval of recruitment procedures was obtained from the University of Washington Human Subjects Division and the Oregon State Health Division Institutional Review Board. A total of 571 death records that met the inclusion criteria were reviewed over a period of two and a half years. Of these, 329 (57.6%) included sufficient information to allow contact with potential subjects. Of the 329 families contacted, 204 families (a total of 261 persons, either single or part of a couple) agreed to participate, for a response rate of 62%. Major reasons for parents' refusal to participate were that the bereavement program would conflict with their work schedule (26%) and that they did not need help (18%). However, in most instances of refusal no explanation could be obtained.

Parents were contacted by letter, which stated that a follow-up phone call would be made if the accompanying form was not returned, in the stamped envelope provided, within one week. Because the letter was a vital document — it was the only available means of contacting potential parents — parents from a previous pilot study were asked to review it and a communications expert was also consulted. Prior to baseline data collection, 153 parents (58.6%) were randomly assigned to the intervention group (101 mothers and 52 fathers) and 108 parents (41.4%) were assigned to the control group (70 mothers and 38 fathers). Married and partnered parents were assigned to the same treatment condition. Randomization was based on accrual, with assignment first to intervention, then to control, until all eligible parents in each cohort were assigned. The program was begun within two weeks after recruitment.

Size, Representativeness, and Characteristics of Sample

At baseline, data were provided by 261 parents (171 mothers, 90 fathers), ranging in age from 32 to 61 (mean = 45 years, *s.d.* = 6.01). The sample was 86% Caucasian, educated (mean years of schooling was 13.8), 65.4% employed, and 70.4% in a partnered relationship. More fathers (85.4%) were living with a spouse or partner than mothers (62.6%) ($\chi^2 = 14.6, p < .001$). Nearly 80% of the parents professed religious affiliation (41% Protestant). The most common cause

of the child's death was accident (57.8%), followed by suicide (23.6%), homicide (9.7%), and other violent causes not classified by the Medical Examiner (8.9%). Time elapsed since death ranged from six weeks (46 days) to seven months (229 days), with a mean of 130 days (*s.d.* = 42.0). The average age of the deceased child was 20.1 years; 60% were male.

Retention procedures. Several strategies, consistent across both intervention and control groups, were initiated to retain the participants. (1) A \$25 stipend was issued within a week following each data-collection session. Parents were given the option of having the stipend sent to them or to a charity or fund of their choice. (2) A newsletter was mailed between data-collection sessions to maintain participants' interest in the study and to keep mailing addresses current. (3) A tracking system was used to keep the research team informed of the precise status of each subject (Johnson, Murphy, & Dimond, 1995). Notations on tracking forms recorded when the letter was mailed; when notices of data collection were sent; when each subject's data were received, coded, and sent to data entry; and when stipends were mailed. (4) Parents were telephoned to determine whether they had received the letter and whether they would be attending data-collection sessions as scheduled.

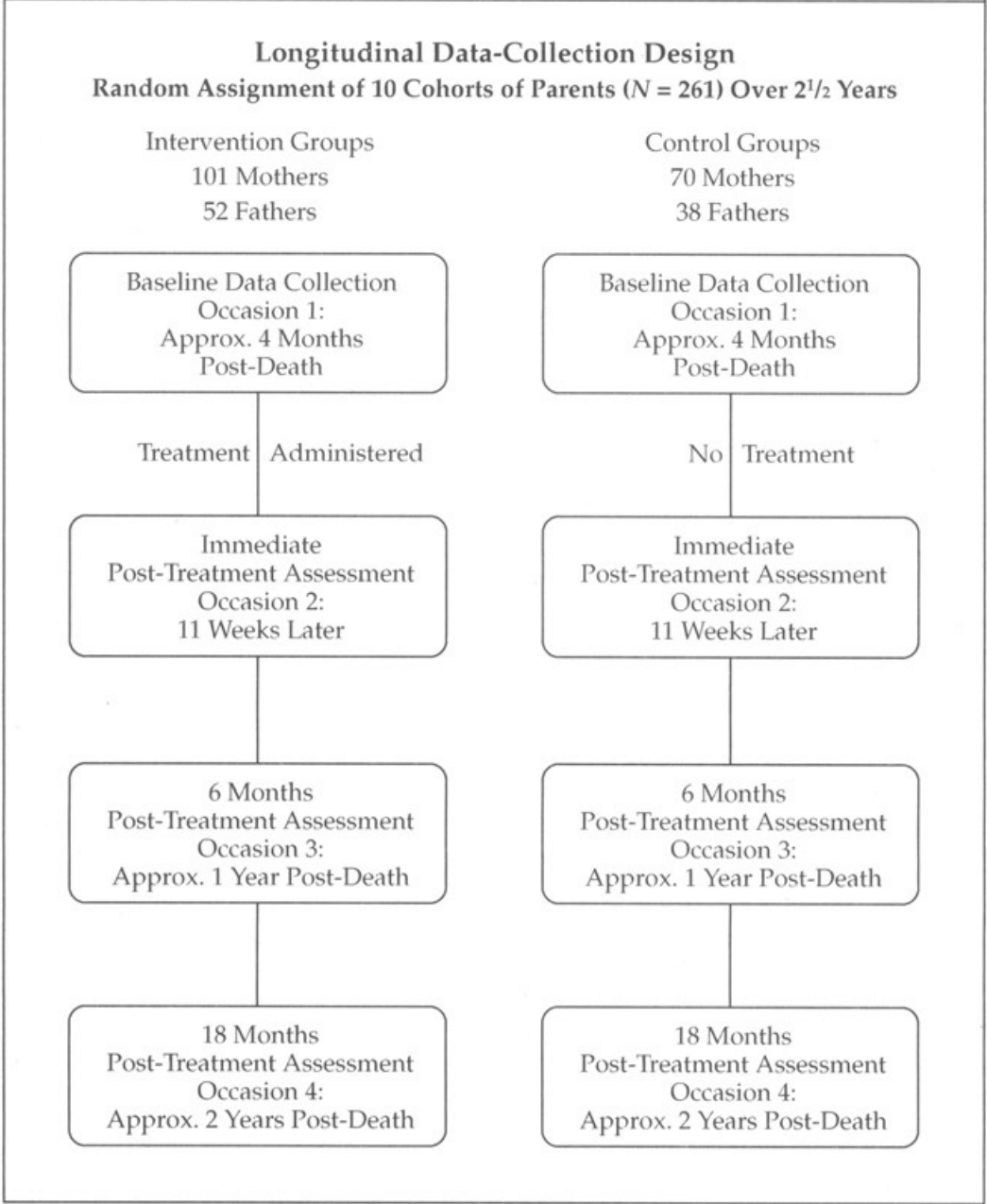
Description of Intervention

The bereavement program was designed to reduce the negative consequences of violent death by targeting five outcomes: mental distress, symptoms of post-traumatic stress disorder (PTSD), loss accommodation (grief), physical health, and marital role strain. The two-dimensional preventive intervention, the manipulated independent variable, provided a broad-spectrum approach to managing the death of a child and related consequences.

Site and structure. Neutral sites such as conference rooms in colleges or office buildings were selected for the sessions. The first and last weekly session of each 12-week sequence was reserved for, respectively, orientation and data collection. Components of the program were implemented by men/women pairs of group leaders — psychologists, nurses, or family therapists — trained by the author. A minimum of five parents is considered a critical mass necessary to facilitate discussion, whereas more than 10 is considered too many to allow for active participation (Corey & Corey, 1992; Yalom, 1985).

Enrolment and orientation. Potential subjects were recruited three times a year by cohort until 10 cohorts had been enrolled. Figure 1 shows the progression of enrolment over time. Each cohort consisted of one to four intervention groups and two control groups across the two study sites. Orientation protocols improve attendance and enhance participation (Yalom, 1985).

Figure 1 *Parent Bereavement Stress and Nursing Intervention*



Content. Problem-focused support, which was offered the first hour of each session in the 10-week program, provided a broad range of information and survival skills designed to reduce the negative consequences associated with bereavement following violent death. Topics supported by a pilot study were: Emotional Responses, Cognitive Responses, Health Responses, Parental Role Loss, Legal Concerns, Marital or Significant Other Relationships, Family Relationships, Feelings Toward Others, and Expectations for the Future. Skills specific to each topic were integrated into the sessions. Some skills were demonstrated and practised, while some were suggested, depending on time constraints. Parents were provided three-ring binders containing objectives and outline of content for each information- and skill-building session. They were encouraged to make brief notes during the presentations.

Emotion-focused support, which was offered in the second hour of each session, provided a milieu for normalizing experiences, helped parents to obtain feedback in reframing aspects of the death and its consequences, and promoted the sharing of emotional support.

Program fidelity. A research monitor tape-recorded all sessions to assess consistency across cohorts and sites, recorded attendance, made notes pertaining to parent interactions, administered weekly evaluations, and participated in staff debriefings at the close of each session. These data were used to evaluate the integrity (fidelity) of the program.

Data Collection and Variable Measurement

Data were collected in group settings from a battery of questionnaires that were administered pre-intervention and immediately following, six months following, and 18 months following the intervention. Only the five-outcome variable measurement is described here.

Mental distress was measured using the 53-item Brief Symptom Inventory (BSI) (Derogatis, 1992). The BSI yields an overall measure of mental distress, the Global Severity Index (GSI), and nine subscale indices of distress. Sample items are "difficulty concentrating" and "feeling hopeless about the future." Symptoms are rated on a five-point scale (0 = not at all, 4 = extremely) as experienced in the preceding 14 days. The GSI range of scores is 0–212. Coefficient alpha for the GSI for the current study is .97 ($N = 283$).

Symptoms of PTSD were measured using the Traumatic Experiences Scale (TES), an 18-item self-report measure based on DSM

III-R criteria (American Psychiatric Association, 1986) and developed by the author for the current study. Items include "I make deliberate efforts not to think about how my child died" and "I have trouble falling/staying asleep." TES items are rated on a six-point scale (0 = never, 5 = almost always) as experienced in the preceding seven days. A total score and three subscale scores (re-experiencing, avoidance, and hyperarousal) can be derived. The range of scores for the total TES is 0–90. Coefficient alpha for the TES was .78 ($N = 287$). Concurrent validity was assessed by correlating the re-experiencing subscale scores with an item on the Parent Bereavement Survey (PBS) that measures the frequency of intrusive thoughts (lower scores suggest greater intrusion). Correlations were in the direction predicted and ranged from $r = -.30$ to $-.40$, $p < .001$.

Loss accommodation was measured using the 25-item Grief Experiences Scale (GES) that was part of the 78-item PBS developed by the author for the current study. Items were developed as a result of focus-group input from parents whose children had died violently. Items include "I fall apart when I see a child who looks like my son/daughter" and "No one wants to talk about my child's death." The GES is scored on a five-point scale (1 = never true, 5 = almost always true). The range of scores for the GES is 25–100. Lower scores reflect better loss accommodation. Coefficient alpha was .90 ($N = 283$).

Physical health was measured using items on the Health Status/Health Behaviors Scale (HHB), a 68-item, self-report, health, health behaviours, and health-care utilization questionnaire developed by the author for the current study. One item pertaining to this report is "As of right now, how do you rate your physical health?" (1 = extremely poor, 9 = excellent).

Marital satisfaction was measured using the 10-item satisfaction subscale of the Dyadic Adjustment Scale (DAS) (Spanier, 1976). DAS items include "How often do you and your partner quarrel?" and "Do you ever regret that you married (or lived together)?" (1 = all the time, 6 = never). The range of scores is 10–60. Higher scores signify greater satisfaction. Coefficient alpha for the subscale for the current study was .88 ($N = 198$).

Pre-treatment variables were gender, marital status, ethnicity, mode of child's death, and other demographic variables such as age, occupation, education, and religious preference. Demographic information was obtained at baseline.

Information-focused and emotion-focused support, the manipulated independent variables, were assessed using the Process Evaluation Form. After each session, parents rated the relevance and timing of content, clarity of presentation, leader support (items developed by the investigator), and Yalom's (1985) nine therapeutic factors shown to facilitate change in members participating in small groups.

Data Analysis

Preliminary analyses. Descriptive statistics were computed for all study variables grouped by gender and intervention and control conditions. Scales were built and reliability was analyzed. Selection bias was assessed by examining the only common data available for both participants and decliners: the deceased child's death certificate. Neither the ethnicity $\chi^2(4, N = 261) = 5.86, p = .21$ nor the cause of death $\chi^2(3, N = 261) = 1.48, p = .69$ of the deceased child was significantly related to the probability of successful parent recruitment. Retention by gender was comparable for both intervention and control groups, and attrition did not significantly affect the representativeness of the sample.

Parents' outcomes. Baseline group means for the demographic and outcome variables were tested for differences between treatment and control conditions. There were no significant differences except for income, which demonstrated that the randomization procedure was successful. *T*-tests and analysis of covariance controlling for baseline values were used to test whether the mean of the outcome variables differed between intervention scores immediately after the treatment was administered and six months later. Plots of change scores versus baseline values were used to explore whether treatment effects differed by baseline values. Since it appeared that some interactions might be present, subjects were divided into terciles by baseline values of distress of each outcome variable. Within each tercile, the mean treatment effect was computed as the mean change score (follow-up minus baseline) in the intervention group minus the mean change score in the control group.

Parents' evaluation of the program. Data were obtained from each parent following each session. The resulting 1,186 "person/session" responses were calculated by multiplying the number of sessions attended by the number of persons attending and then summing the products obtained. Descriptive statistics were used to evaluate both the problem-focused and emotion-focused dimensions of the program.

Results

Program Fidelity

Attendance was high: 94% of parents attended six to 10 sessions. Analysis of tape-recorded data showed both that the problem-focused support was delivered according to protocols and that there was congruence between the concerns raised by parents in the emotion-focused support dimension and the content of the information sessions.

Parents' Outcomes (Aim 1)

Pretreatment (baseline) status. Upon entering the study and prior to treatment (four months post-death, on average), over 80% of the mothers and over 60% of the fathers scored three to four times higher on measures of mental distress than the normative group on which the BSI was tested (Derogatis, 1992). However, a significant minority of parents did not rate themselves as highly distressed, which made it difficult to detect which subjects benefited from the program.

Effects of treatment. The results of hypothesis testing showed that mothers reported significantly higher scores (i.e., poorer outcomes) than fathers and that for both genders reduction in distress over time proceeded at a very slow rate. Mothers who started out with high levels of distress appeared to benefit more from the intervention than mothers who started out with lower levels of distress. Interactions were statistically significant, both immediately following treatment and six months later, for three of the five outcome variable comparisons: mental distress, PTSD, and grief. There were no apparent benefits for mothers regarding physical health or marital role strain. Fathers, regardless of ranking of distress at baseline, did not appear to benefit from the intervention (Murphy et al., in press a).

Results of Within-Group Dependent Variable Analysis (Aim 2)

A second goal of the project was to identify factors associated with fewer negative consequences. Findings that have implications for parent bereavement programs will now be summarized.

Trauma. Among mothers, the prevalence of PTSD was 39% at baseline and 32% two years post-death (18 months post-intervention). Among fathers, diagnostic criteria for PTSD were met by 6% at baseline, but the rate had risen to 16% two years later. Less than 1% of the normal population report PTSD symptoms (Helzer, Robins, & McEvoy,

1987). Parents who met diagnostic criteria for PTSD at baseline differed significantly on all outcome variables when compared to parents who did not meet the criteria (Murphy et al., in review).

Physical health, health-care utilization, and health-protective behaviours. As reported above, status of physical health did not appear to be affected by the intervention. However, when the health-status item "As of right now, how do you rate your health?" (scored 1 to 9) was dichotomized as "poor" (scored 4 or lower) or "good-to-excellent" (scored 5 or higher), 20% reported poor health, compared to 16% for a national sample of comparable age (Thomas, Plo, & Sehnert, 1994). Both mothers and fathers in poor health were at significantly higher risk for mental distress, trauma, grief, and repressive coping than those in good health. A majority of both mothers and fathers reported at least one physician visit per month during the first year of the bereavement period. Seven health-protective behaviours (balanced diet, not smoking, low alcohol consumption, weekly exercise and leisure activity, low repressive coping, high active coping) practised by the majority of both mothers and fathers were significantly associated with fewer stress-related illnesses, fewer days absent from work, and higher productivity at work (Murphy et al., in press b).

Causes of death. When the five major outcome variables were examined by grouping parents by cause of child's death, many significant findings emerged. Significantly, more parents whose child died by homicide were non-Caucasian ($p = .003$). These parents also reported significantly higher levels of mental distress four and 12 months after the death than parents whose children died by other causes. In addition, they reported the most physician visits and the highest rates of prescription drug use.

Parents whose children died as the result of an accident were more likely to be unmarried than parents whose children died by other causes ($p = .02$), and they reported less mental distress, trauma, and grief than parents whose children were murdered.

Parents whose children died by suicide perceived their children as significantly unhappier and less well-adjusted than parents in the other two groups. They also reported perceiving less harmony and more unresolved conflict in the parent/child relationship than parents in the other two groups. These parents also perceived themselves as experiencing more changes in religious practices (i.e., less private prayer, family prayer, and church attendance). Their rates of mental distress, trauma, and grief were similar to those of parents whose child died by accident.

Parents' Evaluation of Program (Aim 3)

The program was strongly endorsed by parents. The most highly rated problem-focused dimensions were readiness — that is, whether an issue had been resolved or whether the respondent was ready to deal with the issue raised — and relevance of content (rated 0 = not relevant, 5 = very relevant, and by identifying most and least relevant topics). The emotion-focused dimensions rated most highly were cohesion (“helped me feel I belonged”) and universality (“helped me feel I’m not alone”). Person/session ratings of the usefulness of each component of the program showed that 63% of the parents rated “both parts equally useful.” The open-ended comment section was completed by 75% of the mothers and 65% of the fathers. These data were analyzed by content analysis. The following comments are representative: “thank you, I need this badly”; “the session tonight helped validate my feelings, actions, and reactions”; “I learned something important tonight about letting others help me”; “talking helps, listening helps even more.” Less than 1% of the comments were negative or suggested how things might be improved (Murphy et al., 1996).

Discussion

Transferability of Clinical Trial to Clinical Practice

An advantage of a large, federally funded study such as the current one is that it can be conducted over a period of time long enough to permit evaluation of both the structure and the effects of the program. Overall, 23 intervention groups of five to 10 parents were observed. The benefits of holding repeated sessions include the opportunity to measure seasonal effects and the effects of major holidays that could confound results, observe therapist characteristics, and note the effects of different group themes that evolve as a result of differing group constellations.

A disadvantage of a clinical trial is its inflexibility: Each group must receive identical treatment. Because time elapsed since death had to be kept constant, it was impossible to “wait-list” parents because of some potentially undesirable effects of randomization. For example, of the 23 groups, two included only one father, four included only one parent whose child had died by suicide, and four included only one parent whose child had died by homicide. No group included more than one non-Caucasian parent or couple. A group-by-group analysis of parent ratings to determine the effects of these factors is being undertaken.

Validity and reliability of findings. A major concern of clinicians who strive to apply theory and empirically based findings is the extent to which the findings are valid and reliable. The effects of sample bias, the effects of attrition, and potential baseline differences between intervention and control groups were all insignificant. The results of program integrity (fidelity) obtained through feedback and the tape-recordings of research monitors demonstrated that the program was implemented consistently across sites and over time.

Recruiting and retaining participants. Although research in this area is limited, it has been suggested that gender differences and self-selection (towards more distress rather than less) occur in participation in mutual-support groups (Levy & Derby, 1992). Widows reporting high levels of distress participate in mutual-support groups at a higher rate than widowers who reported less distress (Stroebe & Stroebe, 1989-90). Parents who join the TCF organization may also be unique — primarily Caucasian, married, educated, and employed full-time (Hogan, Morse, & Tason, 1996). Similar characteristics have been reported for participation in Canadian support groups (Gottlieb & Peters, 1991). Little is known about a broader spectrum of bereaved parents — those who do not participate in support groups, non-Caucasian parents of murdered youth, and parents in the low- to lower-middle-class socioeconomic class.

Format. Parents welcomed the opportunity to meet with the principal investigator for the orientation. Parents expressed satisfaction with the problem-focused and emotion-focused dimensions of the program: 63% said, "Both parts were equally useful." However, since both dimensions were offered to all parents randomized to the intervention it was impossible to measure the separate effects of either, and thus to know if one dimension was more effective than the other in reducing distress. Having a new topic for information- and skill-building at each group meeting apparently created the perception that progress was being made. Parents said, "We would never get to all these topics if the format was discussion-only." Questions parents asked throughout the program indicated a need for both repetition and clarity in the written materials. This finding is consistent with parents' reports of difficulty concentrating, problem-solving, and maintaining productivity at work.

Differences were found according to marital status and gender. Single parents did not rate the Managing the Marital Relationship session highly. In general, the ratings of fathers were somewhat lower than those of mothers.

The high rates of participation among almost all parents in group after group in the emotion-focused support sessions suggest they needed a forum for discussion. Data are currently being analyzed to determine the extent to which parents in the intervention program sought out each other for support and friendship after the program ended. Cause of death did not appear to be a barrier in joint programming; the suddenness of the death and similarity in age of both the parents and their deceased children appeared to contribute to group cohesiveness.

Group effects and individual change. Yalom's (1975, 1985) Therapeutic Group Factors were measured each week. Of the nine factors, five (altruism, catharsis, cohesion, instillation of hope, and universality) were rated significantly higher by the mothers than the fathers. Analyses are yet to be conducted to determine how each group constellation (i.e., all married couples, all mothers, a mix of causes of death, etc.) rated the extent to which Yalom's "curative" factors were present in group sessions.

The results clearly demonstrate that reduction of distress, as measured using the GSI (Derogatis, 1992), occurred at a very slow rate. This finding may have implications for the "strength" of a treatment (Yeaton & Sechrest, 1981). The current program was convened once a week instead of once a month and was more comprehensive (one hour of problem-focused support followed by one hour of emotion-focused support) than those typically offered by peer-support bereavement groups in the community. However, additional sessions, as well as booster sessions, may be needed to reinforce some concepts, especially among the most highly distressed parents. After the program had been implemented, Stewart and Archbold (1992) published their suggestion that individual difference variables measured as outcomes are not sensitive to change and therefore are not to be recommended. These authors suggested identifying elements of the intervention itself as outcome variables to be measured. Therefore, a component was added to the six-month post-intervention follow-up to begin to assess effects directly. For example, it was learned that couples who attended sessions together reported significantly more communication about each other's bereavement responses compared to parents who attended alone ($p < .0001$). These results can guide future studies.

Differences according to gender. One of the most clinically significant findings of the study was the definitive differences according to gender, both in levels of distress reported and in treatment response. These findings can be attributed in part to gender socialization (Cook,

1988). It may be that the orientation program and some sessions need to include breakout sessions by gender.

Trauma. When the study was approved for funding in 1990, there was little in the literature to suggest that bereaved parents were at risk for PTSD. Therefore the program did not place much emphasis on reducing the effects of PTSD. Yet symptoms of trauma, especially re-experiencing, were found to be troubling for a significant proportion of the mothers. The investigators were also surprised by the increase over time in trauma symptoms among fathers. Future programs might attend more aggressively to this important clinical phenomenon.

Health-protective behaviours. The items pertaining to diet, exercise, leisure activities, smoking, use of alcohol, and use of prescription and over-the-counter drugs are very informative and are applicable to other programs. The current program featured only one session on health. However, the finding that engaging in two or more health-protective behaviours per week was associated with fewer stress-related illnesses, fewer days absent from work, and a perception of higher productivity at work suggests that lifestyle is an important factor in bereavement.

Cause of death. Parents whose children were murdered reported higher rates of mental distress than parents whose children died by accident or suicide. The unique differences among parents when data were analyzed according to cause of death suggests that programs should be individualized to meet specific needs.

Finally, the results of the longitudinal follow-up have implications for clinicians whose work does not involve bereavement programming. For example, the very slow rates of stress reduction have implications for clinicians in both family and specialty practice. The deterioration of fathers' health is noteworthy, as are the high rates of prescriptive medication taken by bereaved mothers.

In summary, the following recommendations apply to the early bereavement stage for parents whose adolescent and young-adult children have died violently: (1) Plan the program with explicit goals in mind. (2) Screen applicants to ensure a balanced group constellation. For example, place at least two fathers in a group composed of mothers. If all causes of death are represented in a single group, ensure that at least two different families are represented in each. (3) Provide orientation. Participants are active consumers of care and need to know what to expect. Moreover, parents want to meet the investigators. (4) Provide both problem-focused and emotion-focused support. Parents in the

current study were extremely positive about this format. (5) Provide written materials. Parents are anxious and exhausted and have trouble concentrating. (6) Individualize where necessary. The investigators were surprised by the differences they found among just five to 10 people. For some parents, a crisis service or phone service may be adequate; other parents may require extensive information and support. Baseline assessment data will help clinicians to meet the unique needs of parents. (7) Have participants evaluate each session. Parents like being asked for their opinions. A well-designed form can be administered quickly to gather essential information about the functioning of the program.

Conclusion

The results of a large randomized clinical trial with bereaved parents provide numerous applications for both bereavement programs and general and specialty clinical practice. Among the most important findings are: differences according to gender in both baseline distress and treatment response; a very slow rate of reduction in distress over time, irrespective of participation in an intervention; and a lack of congruence between parents' reports of satisfaction with the program and their outcomes measured as individual difference variables. Nonetheless many valuable clinical applications are possible, provided they include careful planning, recruitment, screening, and orientation, both problem-focused and emotion-focused support, and collection of evaluation data.

References

- American Psychiatric Association. (1986). *Diagnostic and statistical manual of mental disorders* (3rd rev. ed.). Washington: American Psychiatric Association Press.
- Amick-McMullan, A., Kilpatrick, D.G., Veronen, L.J., & Smith, S. (1989). Family survivors of homicide victims: Theoretical perspectives and an exploratory study. *Journal of Traumatic Stress*, 2(1), 21-35.
- Bahrey, F., McCallum, M., & Piper, W. (1991). Emergent themes and roles in short-term loss groups. *International Journal of Group Psychotherapy*, 41(3), 329-345.
- Bloom, B.L. (1981). The logic and urgency of primary prevention. *Hospital and Community Psychiatry*, 32, 839-843.
- Calhoun, L.G., Selby, J.W., & Abernathy, C.B. (1984). Suicidal death: Social reactions to bereaved survivors. *Journal of Psychology*, 116, 225-261.

- Carter, B., & McGoldrick, M. (1988). *The changing family life cycle*. New York: Gardner.
- Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310–357.
- Cook, J.A. (1983). A death in the family: Parental bereavement in the first year. *Suicide and Life-Threatening Behavior*, 13(1), 42–61.
- Cook, J.A. (1988). Dad's double binds. *Journal of Contemporary Ethnography*, 17(3), 285–308.
- Corey, M.S., & Corey, G. (1992). *Groups: Process and Practice* (4th ed.). Pacific Grove, CA: Brooks Cole.
- Derogatis, L.R. (1992). *BSI-Administration, scoring, and procedures manual-II*. Baltimore: Clinical Psychometric Research.
- Gottlieb, B.H. (1988). Marshalling social support: The state of the art in research and practice. In B.H. Gottlieb (Ed.), *Marshalling social support: Formats, processes, and effects* (pp. 11–51). Newbury Park, CA: Sage.
- Gottlieb, B.H., & Peters, L. (1991). A national demographic portrait of mutual aid group participants in Canada. *American Journal of Community Psychology*, 19(5), 651–666.
- Health Statistics Division, Canada. (1994). *Statistics Canada. Table of causes of death by gender*. Ottawa: Ministry of National Health and Welfare.
- Helzer, J.E., Robins, L.N., & McEvoy, L. (1987). Post-traumatic stress disorder in the general population. *New England Journal of Medicine*, 317(26), 1630–1634.
- Hogan, N., Morse, J.M., & Tason, M.C. (1996). Toward an experiential theory of bereavement. *Omega*, 33(1), 433–465.
- Jacobson, D.E. (1986). Types and timing of social support. *Journal of Health and Social Behavior*, 27, 250–264.
- Janoff-Bulman, R., & Frieze, I. (1983). A theoretical perspective for understanding reactions to victimization. *Journal of Social Issues*, 39(2), 1–17.
- Johnson, L.C., Murphy, S.A., & Dimond, M. (1995). Tracking subjects in longitudinal studies with complex protocols. *Communicating Nursing Research*, 28, 224.
- Lehman, D.R., Ellard, J.H., & Wortman, C.B., (1986). Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology*, 54, 438–446.
- Lehman, D.R., Wortman, C.B., & Williams, A.F. (1987). Long-term effects of losing a spouse or child in a motor vehicle crash. *Journal of Personality and Social Psychology*, 52, 218–231.
- Levy, L.H., & Derby, J.F. (1992). Bereavement support groups: Who joins; who does not; and why. *American Journal of Community Psychology*, 20(5), 649–662.
- Lord, J.H. (1987). Survivor grief following a drunk-driving crash. *Death Studies*, 11, 413–435.
- McIntosh, J.L. (1993). Control group studies of suicide survivors: A review and critique. *Suicide and Life-Threatening Behavior*, 23(2), 146–161.

- Murphy, S.A., Baugher, R., Lohan, J., Scheideman, J., Heerwagen, J., & Johnson, L.C. (1996). Parents' evaluation of a preventive intervention following the sudden, violent deaths of their children. *Death Studies*, 20, 453-468.
- Murphy, S.A., Braun, T., Tillery, L., Cain, K.C., Johnson, L.C., & Beaton, R.D. (in review). PTSD among bereaved parents following the violent deaths of their 12 to 28-year-old children: A longitudinal prospective analysis.
- Murphy, S.A., Johnson, L.C., Cain, K.C., Das Gupta, A., Dimond, M., Lohan, J., & Baugher, R. (in press a). Broad spectrum group treatment for parents bereaved by the violent deaths of their 12- to 28-year-old children: A randomized controlled trial. *Death Studies*.
- Murphy, S.A., Lohan, J., Braun, T., Johnson, L.C., Cain, K.C., Baugher, R., Beaton, R.D., & Dimond, M. (in press b). Parents' health, health care utilization, and health behaviors following the violent deaths of their 12- to 28-year-old children: A prospective longitudinal analysis. *Death Studies*.
- Ness, D.E., & Pfeffer, C.R. (1990). Sequelae of bereavement resulting from suicide. *American Journal of Psychiatry*, 147(3), 279-285.
- Pennebaker, J.W., & O'Heeron, R.C. (1984). Confiding in others and illness rate among spouses of suicide and accidental-death victims. *Journal of Abnormal Psychology*, 93, 473-476.
- Perrine, R.M. (1993). On being supportive: The emotional consequences of listening to another's distress. *Journal of Social and Personal Relationships*, 10, 371-384.
- Piper, W.E., McCallum, M., & Azim, H.F.A. (1992). *Adaptation to loss through short-term group psychotherapy*. New York: Guilford.
- Rando, T.A. (1986) *Parental loss of a child*. Champaign, IL: Research Press.
- Rinear, E.E. (1988). Psychosocial aspects of parental response patterns to the death of a child by homicide. *Journal of Traumatic Stress*, 1(3), 305-322.
- Rynearson, E.K., & McCreery, J.M. (1993). Bereavement after homicide: A synergism of trauma and loss. *American Journal of Psychiatry*, 150, 258-261.
- Schwab, R. (1990). Effects of a child's death on the marital relationship: A preliminary study. *Death Studies*, 16, 141-154.
- Shanfield, S.B., & Swain, B.J. (1984). Death of adult children in traffic accidents. *Journal of Nervous and Mental Disease*, 172, 533-538.
- Silverman, P.R. (1980). *Mutual help groups: Organization and development*. Beverly Hills, CA: Sage.
- Spanier, G.B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-27.
- Spratt, M.L., & Denny, D.R. (1991). Immune variables, depression, and plasma cortisol over time in suddenly bereaved parents. *Journal of Neuropsychiatry and Clinical Neurosciences*, 3, 299-306.
- Stewart, B.J., & Archbold, P.G. (1992). Nursing intervention studies require outcome measures that are sensitive to change: Part One. *Research in Nursing & Health*, 15, 477-481.

- Stroebe, M.S., & Stroebe, W. (1989-90). Who participates in bereavement research? A review and empirical study. *Omega*, 20(1), 1-29.
- Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, 54, 416-423.
- Thoits, P.A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior (Extra Issue)*, 53-79.
- Thomas, R.K., Plo, L.G., & Sehnert, W.F. (1994). *Health care book of lists*. Winter Park, FL: PMD Publishers.
- Trolley, B.C. (1993). Kaleidoscope of aid for parents whose child died by suicidal and sudden, non-suicidal means. *Omega*, 27(3), 239-250.
- U.S. Bureau of the Census. (1995). *Statistical Abstract of the United States* (115th ed.). Table 127, Deaths by Age and Leading Causes of Deaths in 1992 (p. 94). Washington: U.S. Government Printing Office.
- Van Dongen, C.J. (1991). Experiences of family members after a suicide. *Journal of Family Practice*, 33(4), 375-380.
- Wellman, B., & Wortley, S. (1990). Different strokes from different folks: Community ties and social support. *American Journal of sociology*, 96, 558-588.
- Wortman, C.B., & Lehman, D.R. (1983). Reactions to victims of life crises: Support attempts that fail. In I.G. Sarason & B.R. Sarason (Eds.), *Social support: Theory, research and applications* (pp. 463-489). The Hague: Martinus.
- Yalom, I. (1975). *The theory and practice of group psychotherapy* (2nd ed.). New York: Basic.
- Yalom, I. (1985). *The theory and practice of group psychotherapy* (3rd ed.). New York: Basic.
- Yalom, I., & Vinogradov, S. (1988). Bereavement groups: Techniques and themes. *International Journal of Group Psychotherapy*, 38(4), 419-446.
- Yeaton, W.H., & Sechrest, L. (1981). Critical dimensions in the choice and maintenance of successful treatments: Strength, integrity, and effectiveness. *Journal of Consulting and Clinical Psychology*, 49, 156-167.

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Correspondence should be addressed to Shirley A. Murphy, Box 357263, University of Washington, Seattle, WA 98195-7263. E-mail: samurphy@u.washington.edu

Loss and Bereavement: HIV/AIDS Family Caregiving Experiences

Kelli I. Stajduhar

Le but de cette étude théorique fondée sur une recherche empirique était de décrire l'expérience des soins prodigués en milieu familial aux personnes atteintes du VIH-sida lors de la phase palliative. Sept entrevues en profondeur ont été réalisées et analysées à l'aide d'une méthode comparative constante. L'analyse a mené à une conceptualisation des soins donnés en milieu familial. Le présent article décrit le « travail personnel » des personnes prodiguant des soins à un proche atteint du VIH-sida, à savoir l'acceptation de la mort prochaine de l'être cher, la prise de décisions critiques et le lâcher prise. La nature du soutien reçu pour effectuer ce travail est soulignée ici en mettant l'accent sur son influence sur le deuil des personnes soignant un proche atteint du VIH-sida. Les conclusions de cette étude fournissent un début de compréhension de l'expérience vécue par ces personnes et révèlent l'existence d'un besoin significatif pour des interventions visant à les aider à enclencher les mécanismes de résolution du deuil. Il est essentiel de créer et de fournir des réseaux de soutien aux personnes chargées de soigner un proche vivant avec le VIH-sida, et davantage de recherches sont nécessaires pour clarifier et explorer plus avant la question de l'impact du support social sur le deuil. Grâce à ce savoir, les professionnels de la santé seront mieux préparés pour anticiper les difficultés auxquelles font face les personnes soignant un proche atteint du VIH-sida, planifier des interventions répondant à ces difficultés, prévenir les problèmes futurs et mettre sur pied des soins fondés sur la théorie et la recherche.

The purpose of this grounded theory study was to describe the experience of HIV/AIDS family caregiving in the palliative phase. Seven in-depth interviews were conducted and analyzed using the constant comparative method. The analysis resulted in a conceptualization of HIV/AIDS family caregiving. This paper describes the "personal work" of caregivers, including reconciling that a loved one would die, making life-and-death decisions, and letting go. The nature of support received to attend to this work is highlighted, with attention to its influences on HIV/AIDS caregiver bereavement. The findings of this study provide some insights into the HIV/AIDS family caregiver experience and reveal a significant need for interventions designed to support caregivers in establishing the mechanisms required for bereavement resolution. The need for the creation of supportive networks for HIV/AIDS caregivers cannot be overstated. Further research is required to help clarify and expand on how social support might have an effect on HIV/AIDS family caregiver bereavement. With this knowledge, health-care providers will be better prepared to anticipate difficulties faced by caregivers, plan appropriate interventions to address these difficulties, prevent future problems, and plan care based on theory and research.

Kelli I. Stajduhar, R.N., M.S.N., is a doctoral student in the School of Nursing, University of British Columbia, Vancouver.

My partner of seven years, Christopher Esposito, was rushed to the hospital in a coma. "AIDS," they said. "Six months," they said. I clasped my hands over my ears, but the message penetrated through. Death. Destruction. Gloom. Doom. I screamed the loudest scream I ever heard in my life. It emerged from my gut and built up momentum as it raced to my heart, to the lump in my throat, to my mouth. But no sound passed my lips as the scream echoes through my brain. (Hitchens, 1992, p. 13)

Introduction

The concept of death instills fear in and seriously affects family members in a society that generally denies or does not accept death (Macklin, 1989).

The physical and emotional devastation of HIV/AIDS poses extraordinary challenges to the health-care system and to family members who frequently care for persons living with (PLW) HIV/AIDS (PLWHIV/AIDS) during the chronic and palliative phases of life (Hitchens, 1992; McShane, Bumbalo, & Patsdaugher, 1994). Caregivers attending a national HIV/AIDS family caregiver (e.g., any person whom the PLWHIV/AIDS identified as significant to him or her, regardless of kinship ties, marital relationship, or whether they shared a residence) conference identified the death of their loved one as one of the major difficulties they faced (Health & Welfare Canada, 1990). Such caregivers experience multiple loss: the loss of partners and friends, financial status, health, independence, intimacy, and freedom of sexual expression (Barouh, 1992; Grief & Porembski, 1988; Powell-Cope, 1995; Powell-Cope & Brown, 1992). This multiple loss is compounded by unique challenges such as the fact that they might be infected with HIV themselves and the deterioration and death they have witnessed could be their own fate as well (Dick, 1992; Shilts, 1987). HIV/AIDS family caregivers are usually young to middle-aged and thus might not have acquired the perspectives on death and loss that can accompany middle to old age (Brown & Powell-Cope, 1993; Folkman, Chesney, Cooke, Boccellari, & Collette, 1994). The multiplicity of societal taboos associated with HIV/AIDS can be overwhelming for caregivers (Takigiku, Brubaker, & Hennon, 1993). HIV/AIDS-related stigma can lead them to attribute the illness or death of their loved one to other causes such as cancer (Barbo, 1987; Worden, 1991). Moreover, many of the family relationships within the HIV/AIDS community are not legally acknowledged or formalized in a socially acceptable way, which can serve to accentuate the stigma.

A search of the literature reveals that caring for a person with a life-threatening illness can cause tremendous uncertainty (Brown & Powell-Cope, 1991). It can place a financial burden on family members and put them at risk for chronic fatigue and physical and emotional exhaustion (Folkman, Chesney, & Christopher-Richards, 1994; Pearlin, Semple, & Turner, 1988; Smith & Rapkin, 1996). While studies have focused on families caring for persons with cancer (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Brown, Davies, & Martens, 1990; Hull, 1989; Martens & Davies, 1990) and for the frail elderly (Horowitz, 1985; Knight, Lutzky, & Macofsky-Urban, 1993; Lindgren, 1993; Rabins, Fitting, Eastham, & Fetting, 1990), there is little information on the experiences of HIV/AIDS family caregivers, even though the majority of home-based HIV/AIDS care is provided by family caregivers (Pearlin, Mullan, Aneshensel, Wardlaw, & Harrington, 1994; Raveis & Siegel, 1990).

To address this dearth of information, an exploration and description of HIV/AIDS family caregiving in the palliative phase was conducted. The complete results are presented elsewhere (Stajduhar, 1995). This paper will focus on the consequences to those in the HIV/AIDS caregiving role and the effects that these consequences have had on caregiver bereavement.

Methods

This study focused on developing an inductively derived description and theoretical explanation of family caregiving in the palliative phase. Grounded theory (Glaser, 1978; Strauss & Corbin, 1990) was used to examine the processes through which caregivers tended their dying loved one in the context of the home setting. This method was selected because it is particularly amenable to researching topics that have been subjected to little formal inquiry (Burns & Grove, 1987; Chenitz & Swanson, 1986).

Sample

Participants were recruited through various AIDS service organizations, home health-care providers, and community newsletters. Theoretical sampling (Morse, 1991a) was used to deliberately select participants according to the theoretical needs of the study. A total of seven family caregivers, ranging in age from 31 to 65 years, agreed to participate. All but one caregiver had lost their loved one to HIV/AIDS within a year of the study taking place. Four of the participants were partners in a gay relationship, two were mothers, and one was a sister.

Two of the participants relocated from their permanent residence to provide care, and all seven shared the household with their loved one throughout the caregiving period. More than half of the sample had received some post-secondary education. At the time of caregiving, two participants were employed full-time and one was employed part-time outside the home. Two participants were unemployed and receiving income assistance, one was unemployed and not receiving income assistance, and one was retired.

Data Collection

Data were collected through unstructured, face-to-face interviews in the home where caregiving took place. The open-ended interview format allowed for probing and clarification of participant responses. As a result, there was considerable variance in the time it took to complete each interview, which ranged from two and a half to four hours. Observational fieldnotes (Boyd, 1990; Lincoln & Guba, 1985) and theoretical memos and diagrams (Corbin & Strauss, 1990) were recorded immediately after each interview to maximize richness and depth of the data. Concurrently, newspaper clippings and videotapes pertaining to HIV/AIDS family caregiving were collected, reviewed, and analyzed to ensure a broad perspective throughout the research process. Because the interviews could be emotionally charged and draining, the researcher kept a personal journal and debriefed with colleagues as a way of reflecting on various aspects of the research and to explore and examine the researcher's own assumptions throughout the research process. As Hutchinson (1986) points out, "only through self-awareness of mind-set can the researcher begin to search out and understand another's world" (p. 115).

Analysis

Tape-recorded and transcribed interviews and fieldnotes were analyzed using the constant-comparative method. Analysis proceeded with examination of the data line by line, important passages and themes being highlighted. Each theme involved open substantive codes. *The Ethnograph* computer program (Seidel, 1988) was used to facilitate coding and to sort and manage code files. Following open coding, codes were condensed, conceptually labelled, and categorized. The categories were tested, revised, and modified throughout the process of data collection and analysis. After repeated analysis, a core category emerged, which linked to other categories and explained most of the variation in

the data. The final analysis resulted in a conceptualization of HIV/AIDS family caregiving (Stajduhar, 1995).

Several strategies were used to reduce threats to validity and reliability (Lincoln & Guba, 1985; Sandelowski, 1986). Credibility and fittingness were achieved by triangulating data sources and data-collection procedures to ensure congruence. Follow-up telephone interviews were conducted with two participants. All participants were given a summary of the analysis and asked to comment on its accuracy. The results in their entirety were presented at a national HIV/AIDS conference and to HIV/AIDS family caregivers who had not participated in the study. These steps were taken to ensure "trustworthiness" of the research (Lincoln & Guba).

Results

This study resulted in a conceptualization of HIV/AIDS family caregiving in the palliative phase. While the conceptualization has several components, only data related to loss and bereavement will be presented here.

Personal Work

Caregivers of PLWHIV/AIDS engaged in "personal work" while caring for their dying loved one at home. Personal work comprised three distinct processes. First, *reconciling* that a loved one would die began when family members noticed a decline in their physical condition. Then they perceived that their loved one was dying rather than getting better. Caregivers often characterized reconciling as a series of stages or transitions. One mother compared it to the process of discovering her son was gay:

I think you go through stages. It's the same when you find out your child is gay. You can't believe it. Go and get checked out is the first thing. Then you get over it and after a while you accept it. It's the same thing with this... knowing that he's dying.

Reconciling was difficult because the caregiver had little control over the situation, which resulted in feelings of helplessness:

You are going through hell. I mean, you're standing every day at the side of the bed of someone you love who is dying and you can't change it. There is nothing you can do. You can't sell your soul. They are dying, that's it. And you have to watch that and accept it.

Reconciling was easier when the caregiver and the loved one were able to reminisce about the good times they had shared:

We were talking about this profound love that we had for one another and the commitment that we shared. We had never had those discussions before... It became easier for me to accept he was going as long as I knew how he loved me.

Making decisions related to cessation of treatment and *letting go* were two other dimensions of personal work. In many cases caregivers struggled with wanting their loved one to live while at the same time knowing they were dying:

I knew that he was terminal, but even if he could just stay sick that was okay. Just don't die on me... that was what I was hoping for. Stay sick. I'll take care of you. We can bandage this and bandage that but just stay sick. Don't die on me.

Making decisions, particularly related to cessation of treatment, made things complicated:

He was sick and he [the doctor] said you've got to make a decision... I didn't want to make the decision... it's 100% responsibility... I literally had control over his life. I said I think we should let nature take its course. That was the most difficult decision I've ever had to make in my life.

Reconciling that a loved one was going to die and letting go were profound and difficult processes. This experience was less complicated when the caregivers were able to reflect on and discuss their life with the loved one, when they were aware of the wishes of their loved one, and when the loved one could participate in decision-making:

I knew what he wanted. We had talked about it long before he got sick. So when the time came there wasn't any problem. We were very open and honest with each other. I held his hand and ran my fingers through his hair and I'd tell him, it's okay, you don't have to fight this. It's acceptable for you to let go. So it was easier because I knew what he wanted.

Approaches to Dealing with Impending Death

Family caregivers developed and took various approaches to dealing with the impending death of their loved one. *Being with* helped them accept the fact that their loved one was going to die, and they used it as an opportunity for reconciliation:

Every minute is important because you know what the end result is... it [being with] helps in the long run. The time I spent with him ... made it okay.

Seeking support through both formal and informal mechanisms helped caregivers with personal work. Formal systems such as organized support groups and AIDS service organizations, and informal supports such as friends and family members, helped caregivers face the inevitability of death:

I think it's really great [the support group], because they set a box of Kleenex in the middle of the table and we can all tell our stories ... it's just good to have other people ... those who are going through the same thing...it helps to deal with what's to come.

When caregivers *worked as part of a team*, with nurses, social workers, physicians, and volunteers, they felt supported in their personal work. It enabled them to be acknowledged and recognized for their role. Central to the success of working as part of a team was the reciprocal trust and respect that developed between the HIV/AIDS caregiver and other members of the team:

His doctor was someone who believed in participating in care. This was a team effort...it was the three of us sitting down and saying, here are the options, what do you think? — actually listening to me as if I was a reasonably intelligent being...that my opinion mattered.

Planning for death was a final approach taken by family caregivers to deal with the impending death of their loved one. This approach helped them identify their loved one's "last wishes." Knowing these wishes gave caregivers confidence:

We talked about it right from the very beginning ... so I knew what he wanted and I could carry that out.

Planning for death also helped circumvent potential problems with other family members. More than half of the participants in the study were not related by blood to their loved one. These caregivers saw the possibility of interference and disagreement on the part of the family of origin. One partner caring for his lover said that planning for death helped him to avoid a potentially difficult situation:

I told him ... I want you to tell your mother ... I want it to come out of your mouth. I don't want her to think that I concocted this [planned memorial service]. She has got to know what you want, because we've had problems before.

Some family caregivers failed to plan for death, citing their difficulty accepting the inevitability of the death of their loved one.

The Nature of Support

HIV/AIDS family caregivers sought support in dealing with their loss and grief, but the nature of that support was a critical factor for them. One caregiver said that life would have been unmanageable without good counselling:

I don't know what we would have done without them [the social workers]. They were our backbone... they were the best support we got. It kept us upright.

When asked to explain how this support was helpful, the caregiver elaborated:

She told me the lovers tend to be forgotten. And her focus was, if you fall apart, what the hell's going to happen?... She saw an integral part of her job as keeping the partners reasonably healthy. We get supported so that we can continue to look after our lovers at home.

Support from the family of origin was a factor as well. Some caregivers were estranged from both their own family and the family of their loved one, and in some cases they received no family support at all. Other families were able to overcome their homophobic feelings, leaving the caregivers surprised and appreciative:

I think one of the biggest recognitions I got was from my parents, particularly my mother. She said, "You've gone through something I hope I never have to... you are remarkable." Coming from my mother, whoa... that was real good. It was the full acknowledgement of what I did and of our relationship, that our relationship was as significant as any straight couple's relationship.

Caregivers experienced emotional pain, feeling rejected and isolated when support was not forthcoming:

...his family was not there. It was really disappointing... I phoned his mother and she said she would come, but she never did... she was really removed. That hurt a lot. How could a mother not come to see her own son?

I had very little contact with my family. In fact there were no flowers or no card or anything saying we're sorry for your loss... you know, there are phone lines between the provinces, and airplanes, but there was never any offer of coming out, so I was disappointed by that.

Unsupportive interactions most often involved people with whom the caregivers came in frequent contact — physicians, nurses, social workers, and in some cases volunteers. They repeatedly reported encounters with health-care providers that left them feeling angry, bitter, isolated, and disillusioned. The caregivers had assumed that

health-care providers would be supportive, but their expectations were not always met:

We went to see a social worker ... I felt really good about this because we really needed help dealing with this, but this woman was hopeless. She does not belong ... with AIDS patients at all. She has no understanding. She's very good at shuffling papers, but as far as dealing with people on an emotional level she is pathetic ... we were looking for a little bit more nurturing but that was never forthcoming ... it never came ... I had no one. I was at my wit's end.

Some caregivers had their hopes dashed when they sought help from community health services:

This woman [a volunteer] from the hospice called me to see how I was doing. I said, I'm not doing that well today. Today is my birthday and birthdays were really big for G. and I. She triggered something inside me and I started to cry. As soon as she heard me crying she said, well, I'll let you go now. You take care of yourself. Take care of myself? Why did you call? What did she expect? I told her I was profoundly lonely and she hung up on me ... she literally hung up on me.

One of the caregivers, a nurse caring for his partner, experienced difficulties when he sought support from nurses in a palliative-care unit:

I think health professionals providing support to health professionals forget that we are family — that we are there just to be there. I think there is an assumption that those of us who are health-care professionals can bear the weight a bit more. So they tended not to attend to me as much, which they really needed to do.

HIV/AIDS caregivers tried to understand these unsupportive incidents, citing heavy workloads and staff stress. They believed that professional caregivers were unable to be supportive because they were not supported themselves:

Unfortunately, the majority of nurses are terribly overworked and they don't have the time to spend with patients ... I feel sad about watching the level of burnout because there are not enough of them [nurses]. They are exhausted. None of them are debriefed after someone dies. That process isn't there. They are burnt.

Consequences of Caring for a Dying Loved One with HIV/AIDS

The approaches family caregivers took in dealing with the impending death of their loved one ultimately affected their bereavement. When caregivers were able to build supportive networks they were better able to find meaning in their loss and come away with a renewed sense of self:

It was a learning experience... when you come through that whole experience you develop a certain profound sense of something. I know I definitely came out a different person. I came out with a different sense of life.

This renewed sense of self helped them to make constructive changes in their lives and acknowledge the love and commitment they had shared with their loved one:

I'm fortunate in a sense that I was loved and I was able to love so profoundly... I was there to say goodbye to him and hold him when he died.

On the other hand, caregivers who were unable to obtain support faced difficulties with their bereavement and were challenged to find meaning in their experience. Feelings of cynicism, anger, and disillusionment permeated their lives:

...rose-coloured glasses no longer exist... you know, you try and smell the roses but you realize after this that the shit that goes on is really evident. The people you have to deal with, it's just such a problem, so I don't expect that support to be there any more.

Caregivers seemed stuck in their grief and resentment:

It just replays in my mind... like that emergency room guy that I'd like to run over with a truck... it's going to be a long time until I deal with that anger, never mind my own stuff about his death.

Discussion

The findings of this study lend support to the notion that loss and grief are central to HIV/AIDS caregiving both before and following the death of the loved one. How caregivers dealt with the impending death, and what imprint was left in their minds following the death, was found to be highly dependent on the nature of the support they received. While some studies acknowledge that loss is a central theme for HIV/AIDS caregivers (Brown & Powell-Cope, 1993; Folkman, Chesney, & Christopher-Richards, 1994; Powell-Cope, 1995), the relationship between social support and caregiver bereavement remains relatively unexplored in the HIV/AIDS literature. Social support appears to be a necessary component of bereavement resolution (Broadhead et al., 1983; Vachon et al., 1982). However, in HIV/AIDS caregiving the process of family coping with bereavement is severely compromised by societal stigma (Rolland, 1990), a lack of the traditional acknowledgement that can be helpful in bereavement (Geis, Fuller, & Rush, 1986; Murphy & Perry, 1988), and inappropriate support from

health-care providers (Ferrell & Boyle, 1992; Lennon, Martin, & Dean, 1990). The results of this study demonstrate that supportive networks are essential, contributing to caregivers' ability to make sense of their loss and re-emerge to face life without their loved one.

These findings reflect a significant need for interventions designed to support caregivers in establishing the mechanisms necessary for bereavement resolution. Nurses play a pivotal role in supporting family caregivers (Alexander, 1994) and are in a primary position to influence the bereavement outcomes of high-risk grievers (Ferrell & Boyle, 1992). Creating and sharing supportive relationships with nurses and others may help caregivers continue their lives with a renewed sense of self. Relationships must be built on reciprocity — making patients and caregivers equal partners on the health-care team (Morse, 1991b; Thorne & Robinson, 1988). Nurses and other health-care providers must also be aware of the potential relationship between social support and the ability of caregivers to find meaning in their loss. Only through this awareness can health-care providers begin to reflect on their actions, behaviours, and potential impact on caregivers.

Health-care workers must be comfortable caring for those infected and affected by HIV/AIDS. Unsupportive or stigmatized care will only serve to further alienate and isolate those who require care. Nurse administrators can contribute by ensuring that supportive work environments and appropriate staff education are available. For support and genuine caring to be shared, nurses must be given the opportunity to learn and to feel just as accepted, respected, and honoured as unique individuals as they profess to feel about patients and patients' families (Neil, 1994). Open discussion and commitment to creating such an environment are essential to the promotion of self-knowledge and growth.

The importance of creating supportive networks for HIV/AIDS caregivers cannot be overstated. Research is required to clarify and expand on the effect of social support on HIV/AIDS family caregiver bereavement. As well, research on effective care and support strategies for HIV/AIDS caregivers is urgently required if we are to better understand how to intervene in helping caregivers to face life without their loved one.

References

- Addington-Hall, J.M., MacDonald, L.D., Anderson, H.R., & Freeling, P. (1991). Dying from cancer: The views of bereaved family and friends about the experiences of terminally ill patients. *Palliative Medicine*, 5, 207-214.

- Alexander, R. (1994). Family caregivers for people with AIDS in rural communities. *AIDS Patient Care*, 8(4), 206-211.
- Barbo, B. (1987). *The walking wounded*. Linsborg, KS: Carlsons.
- Barouh, G. (1992). *Support groups: The human face of the HIV/AIDS epidemic*. New York: Long Island Association for AIDS Care.
- Boyd, C.O. (1990). Qualitative approaches to research. In G. Lobiondo-Wood & J. Haber (Eds.), *Nursing research: Methods, critical appraisal and utilization* (2nd ed.) (pp. 181-208). Toronto: Mosby.
- Broadhead, W.E., Kaplan, B.H., James, S.A., Wagner, E.H., Schoenback, V.J., Grimson, R., Heyden, S., Tibblin, G., & Gehlbach, S.H. (1983). The epidemiological evidence for a relationship between social support and health. *American Journal of Epidemiology*, 117, 521-537.
- Brown, M.A., & Powell-Cope, G.M. (1991). AIDS family caregiving: Transitions through uncertainty. *Nursing Research*, 40(6), 338-345.
- Brown, M.A., & Powell-Cope, G.M. (1993). Themes of loss and dying in caring for a family member with AIDS. *Research in Nursing and Health*, 16(3), 179-191.
- Brown, P., Davies, B., & Martens, N. (1990). Families in supportive care. Part II: Palliative care at home: A viable care setting. *Journal of Palliative Care*, 6(3), 21-27.
- Burns, N., & Grove, S.K. (1987). *The practice of nursing research: Conduct, critique and utilization*. Philadelphia: Saunders.
- Chenitz, W.C., & Swanson, J.M. (1986). Qualitative research using grounded theory. In W.C. Chenitz & J.M. Swanson (Eds.), *From practice to grounded theory* (pp. 3-15). Don Mills, ON: Addison-Wesley.
- Corbin, J.M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.
- Dick, L.C. (Producer/Director). (1992). *In the midst of winter* [Film]. Seattle: AIDS Video Project.
- Ferrell, J.A., & Boyle, J.S. (1992). Bereavement experiences: Caring for a partner with AIDS. *Journal of Community Health Nursing*, 9(3), 127-135.
- Folkman, S., Chesney, M.A., & Christopher-Richards, A. (1994). Stress and coping in caregiving partners of men with AIDS. *Psychiatric Clinics of North America*, 17(1), 35-53.
- Folkman, S., Chesney, M.A., Cooke, M., Boccillari, A., & Collette, L. (1994). Caregiver burden in HIV-positive and HIV-negative partners of men with AIDS. *Journal of Consulting and Clinical Psychology*, 62(4), 746-756.
- Geis, S.B., Fuller, R.L., & Rush, J. (1986). Lovers of AIDS victims: Psychosocial stressors and counseling needs. *Death Studies*, 10(1), 43-53.
- Glaser, B.G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Grief, G.L., & Porembski, E. (1988). AIDS and significant others: Findings from a preliminary exploration of needs. *Health and Social Work*, 12(4), 259-265.

- Health & Welfare Canada. (1990). *Caring together: A national conference for the AIDS caregiver*. Ottawa: Supply and Services Canada.
- Hitchens, N. (1992). *Voices that care*. Toronto: Fireside.
- Horowitz, A. (1985). Family caregiving to the frail elderly. *Annual Review of Gerontological Geriatrics*, 5, 194-246.
- Hull, M.M. (1989). *A family experience: Hospice supported home care of a dying relative*. Unpublished doctoral dissertation, University of Rochester, New York.
- Hutchinson, S. (1986). Grounded theory: The method. In P.L. Munhall & C.J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp. 111-130). Norwalk, CT: Appleton-Century-Crofts.
- Knight, B.G., Lutzky, S.M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *Gerontologist*, 33(2), 240-248.
- Lennon, M.C., Martin, J.L., & Dean, L. (1990). The influence of social support on AIDS-related grief reaction among gay men. *Social Science and Medicine*, 32, 477-484.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lindgren, C.L. (1993). The caregiver career. *Image: Journal of Nursing Scholarship*, 25(3), 214-219.
- Macklin, E.D. (1989). Introduction. In E.D. Macklin (Ed.), *AIDS and families* (pp. 1-11). New York: Harrington Park.
- Martens, N., & Davies, B., (1990). The work of patients and spouses in managing advanced cancer at home. In J.M. Kirschling (Ed.), *Family based palliative care* (pp. 55-73). New York: Haworth.
- McShane, R., Bumbalo, J.A., & Patsdaugher, C.A. (1994). Psychological distress in family members living with human immunodeficiency virus/acquired immune deficiency syndrome. *Archives of Psychiatric Nursing*, 8(1), 53-61.
- Morse, J.M. (1991a). Strategies for sampling. In J.M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 127-145). Newbury Park, CA: Sage.
- Morse, J.M. (1991b). The structure and function of giftgiving in the nurse-patient relationship. *Western Journal of Nursing Research*, 13, 597-615.
- Murphy, S.P., & Perry, K. (1988). Hidden grievers. *Death Studies*, 12(5/6), 451-462.
- Neil, R.M. (1994). Authentic caring: The sensible answer for clients and staff dealing with HIV/AIDS. *Nursing Administration Quarterly*, 18(2), 36-40.
- Pearlin, L.I., Mullan, J.T., Aneshensel, C.S., Wardlaw, L., & Harrington, C. (1994). The structure and functions of AIDS caregiving relationships. *Psychosocial Rehabilitation*, 17(4), 51-67.
- Pearlin, L.I., Semple, S., & Turner, H. (1988). Stress of AIDS caregiving: A preliminary overview of the issues. *Death Studies*, 12(5/6), 501-517.

- Powell-Cope, G.M. (1995). The experiences of gay couples affected by HIV infection. *Qualitative Health Research*, 5(1), 36-62.
- Powell-Cope, G.M., & Brown, M.A. (1992). Going public as an AIDS family caregiver. *Social Science and Medicine*, 34(5), 571-580.
- Rabins, P.V., Fitting, M.D., Eastham, J., & Fetting, J. (1990). The emotional impact of caring for the chronically ill. *Psychosomatics*, 31(3), 331-336.
- Raveis, V., & Siegel, K. (1990). Impact of caregiving on informal or formal caregivers. In *Community-based care of persons with AIDS: Developing a research agenda* (pp. 17-28) (DHHS Publication Number [PHS] 90-3456). Washington: U.S. Government Printing Office.
- Rolland, J.S. (1990). Anticipatory loss: A family systems development framework. *Family Process*, 29, 229-244.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Seidel, J. (1988). *The Ethnograph: A user's guide*. Littleton, CO: Qualis Research Associates.
- Shilts, R. (1987). *And the band played on: Politics, people, and the AIDS epidemic*. New York: St. Martin's.
- Smith, M.Y., & Rapkin, B.D. (1996). Social support and barriers to family involvement in caregiving for persons with AIDS: Implications for patient education. *Patient Education and Counseling*, 27, 85-94.
- Stajduhar, K. (1995). *The caregivers of persons living with HIV/AIDS: The experience of caring for a dying family member at home*. Unpublished master's thesis, University of British Columbia, Vancouver.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Takigiku, S.K., Brubaker, T.H., & Hennon, C.B. (1993). A contextual model of stress among parent caregivers of gay sons with AIDS. *AIDS Education and Prevention*, 5(11), 73-75.
- Thorne, S.E., & Robinson, C.A. (1988). Reciprocal trust in health care relationships. *Journal of Advanced Nursing*, 13(6), 782-789.
- Vachon, M.L.S., Sheldon, A.R., Lancee, W.J., Lyall, W.A.L., Rogers, J., & Freeman, S.J.J. (1982). Correlates of enduring distress patterns following bereavement: Social network, life situation, and personality. *Psychological Medicine*, 12, 783-788.
- Worden, J.W. (1991). Grieving a loss from AIDS. In M.O. Amenta & C.B. Tehan (Eds.), *AIDS and the hospice community* (pp. 143-150). New York: Harrington Park.

Designer's Corner

Investigator Bias in Bereavement Research: Ethical and Methodological Implications

Alicia Skinner Cook

The ethics of conducting bereavement research has received limited attention. While a plethora of research, both qualitative and quantitative, has been published on grief and loss over the last several decades, consideration of the particular ethical issues involved in such endeavours has lagged behind. Formal institutional or governmental reviews of research involving human subjects are typically based on a risk/benefit analysis. While important and even necessary, such analysis does not substitute for the various sensitivities of the investigator. Ultimately, the ethics of a particular research situation reside with the researchers themselves (Cook, 1995).

Understanding the aspects of the "self" that one brings to the research endeavour can help to increase awareness of personal and professional biases concerning grief and loss research. Lipson (1991) writes eloquently about the role of self in the research process and blames lack of self-awareness for some of the most glaring inaccuracies in ethnographic data and analysis. She also raises the suggestion that researchers should be required to undergo some form of systematic self-analysis as part of their training. In the qualitative research literature, the self is acknowledged as influential — "a presence that permeates all methodological decisions and penetrates the very fabric of meaning constructed" (Greene, 1994, p. 539). It can also be asserted that no research, whether qualitative or quantitative, is value-free.

Lee (1993), in his book on socially sensitive research, emphasizes the fact that interviewer effects are never completely independent of the topic under investigation. Interviewer characteristics, as well as the con-

Alicia Skinner Cook is a Professor in the Department of Human Development and Family Studies, Colorado State University, Fort Collins, Colorado.

cerns interviewers might have about the questions they ask, can affect the validity of the responses. "Sensitivity" has the potential to affect almost every stage of the research process, from the formulation of a research problem, through the design and implementation of a study, to the dissemination or application of findings (Sieber & Stanley, 1988).

Rodabough (1981) is one of the few authors to have recognized the threat of investigator bias in the study of death, dying, and grief. Unfortunately, bias in bereavement research has been discussed primarily in the context of sample bias, while the role of investigators themselves in introducing bias has been neglected. This article will delineate four categories of investigator bias (see Table 1): emotional bias, normative bias, cultural bias, and professional bias. Each category will be discussed as it relates to bereavement research.

Table 1 *Types of Investigator Bias in Bereavement Research*

1. **Emotional Bias:** Objectivity becomes difficult because of emotional involvement with individuals/families or due to personal (sometimes traumatic) experiences associated with loss.
2. **Normative Bias:** Value judgements are made regarding normalcy and appropriateness of grief-related feelings and behaviours (i.e., "good grief") based on current conceptual models and available empirical data.
3. **Cultural Bias:** The cultural background of the researcher serves as an interpretative lens, which can limit the understanding of bereavement in a different culture, ethnic group, or social class.
4. **Professional Bias:** The researcher's disciplinary training and perspective determine the particular aspects of grief and loss that are studied and the conclusions that are drawn.

Emotional Bias

Socially sensitive topics are often equated with areas of social life that are considered taboo and/or laden with emotion. Few research methodology courses address the unique issues involved in researching emotionally sensitive topics. Thus experienced investigators trained in sophisticated techniques are often unequipped to confront their own emotional responses. One's own emotions can affect choice of research topic as well as interpretation of findings. Morse (1994) recommends reflection on personal motives for conducting a particular study as a critical stage in the research process.

The feelings and personal issues of investigators might also influence the recruitment and responses of participants. In a study on bereavement, for example, painful family issues surrounding loss can increase researchers' anxieties related to their own experiences and decrease their willingness to contact participants. Also, perceived researcher anxiety can inhibit the interview responses of bereaved persons and thus affect the depth and accuracy of data. To put the investigator at ease, participants might modify their responses in accordance with their interaction with the interviewer. Reflection and examination of one's own needs, vulnerabilities, and expectations can help separate the issues of the researcher from those of the participant. Investigators studying grief and loss need ongoing opportunities to discuss their personal feelings, their concerns, and their frustrations (Boss, 1987; Moriarty, 1990).

Emotional bias is generally viewed solely as a negative force in the research process. Attention should be paid to the productive role emotional bias might play if brought into the researcher's awareness. While experiences of bereavement and residual feelings stemming from personal loss can interfere with the research process, they can also inform and enhance investigators' understanding of their findings. Callahan (1988) believes that emotions energize the ethical quest and that "heart and mind can no longer be seen as antagonistic adversaries in the moral enterprise" (p. 14). Because our emotional and cognitive capacities function interactively, a sound strategy for ethical decision-making includes both trust and critical awareness of all of our capacities and reactions.

Normative Bias

Researchers typically use conceptual models to guide their work. Unfortunately, the assumptions of these models often go unexamined, and researchers tend to hold onto familiar conceptual models even in the face of contrary evidence (Klass, Silverman, & Nickman, 1996).

Wortman and Silver (1989) delineate a number of prevalent assumptions about the grieving process and then demonstrate, through a systematic literature review, that there is questionable empirical support for them. For example, a common assumption is that distress or depression is inevitable (i.e., normative) following the death of a significant other, and that its absence indicates pathology. Wortman and Silver provide evidence of a wide variety of grief responses that are not pathological yet do not conform to prevalent conceptions of "normal grieving."

Another common assumption relates to beliefs about "recovery" or "resolution" as a desirable outcome of loss, usually after disengagement has occurred through a process of active grieving. The recent publication *Continuing Bonds: New Understandings of Grief* (Klass et al., 1996) challenges this assumption and helps us to understand its origins. The authors offer empirical support for an alternative model of grief that presents ongoing attachment to the deceased as a normal and healthy response to loss.

Gender issues should also be considered when researchers contemplate the definitions of normative responses to loss. Research is biased if it tends to over-represent the experience of one sex (McHugh, Koeske, & Frieze, 1986), and inspections of samples used in adult bereavement studies show that the majority of participants are in fact women. Thus much of our knowledge about the grief response is based on the female experience. Even when attempts are made to include both male and female participants, in general fewer men than women return surveys on grief or agree to be interviewed about their loss. This tendency has led to women's grief being seen as the norm, and to findings related to male grief being compared to this norm. As a result, when the male response deviates from this standard it is often viewed from a deficit model and interpreted as pathological or unhealthy (Cook, 1988; Lister, 1991). By examining their own gender biases and the hidden assumptions on which they are based, researchers can increase their sensitivity to gender issues and be open to wider interpretations of "normal" grief.

Cultural Bias

Stereotypes and cultural assumptions can affect the research endeavour. Conflict and misunderstanding are especially likely to emerge in situations in which the investigator and the research participants come from different cultural backgrounds.

Cultural bias on the part of the investigator can result in lack of attention to important ethical concerns in work with diverse cultural groups. Christakis (1992) suggests that since ethics are socially constructed they can vary somewhat, according to the cultural setting in which they are formulated. The concept of voluntary consent, for instance, seems straightforward yet actually involves a number of cultural complexities. For example, persons from some cultural groups might be unfamiliar with the concept of declining to participate or to answer questions. Members of oppressed minority groups may not fully understand the issue of consent. Also, the Western notion of consent is based on the primacy of individual rights. In cultures in

which concern for the welfare of the group takes precedence over that of the individual, the notion of consent may need to be expanded to include group-level concerns.

Members of dominant cultural groups often tend to define normalcy in terms of their own experience. For example, Rooda (1993) found that nurses in clinical settings are likely to have more positive perceptions of patients from their own ethnic and cultural group than of other patients. These tendencies can easily transfer to a research setting involving culturally different subjects. Chavez and Oetting (1995) are of the view that we must come to terms with our own ethnocentric perceptions and values. If we do not deal with them consciously, these perceptions and values "may both overtly and covertly enter the research literature through our writings and findings" (p. 865). Cultural values and mores perceived as healthy in a dominant culture may be perceived as unhealthy and inappropriate in others. Thus a standardized grief inventory might be an inappropriate instrument for assessing the experience of grieving individuals from minority groups if it has been normed on a middle-class, Caucasian population.

Researchers who have insight into their own belief systems will be better equipped to detect cultural influences. A culturally effective researcher is one who has moved from a position of being culturally unaware to being sensitive to his or her own cultural heritage, while acknowledging cultural dimensions of grief and loss issues in others.

Professional Bias

Researchers not only bring their own individual histories and cultural perspectives to bear on the research process, but they also have a particular professional orientation, one that includes a distinct point of view, language, and set of professional skills and perspectives. Most researchers have undergone many years of socialization in their field of specialization. Professional socialization includes attitudes, feelings, and values, as well as cognitive aspects (Cook & Oltjenbruns, 1998).

Theorist Rosemary Ellis defines "perspective" as "an identifiable view, a characteristic approach with persistent themes that can be identified over time" (Algase, 1990). For example, nursing perspectives are reflected in certain research questions that tend to be addressed repeatedly over time regardless of topic (e.g., questions regarding ways of assisting families in times of stress). Furthermore, nursing research in the area of bereavement, as in other areas, will be influenced by prevalent conceptual models in nursing. These conceptual models may direct

researchers towards a particular understanding of the grief process and the many facets of its manifestation. Since nursing has a long history of interest in and involvement with families, researchers in this field are perhaps more likely than those in other disciplines to address the relational aspects of grief and to view the family as an appropriate unit of investigation.

All conceptual views limit, and at times bias, our perspective of the topic under study. Interdisciplinary research teams facilitate the investigation of a broad array of aspects of grief, while respecting each researcher's disciplinary contribution and representing a variety of types of experience with bereaved individuals and their families. Interdisciplinary work can be a fruitful form of collaboration. If differences among team members are viewed as strengths and challenges rather than obstacles, they can add to the integrity of the research effort.

Conclusions

Investigator bias, with its many aspects, can be a potent force in the research process. Lee (1993) is of the opinion that researchers of sensitive topics must be more acutely aware of their ethical responsibilities than researchers of more innocuous topics. Investigators have a responsibility to find ways of dealing with the ethical challenges of research on grief and bereavement, and these challenges must be minimized, managed, or mitigated in a way that does not compromise the research itself.

Investigator bias can serve both positive and negative functions. Uncontrolled, biases can undermine the quality of the research. Acknowledged and made explicit, they can allow for multiple experiences of grief and loss and alternative explanations of the data (Fetterman, 1989). Examining one's own investigator bias will not only enhance the quality of one's research, but will most likely involve new personal and professional insights as well.

References

- Algase, D. (1990). Links between nursing science and nursing practice. In K. Berger & M. Williams (Eds.), *Collaborating for optimal health* (pp. 1628-1657). Norwalk, CT: Appleton & Lange.
- Boss, P.G. (1987). The role of intuition in family research: Three issues of ethics. *Contemporary Family Therapy*, 9(1-2), 92-100.
- Callahan, S. (1988). *The role of emotion in ethical decisionmaking*. Hastings Center Report, 18(3), 9-14.

- Chavez, E.L., & Oetting, E.R. (1995). A critical incident model for considering issues in cross-cultural research: Failures in cultural sensitivity. *International Journal of Addictions*, 30(7), 863-874.
- Christakis, N.A. (1992). Ethics are local: Engaging cross-cultural variation in the ethics for clinical research. *Social Science Medicine*, 35(9), 1079-1091.
- Cook, A.S. (1995). Ethical issues in bereavement research: An overview. *Death Studies*, 19(2), 103-122.
- Cook, A.S., & Oltjenbruns, K.A. (1998). *Dying and grieving: Lifespan and family perspectives* (2nd ed.). Fort Worth, TX: Harcourt Brace.
- Cook, J.A. (1988). Dad's double binds: Rethinking father's bereavement from a men's studies perspective. *Journal of Contemporary Ethnography*, 12(3), 285-308.
- Fetterman, D.M. (1989). *Ethnography: Step by step*. Newbury Park, CA: Sage.
- Greene, J.C. (1994). Qualitative program evaluation: Practice and promise. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 530-544). Thousand Oaks, CA: Sage.
- Klass, D., Silverman, P.R., & Nickman, S.L. (1996). *Continuing bonds: New understandings of grief*. Washington: Taylor & Francis.
- Lee, R.M. (1993). *Doing research on sensitive topics*. London: Sage.
- Lipson, J.G. (1991). The use of self in ethnographic research. In J.M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (rev. ed.) (pp. 73-89). Newbury Park, CA: Sage.
- Lister, L. (1991). *Men and grief: A review of research*. Smith College Studies in Social Work, 61(3), 220-235.
- McHugh, M.C., Koeske, R.D., & Frieze, I.H. (1986). Issues to consider in conducting nonsexist psychological research: A guide for reviewers. *American Psychologist*, 41(8), 879-890.
- Moriarty, H.J. (1990). Key issues in the family research process: Strategies for nurse researchers. *Advances in Nursing Science*, 12(3), 1-14.
- Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220-235). Thousand Oaks, CA: Sage.
- Rodabough, T. (1981). How we know about death: Research strategies. *Death Education*, 4, 315-336.
- Rooda, L.A. (1993). Knowledge and attitudes of nurses toward culturally different patients: Implications for nursing education. *Journal of Nursing Education*, 32(5), 209-213.
- Sieber, J.E., & Stanley, B. (1988). Ethical and professional dimensions of socially sensitive research. *American Psychologist*, 43, 49-55.
- Wortman, C., & Silver, R. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57(3), 349-357.

Book Review

How We Grieve: Relearning the World

Thomas Attig

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Reviewed by Ruth Grant Kalischuk

Edward Munch's captivating painting *The Death Chamber* graces the cover of this book which intrigues and invites one to pick it up and find within its pages an understanding of the grieving process that resonates with the experiences of the bereaved. Influenced by Colin Murray Parkes's "pregnant idea" (p. xii) that grieving entails relearning the world, Attig gives birth to the idea by capturing and expanding it from a humanities-based perspective. Attig claims that the loss of a loved one disrupts a person's biography, which, in turn, forces the person to relearn his or her world. *How We Grieve: Relearning the World*, which is based on more than 20 years of teaching and writing experience, represents one philosopher's reflections on grieving as an important human experience rich with learning opportunities.

The six chapters of *How We Grieve* centre around the stories of bereaved persons. It includes an overview of relevant terminology, a critique of three views of grieving, a chapter on the importance of respecting grieving individuals, and an argument in support of grieving as a process of relearning the world.

In keeping with the grounded and pragmatic approach characteristic of this work, Attig develops four themes to explain why people turn to books on grieving. Specifically, readers seek understanding from others, respect for the uniqueness of their experiences, ideas that will enable them to address the helplessness associated with grieving, and practical guidance in caregiving. These themes provide a framework for validating the ideas presented throughout the book.

Attig does not treat stories as merely anecdotal. He fervently believes that stories are at the heart of reflection on loss and coping. Hence *How We Grieve* begins with stories that depict the personal, varied, rich, and complex lives of several bereaved individuals and families. The stories instantly engage the reader. Attig creatively and

skilfully weaves a fine tapestry, interlacing the stories of bereaved individuals with his own ideas. His ideas are meaningful and credible in that he is able to clearly demonstrate how they have relevance for the day-to-day lives of grieving persons.

In the second chapter Attig criticizes the medical and stage/phase views of grieving for neither adequately nor accurately representing the complexity of the many and varied contextual factors integral to the grieving experience. He offers his "Relearning the World Tasks" view, based on a refinement of Worden's task-based view of grieving, as a framework for understanding the grieving process. This view claims that grieving is an active process that involves relearning one's physical and social worlds, as well as one's self and one's relationship with the deceased. Such an understanding represents a shift in thinking: the individual plays an active rather than passive role in the grieving process. It acknowledges the innate strengths and resilience of grieving persons, and it recognizes our ability to make sound decisions about matters that are important to us, even in the face of adversity and grief.

Respecting and caring for others, as an extension of self-care, is the subject of the third chapter. Respecting others when they grieve, says Attig, involves respecting individual ways of flourishing, individual vulnerabilities, and the often far-reaching impact that loss may have on the life of another. Further, Attig claims that grieving persons are vulnerable to "disenfranchised grieving" (p. 82) — that is, they are stigmatized and/or have the significance of their grieving experience minimized or dismissed. Certain people are especially vulnerable — for instance, the grief of the elderly, young children, parents of adult children, the mentally or physically challenged, homosexual partners, and former heterosexual partners commonly goes unrecognized and unacknowledged. The author encourages the reader to be self-reflective and mindful during interactions with any grieving person.

The final three chapters are devoted to expanding the notion of grieving to mean relearning the world. Attig contends that because the idea of learning is familiar to most people, the concept of relearning will be easy to understand. Relearning the world is not about acquiring information about the world but, rather, coming to terms with how to be different and act differently in a world without the earthly presence of the deceased; for example, an important task is learning how to love the deceased person in spite of separation through death. The author addresses the magnitude and complexity of this task, stating that relearning is a never-ending, "multifaceted transitional process" (p. 107)

fraught with "inevitable struggles in the face of finiteness, continuous change, pervasive uncertainty, and vulnerability" (p. 122).

How We Grieve: Relearning the World is a substantial contribution to the voluminous literature on grieving. It offers a unique and holistic understanding of the grieving process that is sensitive to the shortcomings of many theoretical and personal accounts of grieving. A strength of this thought-provoking work is the author's ability to cogently present ideas through the powerful yet often subtle medium of storytelling. Intended for a broad readership, the book is an excellent resource for lay persons and professionals alike. Attig challenges readers to increase their understanding of how we grieve and — importantly — to act on that understanding by providing appropriate care, comfort, and support to grieving individuals and families.

Ruth Grant Kalischuk is Assistant Professor, School of Health Sciences, University of Lethbridge, Alberta.

Through the Looking Glass: Children's Perceptions of Growing Up with Cystic Fibrosis

Jennifer P. D'Auria, Becky J. Christian,
and LuAnn F. Richardson

Cette étude qualitative, menée selon une approche théorique fondée, examine la vie quotidienne de jeunes en période intermédiaire de l'enfance, qui sont atteints d'une maladie chronique. Un échantillon de 20 enfants atteints de fibrose kystique (âgés de 6 à 12 ans) fut constitué et des entrevues ont été menées auprès de ceux-ci. De ces entrevues s'est dégagé un thème central : les enfants atteints de fibrose kystique au cours de l'enfance moyenne font l'expérience de la différence. À partir de leurs témoignages, quatre éléments communs ont été identifiés : (a) les problèmes de compréhension du diagnostic, (b) les taquineries et le harcèlement auxquels ils sont confrontés, (c) la difficulté d'en parler et (d) la capacité de suivre les autres enfants dans leur fonctionnement. L'étude a conclu qu'il faut axer les interventions auprès des enfants atteints de fibrose kystique sur les exigences psychosociales auxquelles ils sont confrontés tout au long de leur croissance. En orchestrant ces interventions autour des événements significatifs de leur vie quotidienne, nous aiderons les enfants atteints de fibrose kystique à se sentir normaux, dans un contexte où ils doivent se soumettre à une série de traitements. Nous contribuerons ainsi à améliorer leur qualité de vie.

This qualitative study used a grounded theory approach to explore the unfolding of the chronic illness experience for children during middle childhood. A purposive sample of 20 children (6-12 years) with cystic fibrosis (CF) were interviewed. Discovering a sense of difference was found to be the central phenomenon that described the experience of having CF during the middle childhood years. Four central themes emerged in the stories of these children: (a) puzzling out the diagnosis, (b) being teased and picked on, (c) telling others, and (d) keeping up. The study concluded that interventions must focus on the psychosocial demands made on children with CF along their course of development. By designing interventions around meaningful outcomes in their daily lives, we will help children with CF find ways to feel normal while adhering to treatment regimens, thereby helping to improve the quality of their lives.

Over the past two decades, technological advances have dramatically changed survival rates among children with chronic illnesses. Global trends indicate that cystic fibrosis (CF) is the disease for which the change has been most dramatic (Suris, 1995). The median age of sur-

Jennifer P. D'Auria, Ph.D., R.N., C.P.N.P., and Becky J. Christian, Ph.D., R.N., are assistant professors in the School of Nursing, University of North Carolina at Chapel Hill. LuAnn F. Richardson, R.N., M.S.N., C.P.N.P., is associated with Wake County Human Resources, Raleigh, North Carolina.

vival in CF has risen from 14 years in 1969 to slightly over 30 years in 1995 (Cystic Fibrosis Foundation [CFF], 1996). This transformation in the course of CF challenges nurses to identify supportive strategies to facilitate the adjustment of children with CF as they move through childhood and adolescence into adulthood.

CF is the most common (1:3,100) hereditary disease in Caucasian children (CFF, 1996). Its primary manifestations are chronic progressive obstructive pulmonary disease, pancreatic insufficiency, and sweat-gland dysfunction (Ewig, 1997). Lung involvement is evidenced in 90% of children with CF and is the leading cause of morbidity and mortality in the disease. Typically, children with CF have a chronic cough with mucus production, shortness of breath on exertion, diminished exercise tolerance, and such chronic physical characteristics as barrel chest and digital clubbing. There is great variation, according to the severity and progression of the disease, in the intensity and frequency of treatment regimens. An intensive daily regimen involving chest physical therapy and pharmacologic and nutritional management is vital to the maintenance of health.

In two earlier qualitative studies, Christian and D'Auria (1993, 1997) used a grounded theory approach to explore how adolescents and young adults perceived growing up with CF and managed their disease. The youths identified three critical transitions, during childhood and adolescence, in adjusting to CF: (a) the transition from home to elementary school, during which they first experienced the social consequences of having a chronic illness; (b) the transition to early adolescence, when many experienced acute exacerbations of the disease; and (c) the transition to mid- or late adolescence, when they realized that their management of self-care had a direct bearing on the course of their illness. Findings across these two studies identified middle childhood (6–12 years) as a particularly vulnerable period in adjusting to CF. Therefore, the purpose of this study was to explore in further detail the unfolding of the chronic illness experience for children with CF during middle childhood.

Theoretical Perspective

Social ecological theory focuses on the role of settings and contexts in determining children's responses to disease and treatment. Bronfenbrenner's (1989) ecological model of development places the child at the centre of a series of nested rings, and focuses on relationships between the developing child and the environment in which these interactions occur. Children play an active role in determining the responses of

others, and these reciprocal interactions help shape their behaviour and their understanding. Consequently, researchers must address the interplay between contextual influences and children's developing perspectives of chronic illness and treatment (Eiser, 1993).

Middle childhood (6–12 years) is the developmental period in which children enter elementary school and progress through middle school into pre-adolescence. During these years children make significant advances in both cognitive ability and social understanding. However, although their ability to think logically and systematically has increased, during this period children still lack a broad base of knowledge and have had little time to practise new ways of thinking in real-life situations (Sroufe, Cooper, & DeHart, 1996). Nevertheless, by approximately six years of age children are able to use cognition, including memory, to effectively solve problems, begin to put together their "histories of experience" in ways that shape and guide how they relate to others, and begin to consolidate a self-image (Sroufe et al.).

Methods

Design

A grounded theory approach was used to capture children's memories of the chronic illness experience and related life events (Strauss & Corbin, 1990). Subjects were recruited from a regional CF centre in the southeastern United States. Purposeful sampling continued until data saturation or redundancy was achieved, to ensure appropriateness and adequacy of the data (Lincoln & Guba, 1985). Interviews were conducted with 20 children between the ages of six and 12 (mean age 9.1 years; median age 9 years). All 20 of the children were Caucasian; 12 were male and eight were female. All participants had been diagnosed with CF by the age of three years. Informed consent was obtained from parents. The children agreed to participate.

Interview

Children as young as age six are valid and reliable informants when reporting their experiences of daily life stressors and coping ability (Faux, Walsh, & Deatricks, 1988). Therefore, the children in this study were considered experts on what it is like to grow up with CF. It is important to recognize that children's interpretations of what they do differ qualitatively from the interpretations of their parents (Bigelow, Tasson, & Lewko, 1996). The children were asked to visualize what it is like to grow up with CF. We began the interview by having them focus

on their earliest memory, which was explored in depth: the children were asked to describe the memory by telling us what happened, when it happened, why it was important, and how it made them feel. Finally, they were asked what advice about growing up with CF they would give a child newly diagnosed with the disease. Reflection on and paraphrasing of critical events was used to check for data inconsistencies, clarify meaning, and confirm accuracy and credibility of the data (Lincoln & Guba, 1985). Probes were constructed to suggest that other children might feel the same way; questions progressed from concrete to abstract concepts, to accommodate the range of cognitive ability in the sample and minimize social desirability (Faux et al.).

Interviews were conducted by experienced, advanced-practice pediatric nurses who were not members of the CF team. Each interview, which was coordinated to coincide with a clinic appointment, was held in a private room. It ranged from 30 to 60 minutes in duration and was audiotaped for verbatim transcription. At the end of the interview, a life-event line was used to visually represent and validate the children's perceptions of their chronic illness experience. The anchors of the line corresponded to the child's age at the time of the earliest memory of CF and the child's present age. Children under eight years required assistance with spelling, marking, and labelling of critical events along the time line. Field notes were recorded to document personal characteristics, emotional responses, and the conditions for data collection.

Data Analysis

Transcribed interview data were systematically analyzed using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Investigators checked each transcription against the audiotape to ensure accuracy. Each interview was read several times and a summary of themes for each child was prepared. A process of reviewing major themes; open, axial, and selective coding; and theoretical memos was established for each interview. Codes were compared and contrasted across all interviews and categorized hierarchically. Open coding was used to identify and name major categories, properties, and dimensions of the core category. Axial coding was used to put data back together in a new way by making connections between categories. Selective coding was used to identify the core category and systematically relate it to all subcategories. Textbase Alpha (Tesch, 1993), a qualitative data analysis program, was used for data management and cross-comparative analysis.

Findings

Discovering a sense of difference was the central phenomenon that described children's memories of growing up with CF during middle childhood. Four central themes emerged in the stories of the children: (a) puzzling out the meaning, (b) being teased and picked on, (c) telling others, and (d) keeping up. These stories highlighted the children's struggles to understand CF, deal with teasing, explain CF to peers, and compete on an equal basis with peers throughout the elementary school years. They attempted to integrate others' views of them into their developing views of who they were and who they were to become. The children tried to appear normal in the face of mounting evidence that they were different from their peers.

Puzzling Out the Meaning

Many of the children remembered being told by their mothers at approximately four to five years of age that they had "cystic fibrosis." Because of the cognitive constraints of early childhood, they were puzzled by this new information and were surprised to find that they were not like everyone else.

My mom just took me and sat down on my bed and said, "Son, you got cystic fibrosis. It's this thing that they can't get off of you now, and you're just as good as anybody else. It's just that you got this disease, and you're not like other people." I just thought she must be insane ... because I always thought I was just like everybody else.

These experiences introduced into their lives the idea of a standard and the inherent contradiction that they were normal yet "not like" other children.

Since the majority of the children were diagnosed in infancy, they did not experience a diagnostic period as a beginning point for becoming chronically ill. For these children, entering the world of peers and school marked the beginning of their chronic illness experience. In peer society, they discovered they had perceptible differences. They were confused by the responses of peers to their differences and did not understand the meaning their CF symptoms had for others.

The attempts of the children to puzzle out the meaning of CF were further constrained by their limited understanding of illness causation. The visibility of the CF cough suggested to peers that they were sick and had something contagious. As a result, the CF symptoms jeopardized their social interactions. Younger children (six to nine years) did not understand they were born with CF and thought peers avoided

them because they were afraid of "catching" CF. Although older children understood they were born with CF and that they were not contagious, their peers continued to ask questions about the CF cough and contagion.

Being Teased and Picked On

During middle childhood, children begin to define themselves by the groups to which they belong and to assess their personal ability by making peer comparisons. Children begin to make judgements about their competence in different domains and construct a view of their general self-worth (Harter, 1982). They strive for acceptance by seeking the approval of peers and conforming to group norms, and they come to view themselves in terms of how others view them, which Cooley (1902) refers to as the "looking-glass self."

Learning to cope with negative peer responses to their visible differences was found to be the most stressful event in the daily lives of the children. Their experiences of being teased and picked on evoked painful feelings of embarrassment, sadness, hurt, and anger.

They're picking on me because I have cystic fibrosis, and every time I have to go into the back and spit it out in the toilet they always follow me.... They think I am a weird girl.

They developed fears and anxieties as they anticipated events and the potential reactions of other children to their differences. They were afraid peers would spread rumours about them and not want to befriend or play with them. To make friends, most of the children learned to hide their visible differences by using a "public cough," not taking medications in front of other children, and pacing themselves during physical activities. Some had good friends who knew about CF and accepted their differences, supporting them and protecting them from teasing. However, at times even the good friends "worried about" the children with CF and helped them "too much," which emphasized their differences and resulted in even more teasing.

The children began to realize that others may not always accept them for who they were. Being teased and picked on told them they did not measure up to the standards of peer culture. The children with CF began to incorporate the standards of peer society into their developing identities. They began to view themselves as others viewed them — as different. Over time, they learned to reject the "looking-glass self" created by peer culture and see themselves as normal:

People sometimes don't take you for who you are...knowing that he's a little bit different from other people. That might make him a little bit sad or angry.... He might be worried about kids making fun of him and stuff like that.... Us cystic fibrosis people have the same feelings as everybody else, but other people don't think that.... We're really not different than anybody else because we just have a little problem just like everybody else does.

Telling Others

Coughing and taking medications were the two characteristics of CF that called most attention to their differences. The children remembered being stared at by other children when they had to cough or take medications. Frequently their coughing interrupted class and embarrassed them. Leaving the classroom to take medication made them miss school activities or playground time, or arrive late in the lunchroom. More important, it precipitated questions from peers about why they had left class. Having to explain these differences introduced the need to control information about their illness in the context of school and peers. They changed health behaviours, such as developing a public cough and skipping medications, to avoid having to tell others about CF and thus minimizing the social consequences of being seen as different.

The children were uncertain about how others would identify them and receive information about CF. Moreover, they did not understand CF and had difficulty explaining it to peers, who had the same cognitive and verbal limitations. The dilemma of telling others about CF and the fear of the negative social consequences of the disclosure threatened their ability to form friendships. They worried that peers would spread rumours about them and think they were contagious. To find trustworthy friends, they watched children in the playground: those who played without fighting or teasing were viewed as potential friends. If they became a "good friend," they could be trusted with the secret of CF. However, disclosure involved the risk that the friend might tell others.

I like to tell the people who I really think are trustful. I got some kids at school that you can't really trust. I mean you can tell them, but you don't want no one spreading it — anybody who'll go around telling anybody what you said and everything.

Instead of telling others, they kept secrets, to control how others viewed them. Indeed, when we asked them what they would tell younger children with CF about growing up, they said they would advise them to keep secrets about their chronic illness.

Keeping Up

Being able to participate in activities and being energetic are important to children's developing views of health (Nataf, 1978). During middle childhood, developing physical competence is the basis for peer comparison (Damon & Hart, 1992). The functional limitations of CF threatened the ability of the children in the study to compete with peers and created new challenges to fit in. The CF symptoms — coughing, shortness of breath, and limited energy and exercise tolerance — highlighted their physical differences. At a time in their lives when athletic performance is used as a standard for comparison and evaluation, these CF differences were magnified and took on added importance. For example, the CF cough drew unwanted attention to them when they tried to participate in sports. However, the most restrictive problem associated with CF was lacking the energy to run as fast as their friends.

In response to their symptoms, many children were teased and began to withdraw and isolate themselves, thereby reducing their opportunity to participate in peer activities. Others learned to pace themselves to control their symptoms and minimize their differences, so peers would be less likely to notice they were different. Children who were able to participate in sports were proud of their physical capabilities. Being physically active allowed them to be viewed as normal, by themselves and others.

Well, nobody really believes that I have CF. 'Cause I don't act like it! But some of them are real sick and they can't run and things and they get out of breath a lot and stuff.... I'll cough and stuff, then I just get back up and just do all these fun things.

Discussion

Although a great deal of research has focused on the adjustment of the parents and families of children with chronic illness, few studies have focused on the children's own perspectives of the illness, and even fewer have addressed adaptation issues relevant to peer society (Eiser, 1993; Kazak, 1992; Thompson & Gustafson, 1996; Wallander & Varni, 1992). The interpretations of children's own perspectives provide a window onto the significance and meaning of events from their point of view (Bigelow et al., 1996).

The children showed tremendous insight as they told their stories of living with CF during middle childhood. Four themes emerged from their stories of discovering a sense of difference: (a) puzzling out the meaning, (b) being teased and picked on, (c) telling others, and

(d) keeping up. Interactions with peers introduced them to the social implications of having a chronic illness. Peers labelled their CF-related behaviours as different, which challenged their views of normality. It is noteworthy that these children focused on their personal experiences in peer society, rarely mentioning other aspects of their lives (i.e., home and family).

Entry into the world of peers and school introduced the children to the social and functional implications of having a chronic illness (Turner-Henson & Holaday, 1995). The first challenge for learning to live with a chronic disease was puzzling out the meaning of the diagnosis. They were uncertain about what the term "cystic fibrosis" means and how it could account for their differences. In addition, their constant cough supported the idea that CF is a contagious disease. The children began to worry about their peers' inaccurate perceptions of their symptoms and inability to accept anyone who appeared different from the norm. They were caught in the difficult position of learning about standards while simultaneously coming to a realization that they did not meet these standards. The distinctions between normal and abnormal depicted the unfolding of stigmatization for the children with CF (Goffman, 1963; Sigelman & Singleton, 1986). The interpretation of other people's responses to a chronic illness is an important component of coming to terms with it (Radley, 1994; Thorne, 1993). For these children, puzzling out the meaning of peer responses was a great challenge, because of their limitations in memory formation, cognitive maturity, verbal dexterity, understanding of illness causation, and social experiences.

The type of social input children receive during middle childhood may affect the quality of their future interpersonal relationships (Buhrmester & Prager, 1995). In this study, negative gossip and teasing threatened the children's ability to form friendships and be effective members of a peer group. Because they were at the same life stage as their peers — experiencing the same insecurities — they began to hide their differences, to obtain social approval and control their self-image. The children were embarrassed about being different and did not know how to deal with teasing and name calling. Thompson (1990) notes that the long-term effects of being teased as children include dissatisfaction with body image, low self-esteem, and depression.

The children worried about being found out and struggled with how and to whom to tell their secret. These data support Eiser's (1993) contention that disclosure of the diagnosis is a difficult issue during childhood and controlling who knows about the diagnosis may help

minimize the impact of the disease. Gallo, Breitmayer, Knafl, and Zoeller (1991) found that siblings of children with chronic illness used similar strategies for concealing and disclosing information. For these children with CF, it was even more difficult to disclose information to peers, who had the same limitations in cognitive ability and social experiences.

Self-disclosure to friends is a self-presentation strategy, to control the image children offer to peers. Early adolescence is a time of heightened concern about self-disclosure (Buhrmester & Prager, 1995). In a recent qualitative study of 10 adolescents and young adults with CF (16–25 years), Admi (1995) found that stigmatizing information was first managed by participants during early adolescence (10–13 years) in an effort to minimize negative reactions. The findings of this study and our two earlier studies with adolescents and young adults with CF (Christian & D'Auria, 1993, 1997) indicate that children as young as six are concerned about negative gossip and disclosure of the CF label; as a result, managing information is a source of intense concern beginning in middle childhood.

Children with chronic illness must cope with stressful situations related to their disease and treatments as well as the interpersonal situations related to managing their illness (Eiser, 1993; Thompson & Gustafson, 1996). Sources of stress for such children include physical and functional limitations, difficulty adhering to treatment regimens, absences from school, social isolation, difficulty making close friends, and limited opportunities to interact with peers (Bennett, 1994; La Greca et al., 1995; Noll et al., 1996; Patton, Ventura, & Savedra, 1986). The children with CF were further set apart by their inability to fully participate in physical activities. They frequently had less energy and became short of breath, or the activity was interrupted by coughing. Each symptom was a visible marker differentiating them from their peers. Indeed, as Loutzenhiser and Clark (1993) found, for children and adolescents with CF exercise is social activity; and because, during middle childhood, physical activity is also a measure of social competence (Harter, 1985) these children had difficulty maintaining peer relationships.

Numerous studies have demonstrated that social competence with peers is a major problem for children growing up with a chronic illness (Breitmayer, Gallo, Knafl, & Zoeller, 1992; Cadman, Boyle, Szatmari, & Offord, 1987; La Greca, 1990). In a review of adherence behaviours across groups of chronically ill children, La Greca (1988) found that treatment regimens that included medications were a major barrier to

adherence. With adherence rates at about 50% for children with chronic illnesses, treatments that interfere with peer activities or disrupt developmental processes are at risk (Thompson & Gustafson, 1996). This study found that being seen taking medications presented a major barrier to adherence. In an effort to minimize their visible differences, many children began to skip taking their medications when at school, thus increasing their chances of social acceptability.

Buhrmester and Prager (1995) note that close friendships protect children from self-presentational concerns and provide a secure context for self-disclosure. During middle childhood, friends provide a way to share similarities as well as differences, to gain peer approval. For these children, finding friends who could be trusted with the secret of the CF diagnosis was critical to their adjustment to chronic illness. The children had difficulty finding peers who shared their differences. They formed friendships by hiding their CF-related differences and pretending to be just like the other children. By focusing on the similarities, they achieved a sense of solidarity with friends (Dunn, 1993), which protected them when they decided to disclose the diagnosis. Thus good friends helped them find a way through the looking-glass of peer society.

Implications

To understand how children with CF think and feel about having a chronic illness, we must understand the developmental constraints of middle childhood and the social demands of peer culture. Children with CF are faced with trying to understand their illness and deal with a complicated treatment regimen at a time in their lives when they are most concerned about being the same as their peers. No child wants to be different, yet the CF symptoms of these children created a sense of difference in their daily lives. They coped by concealing aspects of themselves to project the right image in peer society.

Interventions must focus on the psychosocial demands made on children with CF during their developing years. Interventions should not only promote adherence to treatment regimens, but also facilitate understanding and management of feelings associated with having a chronic illness. Children should be given developmentally appropriate information about CF, including its diagnosis and management, to help them construct their own personal history of CF and the meaning of CF for their lives. Because they have limited social experience in peer society, they need to learn problem-solving strategies and to acquire the social skills necessary to explain CF-related differences to peers, deal

with the differences on a daily basis, and cope with gossip and teasing. Finally, these children require information on how to participate, to the fullest extent possible, in physical activities, so they can form supportive peer relationships and develop a positive self-image. By designing interventions around meaningful outcomes in their daily lives, we will help children with CF find ways to feel normal while adhering to treatment regimens, thereby improving the quality of their lives.

References

- Admi, H. (1995). "Nothing to hide and nothing to advertise": Managing disease-related information. *Western Journal of Nursing Research*, 17(5), 484-501.
- Bennett, D.S. (1994). Depression among children with chronic medical problems: A meta-analysis. *Journal of Pediatric Psychology*, 19(2), 149-169.
- Bigelow, B.J., Tesson, G., & Lewko, J.H. (1996). *Learning the rules: The anatomy of children's relationships*. New York: Guilford.
- Breitmayer, B.J., Gallo, A.M., Knafl, K.A., & Zoeller, L.H. (1992). Social competence of school-aged children with chronic illnesses. *Journal of Pediatric Nursing*, 7, 181-188.
- Bronfenbrenner, U. (1989). Ecological systems theory. *Annals of Child Development*, 6, 187-249.
- Buhrmester, D., & Prager, K. (1995). Patterns and functions of self-disclosure during childhood and adolescence. In K.J. Rotenberg (Ed.), *Disclosure processes in children and adolescents* (pp. 10-56). New York: Cambridge University Press.
- Cadman D., Boyle, M., Szatmari, P., & Offord, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario child-health study. *Pediatrics*, 79, 805-813.
- Christian, B.J., & D'Auria, J.P. (1993). *Looking back: Perceptions of growing up with chronic illness*. University Research Council Grant. Chapel Hill, NC: University of North Carolina at Chapel Hill.
- Christian, B.J., & D'Auria, J.P. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 12, 3-11.
- Cooley, C.H. (1902). *Human nature and the social order*. New York: Charles Scribner's Sons.
- Cystic Fibrosis Foundation (1996). *Cystic Fibrosis Foundation National CF Patient Registry 1995 Annual Data Report*. Bethesda, MD: Author.
- Damon, W., & Hart, D. (1992). Self-Understanding and its role in social and moral development. In M.H. Bornstein & M.E. Lamb (Eds.), *Developmental psychology: An advanced textbook* (pp. 421-464). Hillsdale, NJ: Lawrence Erlbaum.
- Dunn, J. (1993). *Young children's close relationships: Beyond attachment*. Newbury Park, CA: Sage.

- Eiser, C. (1993). *Growing up with a chronic disease: The impact on children and their families*. London: Jessica Kingsley.
- Ewig, J.M. (1997). Cystic fibrosis. In R.A. Hoekelman, S.B. Friedman, N.M. Nelson, & H.M. Seidel (Eds.), *Pediatric primary care* (2nd ed.) (pp. 416-422). St. Louis: Mosby.
- Faux, S.A., Walsh, M., & Deatrick, J.A. (1988). Intensive interviewing with children and adolescents. *Western Journal of Nursing Research*, 10, 180-194.
- Gallo, A.M., Breitmayer, B.J., Knafl, K.A., & Zoeller, L.H. (1991). Stigma in childhood chronic illness: A well-sibling perspective. *Pediatric Nursing*, 17, 21-25.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Goffman, E. (1963). *Stigma: Notes on management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Harter, S. (1982). The perceived competence scale for children. *Child Development*, 53, 87-97.
- Harter, S. (1985). *Manual for the self-perception profile for children*. Denver: University of Denver.
- Kazak, A.E. (1992). Social context of coping with childhood chronic illness. In A.M. La Greca, L.J. Siegel, J.L. Wallander, & C.E. Walker (Eds.), *Stress and coping in child health* (pp. 262-278). New York: Guilford.
- La Greca, A.M. (1988). Adherence to prescribed medical regimens. In D.K. Routh (Ed.), *Handbook of pediatric psychology* (pp. 299-320). New York: Guilford.
- La Greca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention? *Journal of Pediatric Psychology*, 15, 285-307.
- La Greca, A.M., Auslander, W.F., Greco, P., Spetter, D., Fisher, E.B., & Santiago, J.V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology*, 20, 449-476.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Loutzenhiser, J.K., & Clark, R. (1993). Physical activity and exercise in children with cystic fibrosis. *Journal of Pediatric Nursing*, 8, 112-119.
- Natapoff, J.N. (1978). Children's views of health: A developmental study. *American Journal of Public Health*, 68, 995-1000.
- Noll, R.B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W.M., & Davies, W.H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development*, 67, 423-436.
- Patton, A.C., Ventura, J.N., & Savedra, M. (1986). Stress and coping responses of adolescents with cystic fibrosis. *Children's Health Care*, 14, 153-156.
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.
- Sigelman, C.K., & Singleton, L.C. (1986). Stigmatization in childhood: A survey of developmental trends and issues. In S.C. Ainslay, G. Becker, & L.M.

- Coleman (Eds.), *The dilemma of difference: Multidisciplinary views of stigma* (pp. 185–208). New York: Plenum.
- Sroufe, L.A., Cooper, R.G., & DeHart, G.B. (1996). *Child development: Its nature and course* (3rd ed.). New York: McGraw-Hill.
- Strauss, A., & Corbin, J.M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Suris, J.C. (1995). Global trends of young people with chronic and disabling conditions. *Journal of Adolescent Health, 17*, 17–22.
- Tesch, R. (1993). *Textbase alpha manual*. Desert Hot Springs, CA: Qualitative Research Management.
- Thompson, R.A. (1990). Vulnerability in research: A developmental perspective on research risk. *Child Development, 61*, 1–16.
- Thompson, R.J., & Gustafson, K.E. (1996). *Adaptation to chronic childhood illness*. Washington: American Psychological Association.
- Thorne, S.E. (1993). *Negotiating health care: The social context of chronic illness*. Newbury Park, CA: Sage.
- Turner-Henson, A., & Holaday, B. (1995). Daily life experiences for the chronically ill: A life-span perspective. *Family Community Health, 17*(4), 1–11.
- Wallander, J.L., & Varni, J.W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A.M. La Greca, L.J. Siegel, J.L. Wallander, & C.E. Walker (Eds.), *Stress and coping in child health* (pp. 279–298). New York: Guilford.

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Correspondence should be directed to Jennifer P. D'Auria, Ph.D., R.N., C.P.N.P., Assistant Professor, School of Nursing, University of North Carolina at Chapel Hill, CB #7460, Carrington Hall, Chapel Hill, NC 27599–7460. Telephone: (919) 966-3586. E-mail: jdauria.uncson@mhs.unc.edu

Applicants to B.Sc.N., R.N., and R.P.N. Nursing Programs: Differences and Predictors

**Anita M. Myers, Nancy E. Keat, Christine Pelkman,
and Susan E. French**

Nous avons examiné 205 candidatures aux trois types de programmes en sciences infirmières (baccalauréat en sciences infirmières, programme d'accréditation et technique infirmière) offerts à Toronto, en Ontario. Les candidats étaient majoritairement des femmes blanches et célibataires, demeurant à une distance qui leur permet un accès aux institutions où elles ont postulé. Les candidats aux programmes de techniques infirmières ont tendance à être plus âgés que ceux inscrits au baccalauréat en sciences infirmières et au programme d'accréditation; ils sont mariés, ont au moins une personne à leur charge, proviennent de familles de cols bleus, ont quitté l'école depuis plus longtemps que les candidats des autres programmes et sont moins nombreux à soumettre une demande. On note que 11 fois plus de candidats ayant une ou plusieurs personne(s) à charge ont choisi un programme en technique infirmière plutôt qu'un programme d'accréditation. Le temps écoulé depuis l'obtention du diplôme d'études secondaires et la moyenne des notes obtenues indiquent, chez les candidats, une préférence pour un programme plutôt qu'un autre. Bien que les diplômés de 1992 aient été conscients des défis auxquels est confrontée la profession infirmière, la plupart des candidats s'attendaient encore à décrocher, à la fin de leurs études, un emploi à temps plein en soins intensifs. Ces données constituent un outil de référence important, permettant de comparer l'ensemble des candidatures actuelles et futures en ce qui a trait aux caractéristiques socio-démographiques et aux attentes liées à un choix de carrière en sciences infirmières.

We surveyed 205 applicants to three types of nursing programs (B.Sc.N., diploma-R.N., and diploma-R.N.A.) offered in Toronto, Ontario. Applicants were predominately white, unmarried women living within commuting distance of the institutions to which they applied. Applicants to practical nursing programs tended to be older than applicants to B.Sc.N. and diploma-R.N. programs, be married, have at least one dependant, come from blue-collar families, be out of school longer, and submit fewer applications. Applicants with dependants were 11 times more likely to choose R.P.N. over R.N. programs. Recency of graduation and high school average were predictive of choosing B.Sc.N. over R.N. programs. While this 1992 cohort had some appreciation for the challenges facing the nursing profession, most applicants still expected to secure full-time employment in acute care post-graduation. The data provide an important benchmark for comparing current and future cohorts of applicants with respect to socio-demographic characteristics and expectations of nursing as a career choice.

Anita M. Myers, Ph.D., Nancy E. Keat, R.N., M.Sc., and Christine Pelkman, M.Sc., are associated with the Department of Health Studies, University of Waterloo, Ontario. Susan E. French, R.N., Ph.D., is associated with the School of Nursing, McMaster University, Hamilton, Ontario.

Considering the changing employment prospects of Canadian nurses (Hiscott, 1994), we need to determine whether the characteristics and expectations of the applicants are also changing. The majority of studies on expectations of nursing as a profession have used samples from among high school students (Grossman & Northrop, 1993) or nursing students (Wertenberger, Gushuliak, & Williams, 1993). Studies with applicants have been limited for the most part to one type of program (Hicks & Lobin, 1993; Treece, 1967). The only study among applicants to different types of programs (baccalaureate, associate degree, and diploma) was conducted 15 years before our survey. Nash (1976) mailed a questionnaire to more than 2,000 applicants to 20 nursing schools in the United States, soliciting information about the application process, socio-demographic characteristics, education and work history, and motivations and expectations. Only descriptive findings were reported, and factors influencing exclusivity of applications (i.e., to only one type of nursing program) were not addressed. Neither Nash's study nor any other investigation has compared the characteristics of applicants to practical nursing programs with those of applicants to other types of nursing programs. The purpose of this study was to examine predictors of who applies to different types of Canadian nursing programs.

Method

A survey of applicants to three different programs offered in Toronto was used to compare the characteristics of persons seeking a university baccalaureate degree in nursing (B.Sc.N.), a diploma leading to registered nursing status (R.N.), and a diploma leading to registered practical nursing status (R.P.N.) — the latter two programs being offered at the same community college. The registrar's offices of both the university and the community college agreed to stratify the fall 1992 successful applicants (666 in total) into those who accepted and those who declined admission, allowing us to sample proportionately from each program and category.

The content of the questionnaire was similar to that of Nash's (1981) questionnaire, and we used a branching format so that a single questionnaire could be used for all three groups. The two registrar's offices supplied identification numbers for applicants according to our random selection and stratification criteria. Each mailing — initial questionnaire, reminder postcard at one week, and second questionnaire at two weeks — was made simultaneously at the two institutions.

The response rate was 53% overall: 72% among the B.Sc.N. group and 35% among the R.P.N. group. The sample for analysis ($n=205$) consisted of 99 applicants to B.Sc.N., 70 to R.N., and 36 to R.P.N. programs. By cross checking each applicant's questionnaire data against the registrar's classification, we identified three homogeneous "exclusive" groups — 89 people who applied *only* to B.Sc.N. programs, 55 who applied *only* to R.N. programs, and 30 who applied *only* to R.P.N. programs. ANOVA was used to compare the three groups on the continuous variable of age; then Tukey B was used to pinpoint significant group differences. Chi square analysis was used for categorical variables. Logistic regression was used to identify the best predictors of application type.

Findings

The vast majority of successful applicants (92%) lived within 60 kilometres of the institution to which they had applied for admission. Slightly over a third (35%) of the entire sample applied to only one nursing program — this tendency being most common among applicants to the R.N.A. program (70%, compared with 33% for R.N. applicants and 23% for B.Sc.N. applicants); B.Sc.N. applicants were far more likely to apply to other nursing programs (57% of these applied to more than three programs). About a quarter of the total sample — similarly apportioned among the three groups — had also submitted applications to non-nursing programs; the majority of general science and medical school applications (71%) came from the B.Sc.N. group.

Table 1 shows the characteristics of the entire sample and each of the exclusive applicant groups. The sample ranged in age from 18 to 57 years (mean=25.7, SD=8.4). Members of the R.P.N. group were significantly older than members of the other two groups and were more likely to be married (especially compared with members of the B.Sc.N. group). More than a quarter ($n=58$) of the sample had children, while eight had an adult dependant. The proportion of the R.P.N. group with dependants (either children or adults) was much higher than for the other two groups.

Although the sample was predominately female and Caucasian, the R.N. group was found to have a stronger representation of males and visible minorities. Concerning the specific question on belonging to a "visible minority (i.e., persons from various racial backgrounds, with disabilities, etc.)," the most frequent responses were Oriental ($n=20$), East Indian ($n=4$), and Native Indian ($n=2$). No applicants indicated that

they had a disability. Only 10% checked the "prefer not to answer" option.

All but four applicants to the R.P.N. program had completed high school. For 61% of the sample, high school was the highest level of education achieved. The majority (84%) were educated in the province of application (Ontario), and 57% had graduated from high school in the previous two years. About 42% reported high school leaving averages of 80% or higher; no one was below 60%. The three groups differed significantly with respect to both high school average and recency of graduation from last educational program completed. Eighteen subjects (9% of the total sample) had undergraduate degrees in general arts or science. Almost a quarter (48) had a diploma, 29 of these in nursing. Twenty-three B.Sc.N. applicants had a diploma at the R.N. level; five R.N. applicants had R.P.N. qualifications; and one R.P.N. applicant had a diploma in nursing.

A greater percentage of the R.P.N. group had either fathers or mothers who had not completed high school (39% and 46%, respectively), compared with the R.N. (30% and 29%) and B.Sc.N. (23% and 24%) groups. Mothers of the R.P.N. applicants were more likely to be homemakers (33%), compared with the R.N. (28%) and B.Sc.N. (20%) groups. Parental occupations were collapsed into blue-collar versus white-collar. A significant group difference emerged concerning mother's occupation (see Table 1).

From a list of 17 options, subjects were asked to check all the reasons they were considering nursing as a career. The most frequently checked statements by the sample as a whole were: "helping profession" (81%), "career opportunities" (63%), "interest in sciences" (56%), "job satisfaction" (53%), "reputable profession" (51%), "financial security" (49%), "job security" (48%), "advancement opportunities" (47%), "challenge" (41%), and "always wanted to be a nurse" (38%). Only one statement — "always wanted to be a nurse" — yielded a significant difference among the three groups (see Table 1).

Acute care ranked as the most desirable area in which to work post-graduation (52%); public health was a distant second (20%). Few respondents selected medical clinics (12%), home nursing (8%), or chronic care (5%). While all groups expected to work primarily in acute care, home nursing was chosen by more R.P.N. (27%) than R.N. or B.Sc.N. applicants.

Table 1 *Characteristics of Total Sample and Exclusive Applicant Groups*

	Total Sample <i>n</i> = 205	B.Sc.N. <i>n</i> = 89	R.N. <i>n</i> = 55	R.P.N. <i>n</i> = 30	Significance
Age (Mean)	25.7	23.6	26.7	31.9	$F = 10.76^{***}$
Never married	72%	82%	69%	41%	$\chi^2 = 22.8^{***}$
Dependants	32%	16%	22%	68%	$\chi^2 = 28.3^{***}$
Female	92%	94%	68%	80%	$\chi^2 = 2.16$
Visible minority	21%	20%	27%	12%	$\chi^2 = 2.70$
Completed high school	98%	100%	100%	86%	$\chi^2 = .51$
High school average >80	42%	54%	30%	27%	$\chi^2 = 11.50^{**}$
Graduated last two years	57%	73%	53%	17%	$\chi^2 = 26.9^{***}$
White-collar mother	48%	66%	48%	30%	$\chi^2 = 10.50^{**}$
White-collar father	49%	62%	47%	39%	$\chi^2 = 4.67$
Always wanted to be a nurse	38%	24%	47%	48%	$\chi^2 = 10.90^{**}$
Prefer full-time	82%	80%	91%	73%	$\chi^2 = 3.80$
Prefer acute-care nursing	52%	51%	38%	41%	$\chi^2 = 1.31$
10-Year Expectations					
Bedside nursing	21%	15%	32%	21%	$\chi^2 = 5.90^*$
Nursing administration	21%	30%	13%	3%	$\chi^2 = 11.50^{**}$
Teaching nursing	18%	22%	13%	10%	$\chi^2 = 3.20$
Home nursing	9%	4%	7%	24%	$\chi^2 = 6.30^*$
* $p < .05$; ** $p < .01$; *** $p < .001$					

Most (84%) did not expect newly graduated nurses to have a choice of working straight days versus shifts, but most (79%) did expect to have the option of working full time or part time. The majority (82%) indicated a preference for full-time work. Over half the sample (59%) expressed a preference for work in the metropolitan Toronto area, but the same percentage (59%) indicated that they would relocate (26% answered "possibly"); the most desirable areas for relocation were found to be British Columbia (54%), Southern Ontario (49%), and the U.S.A. (42%). The three groups did not differ in their preferences for full-time versus part-time work, steady day work versus shifts, or location.

When the respondents were asked where they pictured themselves 10 years hence, bedside nursing and administrative work were each chosen by 21%. As shown in Table 1, B.Sc.N. applicants were more likely to see themselves as future administrators and teachers, R.N. applicants as bedside nurses, and R.P.N. applicants as either bedside or home nurses. Similar proportions of each group (13%–15%) saw themselves in public health. Financial cutbacks (47%), job availability / security (26%), increased professionalism (26%), and changes in health care (24%) were identified most frequently by all three groups as the factors that would influence nursing in the next decade.

A separate profile was created of the 16 males in the sample. They were found to be slightly older than the sample average (mean age=28, $SD=7$); most were unmarried (80%) and did not have dependants (92%). For 59%, high school was the highest level of education completed; 62% had graduated more than two years previously; 31% had a high school leaving average above 80%. Only 32% of the men selected acute care as their first choice post-graduation; 21% chose public health; none selected chronic care or home nursing. The majority of males saw themselves 10 years hence in administration (43%) or teaching (14%). Fifty percent had applied exclusively to diploma, 29% to B.Sc.N., and 21% to practical programs.

We then produced a separate profile of the 23 R.N.s in the B.Sc.N. applicant group. All were female; 50% had dependants. Only five (22%) had a high school average over 80%, and 21 (91%) had graduated before 1990. These findings indicate that the differences found between B.Sc.N. and R.N. applicants would have been even greater if the former category had been restricted to non-R.N. applicants.

Logistic regression analysis was used to identify the best predictors of application type. The data for the 29 applicants who held nursing diplomas were removed for these analyses. Model building consisted of selecting variables significant in univariate analyses, grouping theoretically related variables (demographic, attitudinal, and parental), and then developing a "model" to best fit the data following systematic removal of variables and analysis of changes in scale deviance. Gender could not be reliably modelled, due to the small number of males. An odds ratio is interpreted as the probability of an "event" occurring — namely, applying exclusively to one type of program.

As can be seen in Table 2, three main effects emerged for the first model — B.Sc.N. versus R.N. Those who endorsed the statement "always wanted to be a nurse" were twice as likely to choose the R.N. over the B.Sc.N. program. Conversely, having recently graduated

(within the previous two years), and/or having a high school average over 80%, was associated with a greater likelihood of choosing a B.Sc.N. over an R.N. program. One main effect emerged for the second model: applicants with at least one dependant (child or adult) were 11 times more likely to choose an R.P.N. over an R.N. program.

While B.Sc.N. and R.P.N. applicants differed significantly on three variables — number of dependants, graduation year, and “always wanted to be a nurse” — convergence could not be obtained with 25 iterations. However, when applicants with previous diplomas were included, the model generated showed that those with dependants and those checking the statement “always wanted to be a nurse” were eight times more likely to choose practical over baccalaureate training.

Table 2 *Logistic Models: Predictors of Type of Nursing Program Applications*

B.Sc.N. versus Diploma (R.N.)		
Variable	Parameter Estimate	Odds Ratio
Graduation recency	-3.2909	0.037
High school average	-1.8352	0.160
Always wanted to be a nurse	0.7920	2.208
Overall model	$p = 0.0001$	
Diploma (R.N.) versus (R.P.N.)		
Variable	Parameter Estimate	Odds Ratio
Dependants	2.4136	11.174

Discussion and Conclusions

Even though Nash's (1976) applicant survey was conducted 15 years previously in the United States, our 1992 Canadian cohort showed some striking similarities with it in socio-demographic characteristics and the tendency to apply to schools within commuting distance. However, our sample submitted more applications, and its three groups were more consistent in nursing application patterns (95%, 85%, and 83% applied exclusively to, respectively, a B.Sc.N., R.N., and R.P.N. program).

Like other studies (Nash, 1976; Villeneuve, 1994; Wertenberger et al., 1993), our investigation revealed that nursing programs attract predominantly unmarried, white, young females. While we expected to

find a greater proportion of minority applicants in the metropolitan, multicultural area in which the study was conducted, it is possible that such individuals simply did not respond to our survey. It is also plausible that Canadian nursing-education programs are still failing to attract men and visible minorities proportional to the representation of these groups in society.

Clearly, in 1992, when our study was conducted, baccalaureate and diploma programs were attracting exclusive applicants. Applicants to R.P.N. programs were found to be older; more likely to be married, out of school longer, and have lower high school leaving averages; and significantly more likely to come from blue-collar families. Most striking was the finding that applicants with dependants were eight times and 11 times more likely than baccalaureate and R.N. applicants, respectively, to apply for admission to practical nursing programs. It is valuable to have this 1992 cohort — before major health-care reforms occurred — as a benchmark against which to compare characteristics of current and future applicants to nursing programs across Canada.

Even in 1992, the majority of our sample had some appreciation of the challenges facing the nursing profession. Nonetheless, a substantial proportion said they chose nursing for its financial and job security and its advancement opportunities. The majority expected to be able to work full time, in an acute-care setting close to home. Given the realities of nursing today (Armstrong, Choiniere, & Day, 1993; Hiscott, 1994), our applicant cohort now in the workplace may be experiencing a great deal of disillusionment. Only the older practical nursing applicants who had families seemed willing to accept part-time and home-nursing positions. Post-secondary institutions, and the profession itself, need to undertake proactive marketing strategies targeted to different applicant groups. Changing employment opportunities must be considered; otherwise the applicant pool will decline. As hospitals down-size and the focus shifts from acute-care nursing to community nursing, the need for flexibility in employment status has become paramount (Hiscott).

Long-range human-resources planning must make use of longitudinal studies to track different cohorts of applicants from student status through to graduation, nursing registration, and employment. Application forms must be standardized across educational institutions, and must elicit data on minority status and expectations. The profession itself is likely to change rapidly and dramatically; we need to know whether applicant characteristics and expectations change concurrently.

References

- Armstrong, P., Choiniere, H.J., & Day, E. (Eds.). (1993). *Vital signs: Nursing in transition*. Montreal: Garamond Press.
- Grossman, D.G.S., & Northrop, C. (1993). What high school students think of a nursing career: A survey of Dade County senior high schools. *Journal of Nursing Education*, 32(4), 157-162.
- Hicks, S., & Lobin, T. (1993). Nursing education: Increased enrolment in and graduation from degree programs. *Health Reports*, 5(3), 255-258.
- Hiscott, R. (1994). Changes in employment status: The experiences of Ontario registered nurses. *Canadian Journal of Nursing Research*, 26(2), 43-60.
- Nash, P. (1976). *Evaluation of the student selection processes in schools of nursing*. New York: National League for Nursing. DHEW #1-NU-34081.
- Nash, P. (1981). *Entry into nursing: Part II – Student selection and retention in nursing schools*. New York: National League for Nursing. DHHS #HRA 80-3.
- Treece, E.M.W. (1967). Vocation choice and satisfaction of licensed practical nurses. *Dissertation Abstracts International*, 28(6), 2496-B.
- Villeneuve, M.J. (1994). Recruiting and retaining men in nursing: A review of the literature. *Journal of Professional Nursing*, 10(4), 217-228.
- Wertenberger, D., Gushuliak, T., & Williams, B. (1993). Choosing nursing: An Edmonton perspective. *AARN*, 49(7), 34.

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Correspondence should be addressed to Dr. Anita M. Myers, Department of Health Studies, University of Waterloo, Waterloo, ON N2L 3G1. Telephone: (519) 885-1211, ext. 3664.

La recherche en sciences infirmières, des défis à relever

Francine Ducharme

La recherche dans la discipline infirmière est de jeune tradition en dépit du fait qu'elle a constitué une activité fondatrice de la profession à la fin du 19^e siècle. Florence Nightingale (1859), vers les années 1850, effectuait déjà des recherches sur les facteurs environnementaux associés à la santé tels la qualité de l'air, de l'eau, de la lumière, et la température, et a permis, grâce à ses travaux, de réduire de manière importante la mortalité des soldats de la guerre de Crimée, soit de 43 % à 2 % (Cook, 1913). Il a fallu néanmoins attendre la reconnaissance sociale de la profession pour que la recherche y prenne la place qui lui revient. Plus de cent ans plus tard, ce sont les États-Unis qui ont été, par la suite, les pionniers dans le domaine de la recherche en sciences infirmières. Quant au Canada, la recherche ne s'est développée à un rythme croissant qu'au cours des deux dernières décennies. Cette croissance rapide des activités de recherche s'est effectuée parallèlement à la mise sur pied de nombreux programmes de formation supérieure destinés aux infirmières, à la précision de la nature des investigations scientifiques en sciences infirmières, ainsi qu'à la reconnaissance grandissante des recherches infirmières par les organismes de subvention. La mise sur pied récente de programmes de doctorat est évidemment un des paliers marquants dans le développement et la reconnaissance sociale de la discipline infirmière comme discipline scientifique. Cette formation de troisième cycle souligne et concrétise, tout comme dans les autres disciplines, une activité qui vise le développement d'un corps de connaissance scientifique qui lui est propre. Attendue depuis fort longtemps, cette formation s'avérait essentielle à la préparation de chercheurs, lesquels répondraient à un besoin urgent au niveau des services de santé et de la discipline elle-même.

Les responsabilités des infirmières dans la prestation des soins sont devenues de plus en plus importantes et complexes. L'avancement

Francine Ducharme, Ph.D., est professeure agrégée à la Faculté des sciences infirmières de l'Université de Montréal et chercheuse au Centre de recherche de l'Institut universitaire de gériatrie de Montréal.

technologique, les changements en matière de problèmes de santé, les nouvelles demandes qui émergent des populations diverses sont autant de facteurs qui augmentent, de façon importante, le besoin de recherches infirmières. Dans cette perspective évolutive de la recherche, de grands défis confrontent actuellement les infirmières-chercheuses. Quelques réflexions sur certains de ces défis font l'objet des propos qui suivent. Toutefois, quelques mots s'imposent d'abord sur la nature de la recherche infirmière.

La nature de la recherche infirmière

À l'égal de sa définition dans toutes les disciplines, que celles-ci soient professionnelles ou académiques, la recherche infirmière est considérée comme un outil privilégié pour le développement des connaissances et la création de nouveaux savoirs, en l'occurrence des savoirs infirmiers. Elle vise à explorer, à décrire, à expliquer et à prédire des phénomènes qui présentent un intérêt pour la discipline. Elle permet de valider et de raffiner les connaissances existantes et de générer de nouvelles connaissances qui sont directement ou indirectement utiles à la pratique infirmière.

À l'instar de Carper (1978), le caractère spécifique de toute discipline détermine le type de connaissances à développer, ainsi que les approches utilisées pour le développement du savoir. Ainsi, la recherche en sciences infirmières a pour finalité la santé des populations, en améliorant la qualité, l'efficacité et l'efficience des soins infirmiers au sein du système de santé. Plus spécifiquement, comme la discipline infirmière s'intéresse fondamentalement au soin des personnes, des familles et des communautés qui vivent diverses expériences liées à la santé au sein de leur environnement (Kérouac, Pepin, Ducharme, Duquette, Major, 1994), les recherches entreprises par les infirmières s'inspirent de cette perspective disciplinaire. Ces recherches visent, entre autres : 1) la compréhension des expériences liées à la santé qui se manifestent à travers le cycle de la vie; 2) l'étude des facteurs de l'environnement interne (facteurs personnels) et externe (facteurs contextuels) qui régissent ces expériences; et 3) le développement et l'évaluation d'approches de soins et de gestion des soins favorisant la santé et la qualité de vie des personnes, des familles et des communautés.

Évidemment, la recherche infirmière ne se réalise pas sous vide. Comme la discipline infirmière est une discipline professionnelle, elle nécessite un ancrage clinique et donc des collaborations serrées entre théoriciens, chercheurs et cliniciens. En fait, une des caractéristiques des disciplines professionnelles est que la théorie, la recherche et la pratique

sont interdépendantes. La pratique suggère des situations qui méritent des investigations ainsi que des hypothèses de travail ; la théorie guide la conceptualisation des problèmes et les questions de recherche. Les projets permettent de raffiner les théories ou de contribuer à l'élaboration de nouvelles théories qui guident l'action et le changement. Des infirmières, dans les milieux de pratique, utilisent les résultats de la recherche pour améliorer leur pratique et la qualité des soins (Kérouac, Pepin, Ducharme, Duquette, Major, 1994). Idéalement, théorie, recherche et pratique s'enrichissent mutuellement (Bergman, 1990).

Plus concrètement, nous retrouvons aujourd'hui de plus en plus d'infirmières cliniciennes ayant une formation de niveau deuxième cycle qui participent au développement de projets de recherche clinique dans les milieux de pratique affiliés aux universités. L'évaluation de programmes de soins, le développement d'instruments d'évaluation des soins, le développement, l'implantation et l'évaluation de nouvelles approches de soins sont de tels projets. Il semble par ailleurs, en dépit de cette progression de la recherche dans les milieux de soins, ainsi que de la reconnaissance grandissante de la valeur des recherches en sciences infirmières, que les effets directs de la recherche sur le soin soient encore peu déterminants (Luker, 1992). Ce fait important conduit à l'identification de certains défis à relever au cours des prochaines années.

Quelques défis pour la recherche infirmière

Tout en reconnaissant que la présentation effectuée ici n'est pas exhaustive, les défis retenus dans le cadre de cette discussion ont été classifiés en deux catégories, soit ceux portant plus particulièrement sur les domaines de recherche et ceux portant sur le processus de la recherche.

Les défis portant sur les domaines de recherche

La réflexion porte ici sur trois défis principaux, soit : 1) le développement d'approches de soins efficaces et efficientes ; 2) une orientation des recherches vers des thématiques jugées socialement pertinentes ; et 3) l'accroissement du nombre de projets à caractère interdisciplinaire.

Le développement d'approches de soins efficaces et efficientes

Une analyse critique portée sur les études en sciences infirmières permet de constater que, même si la discipline infirmière est essen-

tiellement une discipline professionnelle centrée sur le soin, relativement peu d'interventions ont été élaborées, implantées et évaluées systématiquement par les infirmières-chercheuses. Cela s'explique évidemment par les connaissances que la discipline devait acquérir avant d'en arriver à proposer de telles interventions. Il existe par ailleurs, à l'heure actuelle, une riche base de données exploratoires, descriptives et prédictives, qui permet de proposer et d'évaluer de telles interventions.

Notre principal défi est de démontrer, par la recherche, l'efficacité de nos interventions tant sur le plan de la promotion de la santé de la population et l'amélioration de la qualité de vie, que sur le plan des coûts générés par ces interventions pour le système de santé. La réduction des durées de séjour et des taux d'utilisation des différents services de santé sont des indicateurs de l'efficacité des interventions dont il faut, dans le contexte budgétaire actuel, tenir compte. Il s'agit là d'un vocabulaire moins connu et utilisé de la majorité des infirmières, vocabulaire qu'il faut maintenant rapidement s'approprier. Un exemple de contribution de la recherche à la rentabilisation des soins a été publié il y a déjà plus de 10 ans dans le périodique *New England Journal of Medicine*. Brooten et ses collaborateurs (Brooten, Kumar et Brown, 1986) ont démontré que les enfants de faibles poids à la naissance pouvaient être retournés à domicile très tôt dans la mesure où ceux-ci étaient suivis par une infirmière clinicienne spécialiste. Celle-ci, lors de visites, fournissait de l'enseignement et du counseling, et les parents pouvaient communiquer avec elle à tous les jours, par téléphone. Un groupe d'enfants soignés à domicile a été comparé à un groupe pris en charge par le milieu hospitalier. Les résultats ont démontré que ces deux groupes d'enfants ne différaient pas, de manière significative, sur le plan de leur croissance physique et mentale, ainsi que sur le plan du taux de réhospitalisations ou de consultations médicales pour des soins aigus. La seule différence entre les deux groupes se situait au niveau des coûts. La prise en charge à domicile permettait d'économiser quelques 18 500 dollars américains pour chaque enfant et cela, en 1986.

Dans cette même perspective, soit celle de démontrer la contribution des infirmières au système de santé, une conférence nord-américaine, intitulée « De l'Hôpital à la communauté » et organisée par l'Ordre des infirmières et infirmiers du Québec, avait lieu en avril 1997, avec pour thème les retombées systémiques des nouveaux organismes de soins infirmiers. On y présentait de nouvelles formes d'administration de soins infirmiers, notamment des modèles de soins de santé primaires, un service prénatal de maintien à domicile et des formes diverses de gestion de cas. Ces initiatives, qui font actuellement pour la plupart l'objet de recherches évaluatives, démontrent une prise de con-

science importante des infirmières face au défi majeur qu'est celui de démontrer l'efficacité et l'efficience de leurs interventions.

Par ailleurs, un document de l'Association des hôpitaux du Québec (AHQ) intitulé *Regards sur les tendances en matière d'organisation des établissements de santé* (1996) soulignait que les nouveaux modes d'organisation qui s'implantent dans les établissements de santé sont, pour la majorité, des adaptations diverses d'un mode d'organisation par programme. On entend par programme un ensemble de services et d'activités intégrés, destinés à une clientèle particulière ayant des besoins distincts et visant des résultats spécifiques. Un des modèles avancés d'organisation par programme qui tend à se développer est celui du *patient-focused care*, dont les objectifs sont centrés d'abord et avant tout sur le client et sur un service de qualité. Cette approche découle directement des résultats de la recherche de Lathrop (1993) qui a permis d'identifier que dans les centres hospitaliers, uniquement 16 % du temps et des coûts sont affectés aux soins directs aux patients. Selon l'AHQ, dans ce nouveau contexte d'organisation par programme, l'accent majeur sera placé sur les résultats, et des activités de recherche sur les caractéristiques des clientèles des programmes, sur les modes d'intervention et leur évaluation, ainsi que sur le développement d'indicateurs de résultats pertinents seront indispensables. N'est-ce pas là une occasion de développer la recherche évaluative pour les infirmières-chercheuses ?

Les organismes subventionnaires encouragent de plus en plus, dans cette même perspective, les études sur les services de santé. En fait, les recherches doivent maintenant déboucher non seulement sur de nouvelles connaissances, mais également sur de nouvelles idées d'action ; elles doivent contribuer à modifier les politiques, à diminuer ou régler les problèmes, à développer ou améliorer les pratiques, et à restructurer les programmes et les services de manière efficace et efficiente. Dans ce contexte, les chercheurs doivent parler de leurs recherches en termes « de retombées, d'effets, d'utilité, de rendement, ou de rendement des investissements » (CQRS, 1997, p. 16). Voilà un défi, celui d'asseoir, sur des fondements scientifiques, les décisions quant à l'adaptation et à l'amélioration de notre système de santé. On parle maintenant d'*evidence-based-decision making*. Même si cela peut paraître mercantile, nous en sommes rendues là.

Plusieurs questions demeurent encore sans réponse au regard des nouveaux modes d'organisation des soins. La recherche sur les services de santé, qui a été plutôt négligée de la part des infirmières, est, dans cette optique, fort importante à développer. Dans son dernier plan

triennal, le Fonds de la recherche en santé du Québec (FRSQ) propose même au Ministère de la santé et des services sociaux d'adopter une politique selon laquelle le gouvernement du Québec aurait pour objectif de consacrer annuellement 0,5 % du budget des services de santé d'ici 2002 et 1,0 % du budget de la santé d'ici 2007 à la formation de chercheurs et au soutien de leurs carrières, aux infrastructures de recherche, ainsi qu'aux projets et à l'exportation de notre savoir unique dans le domaine de la recherche sur les politiques, les programmes, les pratiques cliniques et les organismes de services de santé (FRSQ, 1997, p.46). Voilà une autre occasion à saisir.

Une orientation des recherches vers des thématiques jugées socialement pertinentes

Il est évident que les recherches menées par les infirmières doivent aussi tenir compte des problématiques prioritaires au sein du système de santé, notamment celles des grandes transformations actuelles, qu'il s'agisse du virage ambulatoire, du maintien à domicile des personnes âgées, de la désinstitutionnalisation ou encore de la politique familiale. La réduction des séjours hospitaliers constitue plus particulièrement l'une des grandes priorités de l'heure. Les interventions en chirurgie avec séjour hospitalier d'un jour représentent déjà 24 % des chirurgies totales au Québec. Ce virage majeur est probablement la stratégie la plus visible de la reconfiguration du système de santé (Gouvernement du Québec, 1996).

La pertinence sociale des services, dont le système de santé devient de plus en plus imputable, nécessite des choix judicieux quant à la nature des recherches entreprises par les infirmières. Au Québec, la Politique de la santé et du bien-être (Gouvernement du Québec, 1992) guide présentement l'octroi des nouvelles subventions de recherche. Cette politique constitue, de la part du gouvernement, un effort de direction vers laquelle doivent converger les énergies, le but étant de réduire, de manière importante, les problèmes de santé de notre société, ou, tout au moins, empêcher qu'ils ne s'aggravent. C'est ainsi que les infirmières-chercheuses doivent effectuer de plus en plus ce que l'on appelle de la recherche « orientée ». Il n'y a plus guère de place, malheureusement, pour la recherche que l'on qualifie de « libre ». Le Conseil québécois de la recherche sociale (CQRS) statue clairement à ce sujet : « Plutôt que le modèle classique de recherche universitaire, libre et individuelle, le Conseil préconise la recherche dite appliquée ou orientée, menée en équipes, dans une perspective transdisciplinaire et

transsectorielle, sollicitant le partenariat bidirectionnel entre chercheurs et intervenants » (CQRS, 1997, p. 4).

La politique de la santé qui responsabilise les individus, les familles et les collectivités pour leur propre santé est néanmoins fort congruente avec les orientations des soins infirmiers et offre plusieurs possibilités aux chercheuses en sciences infirmières (Hagan, 1993). Ainsi, parmi les stratégies d'action qui y sont mentionnées, nous retrouvons « favoriser le renforcement du potentiel des personnes » et « agir pour et avec les groupes vulnérables dans la communauté ». N'est-ce pas là des stratégies utilisées quotidiennement par les infirmières ? L'orientation non équivoque de cette politique vers les résultats permet aussi de guider le choix d'études à entreprendre. La recherche évaluative sur les interventions préventives et la promotion de la santé auprès des groupes vulnérables, notamment les jeunes, les personnes souffrant de problèmes de santé mentale, les handicapés, les soignants naturels, les femmes, les personnes âgées, ou encore les membres des différentes communautés culturelles, est donc à développer.

Au Canada, un exercice récent de l'Association canadienne des écoles universitaires en nursing, de concert avec l'Association des infirmières et infirmiers du Canada et le Canadian Nursing Research Group, a permis d'établir des priorités pour la recherche infirmière au cours des prochaines années (ACEUN, 1997). Ces priorités en recherche touchent de près celles énoncées dans la Politique de la santé du Québec (1992) et ont été établies à partir de certains critères. Pour être jugées prioritaires, les recherches devaient notamment : 1) aborder une problématique importante et significative sur le plan de la santé et des soins de santé au Canada ; 2) avoir le potentiel de faire avancer, de manière importante, les connaissances scientifiques ; 3) avoir le potentiel d'améliorer la pratique infirmière ; 4) faire en sorte que les connaissances générées par la recherche infirmière apportent une contribution unique mais non exclusive (importance de l'interdisciplinarité) ; et 5) préserver l'intégrité, la qualité et les coûts du système de santé. À partir de ces critères, les priorités qui ont été établies concernent, entre autres, la recherche sur les services de santé, plus particulièrement sur les répercussions de la réforme de la santé, ainsi que la recherche sur les groupes vulnérables, sur les modèles d'intervention en promotion de la santé et les soins de santé primaire, sur les nouvelles méthodes de recherche, sur la diffusion des résultats pour la pratique et l'orientation en matière politique, et sur les questions d'éthique engendrées par la pratique.

Enfin, aux États-Unis, le plan stratégique pour le développement de la recherche intitulé *Directions for Nursing Research: Toward the Twenty-First Century* et publié par L'American Nurses' Association fait état de priorités pour le 21^e siècle (ANA, 1986). On y retrouve, encore une fois, des priorités similaires, entre autres, l'importance de générer des connaissances qui permettront aux infirmières de : 1) développer, mettre à l'essai et évaluer des modèles alternatifs pour la prestation et la gestion des soins de santé et ce, afin de prodiguer des soins infirmiers de qualité à moindre coût ; 2) identifier les besoins en soins des groupes vulnérables et effectuer des études d'intervention afin que ces besoins soient satisfaits de façon efficace ; 3) développer des instruments pour mesurer les effets des interventions infirmières ; 4) minimiser, par le biais d'études d'interventions, les effets négatifs des nouvelles technologies sur les capacités adaptatives des individus et des familles qui vivent l'expérience de problèmes de santé aigus et chroniques ; et 5) développer des méthodes de recherche intégratives pour l'étude holistique des phénomènes humains.

L'ensemble de ces priorités, qu'il s'agisse de celles émanant du Québec, du Canada ou des États-Unis, font foi d'une profonde mutation de notre société. Pour les chercheurs qui oeuvrent dans le réseau de la santé, incluant les infirmières, cette mutation exige des efforts considérables afin d'adapter le système aux nouveaux besoins de la population, à l'évolution de la technologie, aux normes internationales et, évidemment, aux ressources financières restreintes.

L'accroissement du nombre de projets à caractère interdisciplinaire

Les organismes subventionnaires encouragent de plus en plus un décloisonnement disciplinaire. Le CQRS (1997) mentionne par exemple, dans son plan stratégique, que la vocation de la recherche est délibérément tournée vers une compréhension transdisciplinaire et transsectorielle de la santé. Quant au FRSQ (1997), il parle d'une organisation différente de la recherche ayant comme noyau une masse critique de chercheurs de diverses disciplines qui aura la capacité d'aborder tout le spectre de la recherche d'un même domaine ou thème, ce qui facilitera le transfert des connaissances.

L'impératif actuel quant au développement de ce type de recherche à caractère interdisciplinaire ne peut qu'être favorable au développement de la recherche en sciences infirmières. D'une part, la discipline infirmière s'est construite en intégrant des théories et des concepts provenant d'une grande variété de disciplines scientifiques (psychologie, sociologie, anthropologie, sciences de l'éducation et médecine).

D'autre part, les disciplines scientifiques qui s'intéressent au comportement humain dans les contextes de santé ont besoin de théories et de concepts provenant des sciences infirmières. L'ouverture des infirmières-chercheuses aux autres champs scientifiques leur permet de solliciter, avec les collègues des autres disciplines, des fonds de recherche provenant des organismes subventionnaires qui desservent à la fois les domaines de la santé, du social, et des sciences humaines en général. Pour appuyer cette affirmation, on ne peut que penser au taux de succès des chercheuses oeuvrant en sciences infirmières au CQRS, au cours des dernières années, ainsi qu'à l'ouverture récente du Conseil de recherche en sciences humaines du Canada (CRSH) aux subventions et aux bourses d'études pour les infirmières (on y reconnaît maintenant la discipline infirmière comme une discipline des sciences humaines). S'ajoute à cela le virage actuel du Conseil de recherches médicales du Canada (CRM) et du FRSQ vers la santé. En somme, malgré un contexte actuel peu reluisant sur le plan budgétaire, la recherche infirmière en interdisciplinarité est en plein essor (Faculté des sciences infirmières, 1994).

Il importe enfin de situer ce défi sur un plan un peu plus global. Le phénomène de mondialisation des marchés touche aussi la recherche et est un facteur qui nous invite à rallier nos forces, en interdisciplinarité, afin de mieux rivaliser avec les chercheurs, à l'échelle mondiale (FRSQ, 1997). Apprendre à travailler en interdisciplinarité, c'est-à-dire développer des recherches en collaboration tout en reconnaissant la contribution des chercheurs de chacune des disciplines engagées, voilà un des défis majeurs auquel les infirmières doivent déjà faire face.

Les défis portant sur le processus de la recherche

La réflexion présentée ici touche cinq aspects principaux, soit : 1) le transfert, à la pratique, des connaissances générées par la recherche ; 2) la création de partenariats chercheurs-cliniciens ; 3) l'utilisation de méthodes de recherche adaptées à la nature des investigations en sciences infirmières ; 4) l'ouverture à de nouvelles sources de subvention ; et 5) la formation supérieure des infirmières.

Le transfert, à la pratique, des connaissances générées par la recherche

Le développement des connaissances ne consiste pas uniquement à générer des connaissances mais aussi à diffuser et à utiliser ces connaissances. Même si les chercheurs n'ont pas toutes les habiletés requises

pour assurer une diffusion optimale de leurs résultats, il n'en demeure pas moins que la diffusion de la recherche est une de leurs responsabilités. Il existe une éthique de la dissémination des résultats. N'est-ce pas une question d'éthique que celle de devoir partager l'information recueillie des recherches financées par les contribuables? (Meslin, 1994). La recherche s'effectuant grâce à des fonds publics, la société est donc en droit de s'attendre à certaines retombées des travaux qu'elle finance. Il persiste encore un écart important entre le moment de la fin d'une recherche, sa diffusion et l'utilisation des connaissances. De façon générale, toutes disciplines confondues, il fallait environ 30 ans, au début du 20^e siècle, pour qu'une innovation puisse être utile. Au milieu des années 50, cette période était réduite à environ 9 ans. Dans les années 80, on parle d'une période de 5 ans (Glaser, Abelson et Garison, 1983).

Mais qu'en est-il en sciences infirmières? Sans vouloir minimiser l'importance de la recherche fondamentale, la recherche infirmière appartient en grande partie au champ de la recherche appliquée qui vise à trouver des solutions à des problèmes cliniques. Elle a pour objectif l'introduction de changements dans la pratique des soins. Toutefois, il semble, à l'image d'autres disciplines professionnelles telles la psychologie et l'éducation, que le transfert des connaissances soit plutôt lent. La plupart des pratiques des infirmières ne sont malheureusement pas encore fondées sur des résultats de recherche.

Un exemple concret permet d'illustrer bien simplement cette situation. Nous savons depuis longtemps que la rotation interne du fémur durant une injection intramusculaire au muscle dorso-glutéal dans la position ventrale ou en décubitus latéral réduit l'inconfort et la douleur de l'injection. Une étude américaine (Brett, 1987) a démontré, avec un échantillon stratifié de 216 infirmières provenant de petits, moyens et grands centres hospitaliers, que 44 % des infirmières connaissaient cette technique, 34 % étaient persuadées que ce savoir était important pour la pratique, 29 % utilisaient, à l'occasion, ce savoir dans leur pratique, et seulement 10 % des infirmières l'utilisaient en tout temps. Cette recherche souligne les nombreuses étapes du processus d'utilisation des résultats de recherche : la connaissance du résultat, la conviction qu'il s'agit d'un résultat important, puis la décision de l'utiliser, et enfin l'implantation dans la pratique quotidienne. Mieux comprendre ce processus d'utilisation de la recherche et développer des stratégies pour faciliter l'utilisation des résultats, voilà des enjeux critiques dans notre discipline.

Funk, Tornquist et Champagne (1989) ont proposé un modèle explicatif de la dissémination de la recherche qui peut être utile aux chercheurs et cliniciens et selon lequel les qualités ou les caractéristiques de la recherche, le type de communication utilisé pour la diffuser, les caractéristiques des cliniciens, ainsi que certains facteurs favorables du milieu sont les principales composantes. Un certain nombre de questions doivent ainsi être posées en vue d'une dissémination optimale d'une recherche : Cette recherche est-elle pertinente sur le plan de la pratique ? Peut-elle résoudre un problème ou apporter une réponse à une préoccupation clinique ? Le chercheur communique-t-il bien les résultats de sa recherche ? Quelles connaissances ont les cliniciens du processus de la recherche ? Sont-ils motivés à contribuer au changement ? Ont-ils le pouvoir de modifier les pratiques ? Le milieu soutient-il les innovations ? Y a-t-il des ressources disponibles ?

Il faut toutefois reconnaître que le phénomène de l'utilisation des résultats de recherche est lié étroitement à celui du changement et de la résistance au changement (MacGuire, 1990). Dans cette optique, une étude effectuée par Rogers (1983) a permis de catégoriser, sur une courbe normale, l'attitude des personnes en regard d'une innovation, quelle qu'elle soit. Selon cette étude, il n'y aurait en fait que 2,5 % de vrais innovateurs et 13,5 % de personnes qui adoptent rapidement les innovations, par rapport à 16 % de « retardataires ». Funk et ses collaborateurs (1991) ont par ailleurs décrit, dans leur recherche, 28 barrières à l'utilisation des résultats de recherche. Il semble que ce soit d'abord le milieu organisationnel qui soit l'obstacle le plus important pour les infirmières, notamment le manque de pouvoir pour effectuer des changements, le manque de temps pour implanter de nouvelles pratiques, le manque de soutien administratif et le manque de ressources physiques. D'autres recherches ont également permis d'identifier ce facteur comme un des plus entravants à l'utilisation de la recherche (Crane, 1989). Ceci donne à réfléchir sur nos milieux de pratique.

Dans cette perspective, il serait avantageux d'utiliser certains moyens, afin de favoriser une utilisation maximale des résultats de recherche. À cet égard, certaines stratégies commencent à se concrétiser dans les milieux, qu'il s'agisse de la mise sur pied de comités de recherche, de l'organisation d'ateliers, de conférences, de groupes de discussion, de la création de Journal club, de l'inclusion d'activités de recherche dans la description de tâches des infirmières (ce qui est loin d'être la norme professionnelle), ou encore la mise sur pied d'un système de reconnaissance pour celles qui participent activement aux activités de recherche (Edwards-Beckett, 1990).

En résumé, les chercheurs doivent non seulement présenter maintenant des articles scientifiques mais aussi prendre part au débat social et à l'évolution des pratiques. Cette tendance ira encore même plus loin. À qualités scientifiques égales, le CQRS (1997) pense maintenant qu'il faudrait aussi évaluer la capacité du chercheur à se faire comprendre, à interagir avec les praticiens et à transformer les résultats de recherche en « produits » utiles. Ceci constitue un virage sans précédent et un défi majeur. Traditionnellement, les chercheurs ont eu, pour la plupart, la préoccupation de rejoindre d'abord leurs pairs plutôt que les cliniciens ou même les décideurs. Conséquemment, ils ont peu développé leurs habiletés à communiquer efficacement les résultats de leurs travaux à un plus vaste auditoire. Une des modalités qui nous permettra d'accélérer le transfert des résultats de recherche concerne donc le développement de modes de collaboration entre chercheurs et cliniciens.

La création de partenariats chercheurs-cliniciens

Une culture commune est d'abord à développer. La culture du monde de la recherche et celle des milieux de pratique sont différentes et rendent l'intégration des connaissances scientifiques difficile (Lomas, 1991). Le langage de la recherche doit être mieux compris. La « fameuse tour d'ivoire » doit se modifier en vue de fournir une image du chercheur plus accessible. Les universités se doivent de travailler en étroite collaboration avec les milieux de pratique. C'est dans les milieux de pratique que sont dispensés les soins infirmiers et c'est en tenant compte de ces milieux que peuvent se construire des programmes de recherche qui permettront d'améliorer la qualité des soins.

Par ailleurs, d'une part, la recherche s'est difficilement développée jusqu'à présent, dans ces milieux. Ceci est dû aux conditions (qui perdurent malheureusement) dans lesquelles s'exerce la profession, qui sont plutôt pénibles et peu favorables à la recherche comme pilier du renouvellement des pratiques, ainsi qu'à l'absence d'infrastructure suffisante pour la recherche, et de l'insuffisance du nombre de chercheurs. D'autre part, la plupart des infirmières connaissent encore peu la recherche et leur participation possible sur le plan de la recherche. Elles ne fondent que rarement leur pratique quotidienne sur des résultats de recherche. À ce propos, divers types d'engagement à la recherche peuvent être envisagés et une exploration à cet effet serait souhaitable (Field, Stinson et Thibaudeau, 1992). Une infirmière détenant une formation de niveau baccalauréat aura évidemment une participation différente de celle d'une infirmière formée au troisième cycle. Ce sera

néanmoins la concertation pour le développement et l'utilisation de connaissances scientifiques qui permettra une pratique fondée sur la science.

La conception que nous avons de la relation entre la recherche et la pratique est aussi une des raisons importantes pour laquelle le transfert des connaissances est particulièrement lent dans notre discipline. Le modèle traditionnel, que nous privilégions encore, veut que ce soit le chercheur qui soit responsable du développement des connaissances et que celui-ci provienne de l'extérieur du milieu clinique, plus précisément du milieu universitaire. Ce sont les chercheurs qui posent les questions et génèrent les connaissances. Les consommateurs de résultats sont plutôt passifs. On s'attend du clinicien à ce qu'il reconnaisse la valeur de la recherche et utilise les connaissances que le chercheur lui transmet. Le client est exclu du processus de génération et d'évaluation de la connaissance (la science provient de lois de la nature qui déterminent la causalité et le contrôle des expériences). Le modèle alternatif est par ailleurs consistant avec les visions émergentes de la philosophie de la science. Il origine du client en interaction avec les autres systèmes. Dans ce modèle, les praticiens et les chercheurs utilisent la pratique en tant que source de connaissance et appliquent des méthodes adaptées à cette pratique. Il s'agit d'un modèle interactif d'échanges entre le client, le praticien et le chercheur (Tanner et Lindeman, 1989).

Compte tenu de ce dernier modèle qui favorise le partenariat chercheurs-cliniciens et donc le transfert des connaissances, une analyse et une critique des méthodes de recherche utilisées s'imposent.

L'utilisation de méthodes de recherche adaptées à la nature des investigations en sciences infirmières

La question est ici de savoir si les chercheuses utilisent des méthodes qui facilitent le transfert des connaissances. Il n'y a qu'à penser aux diverses méthodes de recherche-action où un processus interactif entre chercheurs et cliniciens est favorisé, où la participation des cliniciens est nécessaire et essentielle (Swenson, 1991) et où, le plus souvent, l'objet de l'étude concerne un problème pratique (Holter et Schwartz-Barcott, 1993). Ce type d'approche qui permet d'effectuer un pont entre la théorie, la recherche et la pratique incorpore des méthodes scientifiques humanistes et naturalistes. Le but de la recherche-action est précisément de créer un changement dans la pratique. On peut également penser aux études de cas (Yin, 1989). De telles approches inductives apparaissent de plus en plus pertinentes du fait qu'elles permettent un

développement théorique et empirique ancré dans la réalité des observations provenant du terrain.

Néanmoins, ces types de recherches sont encore souvent dédaignées des chercheuses en sciences infirmières, probablement parce que celles-ci sont plus à l'aise avec les méthodes traditionnelles ou encore, parce qu'elles adhèrent à un autre paradigme scientifique. Et là, l'intention n'est nullement d'entrer dans l'épineux débat de la conception de la science, si ce n'est de mentionner que cette conception est un facteur qui peut, à l'occasion, limiter la portée des travaux de recherche. Ainsi, un certain nombre de questions doivent être posées. Par exemple, le devis quasi-expérimental ou expérimental est-il toujours le meilleur devis de recherche pour évaluer l'effet de nos interventions? Est-il vraiment possible de parler de généralisation de nos résultats de recherche dans les milieux de soins? Les activités et les perceptions des chercheuses quant à la science et à la « profession de chercheuse » méritent une réflexion au sein de notre discipline. Le défi de développer et d'utiliser des méthodes adaptées à la réalité de la recherche infirmière est un défi de taille.

L'ouverture à de nouvelles sources de subventions

Tenant compte du contexte budgétaire actuel, une nouvelle philosophie s'impose quant au recours aux diverses sources de financement. Jusqu'à présent, les chercheuses en sciences infirmières ont fait appel aux sources traditionnelles de subvention, soit aux organismes subventionnaires gouvernementaux. Par ailleurs, la compétition pour des subsides de moins en moins nombreuses est de plus en plus féroce. De très bons projets se voient octroyer des évaluations positives mais demeurent sans financement. Il nous faut donc trouver de nouveaux bailleurs de fonds et, dans cette perspective, une ouverture aux fondations et aux organismes privés devient nécessaire. Les chercheuses qui, autrefois, pouvaient dédaigner les subventions de compagnies privées, peut-être par élitisme ou par principes éthiques (peur de l'assujettissement à des intérêts particuliers et conflits d'intérêt), doivent modifier leur philosophie de financement et s'ouvrir à de nouvelles avenues. Les infirmières doivent entrer dans cette nouvelle course au financement. Il s'agit là d'un autre défi de taille.

La formation supérieure des infirmières

Les développements scientifiques, on le sait, requièrent des chercheurs bien préparés. Même si les infirmières, à différents niveaux de for-

mation, peuvent effectuer des contributions importantes dans le processus de la recherche, les programmes de formation supérieure qui privilégient la recherche doivent continuer de se développer. Le nombre d'infirmières détenant un diplôme de deuxième et de troisième cycles est encore limité au Québec et au Canada, et chacun des milieux de pratique est encore bien pauvrement doté de telles ressources pour l'avancement de la recherche

Au Canada, nous avons plus d'une quinzaine de programmes de deuxième cycle et seulement quelques programmes de doctorat qui ont été mis sur pied uniquement depuis les années 1990, décennie qui marque un tournant décisif dans le développement de la recherche en sciences infirmières. Par comparaison, il existe, aux États-Unis, plus de quarante-cinq programmes de doctorat. Une enquête effectuée en 1990 dénombrait 257 infirmières au Canada (sur 240 000) possédant une formation doctorale (Lamb et Stinson, 1990). Seulement 47 % de ces détentrices de diplôme de 3^e cycle avaient complété leur formation en sciences infirmières et 85 % d'entre elles avait plus de 40 ans, avec un âge médian de 42 ans. Ces données nous illustrent l'importance d'une telle formation et celle de développer des ressources financières afin de soutenir les candidates qui s'engagent dans des études supérieures.

Enfin, quelques mots sur la formation postdoctorale. La formation en sciences infirmières, au-delà du doctorat, est plutôt rare jusqu'à présent, même si ce type de formation correspond à une norme dans quelques disciplines. Évidemment, plusieurs raisons sont à l'origine de ce lent développement : d'abord, le faible pourcentage d'infirmières formées au doctorat (compte tenu de l'ouverture récente des programmes) et évidemment, le manque de ressources financières pour soutenir ces étudiantes. Nous avons donc, sur le plan de la formation, d'autres défis à relever.

Conclusion

Une perspective internationale nous permet de situer plus globalement les défis que nous avons à relever. En 1990, parrainé conjointement par le Conseil international des infirmières et le National Center for Nursing Research (NCNR) américain, un groupe de travail sur les recherches infirmières à l'échelle internationale s'est réuni à Genève pour faire le point sur la recherche infirmière dans le monde (Degner, 1990). Plusieurs pays possédant des programmes de doctorat ont participé à cette rencontre. De cette réunion est ressorti le fait que seuls les États-Unis pouvaient être considérés comme pays « établi » dans le domaine de la recherche infirmière. Pour être ainsi classifié, un pays

devait faire état d'un grand nombre d'infirmières détenant une formation de 3^e cycle (de 6000 à 7000) et des sources de financement stables (40 millions de dollars en 1991 par le biais du NCNR aux É.-U.).

Le Canada, comme la plupart des autres pays, s'inscrivait alors dans la catégorie de pays « en transition » sur le plan de la recherche. On y voit l'émergence d'une masse critique de chercheurs ayant une formation de 3^e cycle, sans toutefois qu'un financement stable n'ait été mis en place à l'échelle nationale. Il importe toutefois de mentionner que depuis cette conférence de 1990, d'importantes percées en recherche ont été réalisées. En effet, en dépit d'un contexte général peu reluisant quant aux sommes disponibles, les milieux de pratique se sentent prêts à investir en recherche et les orientations nouvelles des grands organismes subventionnaires de recherche offrent des possibilités. La Fondation canadienne pour l'innovation, créée lors du budget fédéral de 1997 est notamment une occasion qu'il nous faudra saisir. Également, dans le contexte actuel, la volonté d'établir des services de santé de qualité à moindre coûts ne peut que favoriser, tel que mentionné précédemment, la recherche en sciences infirmières. Les infirmières occupent une position stratégique qui les place au coeur du système de santé. Cette position leur permet d'élaborer et de participer à des projets de recherche qui apporteront des réponses à des questions d'importance, au regard de la prestation et de l'évaluation des soins et services.

Enfin, les transformations actuelles à l'échelle de la planète (ne pensons qu'aux phénomènes de la mondialisation, de la privatisation et de la déréglementation) imposent des bouleversements et des changements majeurs dans la façon de voir et de mener la recherche. Certains affirment que nous serions en cours de vivre le troisième changement le plus important du millénaire. Après la Renaissance et la Révolution industrielle, nous en sommes maintenant à la Révolution de l'information (Drucker, 1989). Les changements actuels nous forcent à imaginer autrement l'avenir et à développer de nouvelles solutions aux problèmes de santé. Plusieurs futurologues et philosophes affirment aussi que le 21^e siècle sera celui de la gestion des paradoxes. Pourquoi alors ne pas s'outiller pour gérer ces paradoxes et sortir gagnantes dans cette grande et belle entreprise qu'est devenue la recherche ?

Références

- American Nurses' Association. (1986). *Directions for Nursing Research: Toward the Twenty-First Century*.
- Association canadienne des écoles universitaires en nursing (ACEUN). (1997). *Priorités de la recherche infirmière au Canada. Résultats de la phase III du symposium national sur la recherche infirmière*. Ottawa.
- Association des hôpitaux du Québec. (1997). *Regard sur les tendances en matière d'organisation des établissements de santé*. Montréal : Collection La Reconfiguration du réseau, no. 7.
- Bergman, R. (1990). Interrelations between nursing theory, research, practice and education. Dans *International Nursing Research Round Table Proceedings Book*. Utrecht : University of Utrecht.
- Brett, J. (1987). Organizational integrative mechanisms and adoption of innovations by nurses. *Nursing Research*, 36(6), 344-349.
- Brooten, D., Kumar, S., Brown, L. (1986). A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. *New England Journal of Medicine*, 315, p. 934.
- Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1, 3-23.
- Conseil québécois de la recherche sociale (1997). *Plan stratégique 1997-2000. Pour une politique de recherche et un développement en matière sociale*. Québec : Gouvernement du Québec.
- Cook, E. (1913). *The Life of Florence Nightingale*. London : Macmillan.
- Crane, J. (1989). *Factors associated with the Use of Research-Based knowledge in Nursing*. Doctoral Dissertation, University of Michigan.
- Degner, L. (1990). La recherche en sciences infirmières à l'échelle internationale : Où le Canada se situe-t-il ? *Revue canadienne de recherche en sciences infirmières*, 22(1), 3-5.
- Drucker, P. (1989). The New Realities : In Government and Politics, in Economics and Business. Dans *Society and World View*. New York : Harper and Row.
- Edward-Beckett, J. (1990). Nursing research utilization techniques. *Journal of Nursing Administration*, 20(11), 26.
- Faculté des sciences infirmières. (1994). *Plan directeur de la recherche*. Document de travail. Montréal : Université de Montréal, Vice-décanat à la recherche et aux études supérieures de la Faculté des sciences infirmières.
- Field, P., Stinson, S., Thibaudeau, M.-F. (1992). Graduate education in Nursing in Canada. Dans A. Baumgart et J. Larsen (Éds.). *Canadian Nursing Faces the Future*. (pp. 421-445). Toronto : Mosby.
- Fonds de la recherche en santé du Québec. (1997). *Orientations stratégiques 1997-2000. Bâtir ensemble la recherche de l'avenir*. Montréal : FRSQ.
- Funk, S., Tornquist, E., Champagne, M. (1989). A model for improving the dissemination of nursing research. *Western Journal of Nursing Research*, 11(3), 361-367.

- Funk, S., Tornquist, E., Champagne, M. (1991). Barriers to using findings in practice : The clinician's perspective. *Applied Nursing Research*, 4(2), 90-95.
- Glaser, E., Abelson, H., Garrison, K. (1983). *Putting knowledge to use*. San Francisco : Jossey-Bass.
- Gouvernement du Québec. (1992). *Politique de la santé et du bien-être*. Québec : Ministère de la santé et des services sociaux.
- Gouvernement du Québec. (1996). *La santé et les services sociaux: Enjeux et orientations stratégiques d'un système en transformation*. Sommet de l'économie de l'emploi. Ministère de la santé et des services sociaux.
- Hagan, L. (1993). Les priorités de recherche en sciences infirmières et la Politique de santé et de bien-être. Dans M.-F. Thibaudeau, C. Pelletier, et C. St-Pierre. *Priorités de la recherche en sciences infirmières. Actes du colloque organisé dans le cadre du 61^e congrès de l'ACFAS*. (pp. 25-34) Rimouski, mai 1993.
- Holter, I., Schwartz-Barcott, D. (1993). Action research : What is it? How has it been used and how can it be used in nursing? *Journal of Advanced Nursing*, 18, 298-304.
- Kérouac, S., Pepin, J., Ducharme, F., Duquette, A., Major, F. (1994). *La pensée infirmière*. Montréal : Études vivantes.
- Lamb, M., Stinson, S. (1990). *Canadian Nursing Doctoral Statistics: 1989 update*. Ottawa : Canadian Nurses Association.
- Lathrop, J. (1993). *Restructuring Health Care: The Patient-Focused Paradigm*. San Francisco : Jossey-Bass.
- Lomas, J. (1991). Words without action? The production, dissemination and impact of consensus recommendations. *Annual Review of Public Health*, 12, 41-65.
- Luker, K. (1992). Research and development in nursing. *Journal of Advanced Nursing*, 17, 1151-1152.
- MacGuire, J. (1990). Putting nursing research findings into practice : research utilization as an aspect of the management of change. *Journal of Advanced Nursing*, 15, 614-620.
- Meslin, E. (1994). Toward an ethic in dissemination on new knowledge in primary care research. Dans E. Dunn, P. Norton, M. Stewart, F. Tudiver et M. Bass (Éds.). *Disseminating Research/Changing Practice* (pp. 59-75). Thousand Oaks : Sage.
- Nightingale, F. (1859). *Notes on Nursing: What it is, and what it is not*. Philadelphia : Lippincott.
- Rogers, E. (1983). *Diffusion and Innovations* (3^e éd.). New York : Free Press.
- Swenson, M. (1991). Using fourth-generation evaluation in nursing. *Evaluation and the Health Profession*, 14, 79-87.
- Tanner, C., Lindeman, C. (1989). *Using Nursing Research* (pp. 13-17). New York : National League for Nursing.
- Yin, R. (1989). *Case Study Research*. Newbury Park : Sage.

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

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Volume 29 – 1997

The Canadian Journal of Nursing Research is indebted to the persons below who served as reviewers for Volume 29. They gave generously of their time and shared their knowledge, and in so doing have contributed greatly to the editorial process and to the development of nursing knowledge.

La Revue canadienne de recherche en sciences infirmières est reconnaissante envers les personnes ci-dessous nommées d'avoir révisé son volume 29. Ces personnes ont généreusement donné de leur temps et ont partagé leur savoir. Ce faisant, elles ont largement contribué au processus éditorial et au développement des connaissances en sciences infirmières.

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Call for Papers

Early Family Development

Fall 1998 (vol. 30, no. 3)

The focus of this issue is families during the early child-rearing years, with particular emphasis on the developing child. Topics include: the ecological environment of young children; developing and changing roles and relationships within the family (e.g., parent-child, sibling, grandparents), across situations and settings; cultural diversity in child-rearing practices; coping with transitional events (e.g., pregnancy, birth of a sibling, day care, school entry); changing family structures and demographics; early interventions with high-risk and at-risk families; and educational and health programs that promote family and child health. Qualitative and quantitative research reports as well as state-of-the-art reviews are invited.

Guest editor: Dr. Kathryn Barnard

Submission Deadline: Extended to May 15, 1998

Anniversary Issue

Winter 1998 (vol. 30, no. 4)

In celebration of the Journal's first 30 years of publication, this special anniversary issue will feature a retrospective of the Journal's history and contents, as well as the changes that nursing research has undergone since 1968. This issue will feature "gems from the past" — classic articles that have "weathered the test of time" and are still salient to nursing research — as well as reflections from their respective authors.

No Submissions for this Issue

Please send manuscripts to:

The Editor

Canadian Journal of Nursing Research
McGill University School of Nursing
3506 University Street
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Développement de la jeune famille

Automne 1998 (vol. 30, no. 3)

Ce numéro se penche sur la question des familles dont les enfants sont en bas âge, avec un accent sur l'enfant en cours de développement. Les sujets incluent : l'environnement écologique des jeunes enfants; le développement et la transformation des rôles et des relations au sein de la famille (p. ex. parent-enfant, frère-soeur, grands-parents) dans le cadre de différentes situations et des contextes variés; la manifestation de diversités culturelles dans les pratiques d'éducation des enfants; l'habileté d'adaptation aux événements transitionnels (p. ex. la grossesse, la naissance d'un frère-une soeur, la garderie, l'entrée à l'école); les structures familiales en transformation et la démographie; l'intervention précoce auprès des familles vivant des situations à risque moyen et à risque élevé; et les programmes d'éducation et de santé qui promeuvent la santé de la famille et de l'enfant. Nous demandons des rapports de recherche d'ordre qualitatif et quantitatif, ainsi que des articles critiques de fine pointe.

Rédactrice invitée : Kathryn Barnard, Ph.D.

Date de tombée : reportée au 15 mai 1998

Spécial Anniversaire

Hiver 1998 (vol. 30, no 4)

Dans le cadre du trentième anniversaire de la Revue, ce numéro Spécial Anniversaire vous offrira une rétrospective en ce qui a trait au contenu et à l'historique de cette publication, tout en traitant des changements qui ont eu lieu dans le domaine de la recherche en sciences infirmières depuis 1968. Vous pourrez y lire une chronique intitulée « des trésors du passé », des articles qui ont « franchi avec succès l'épreuve du temps » et qui sont toujours très pertinents à la recherche actuelle.

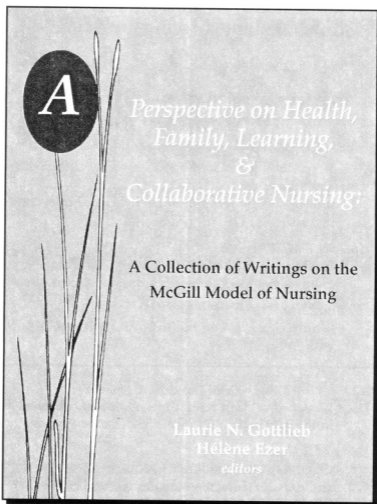
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DEPARTMENT OF NURSING
University of New Brunswick
Saint John Campus

**Positions in Curative/Restorative Care,
Family Nursing and Psychiatric Nursing**

Applications are invited for two probationary tenure-track faculty positions and two full-time term instructor positions in the Department of Nursing at the University of New Brunswick in Saint John (UNBSJ). An employment date of 1 July 1998 is anticipated for all positions subject to budgetary approval. The tenure-track positions are available in curative/restorative care and family nursing. Applicants for the tenure-track appointments should have recent practice and university teaching experience. An established program of research in the field of either acute-care nursing or family nursing is desirable. Applicants for the instructor positions should have practice expertise in acute-care nursing or psychiatric nursing and clinical teaching experience in the respective specialty area.

The Department offers a program leading to a baccalaureate nursing degree and collaborates with the Faculty of Nursing at UNB Fredericton to offer the MN program. Integration of the BN and BN/RN streams of the program is underway. The successful applicants for the tenure-track positions will have primary teaching and practice responsibilities in the undergraduate program; opportunities to work with graduate students are also available. The primary responsibility of the instructor positions is practice teaching at the undergraduate level. UNBSJ is located adjacent to a large teaching hospital. Strong affiliations with colleagues in this and other practice settings in the region, plus developed links in the international arena, provide opportunities for collaborative research projects and/or joint appointments.

The minimum requirement for all positions is a Masters degree in nursing, with doctoral preparation in nursing or a related discipline (either completed or in progress) preferred for the tenure-track appointments. Demonstrated commitment to team and interdisciplinary collaboration, a primary health-care philosophy, and innovative educational approaches are assets for all positions. Candidates must be eligible for registration with the Nurses Association of New Brunswick.

In accordance with Canadian immigration requirements, this advertisement is directed to Canadian citizens and permanent residents. Applicants should forward a curriculum vitae and the names of three referees to be received by 17 April 1998 to Dr. C.K. Tompkins, Dean of Science, Applied Science & Engineering, University of New Brunswick, P.O. Box 5050, Saint John, N.B., E2L 4L5, fax 506-648-5650, email cktomp@unbsj.ca. The University of New Brunswick is committed to the principle of employment equity.

St. Francis Xavier University

FACULTY POSITIONS

BACHELOR OF SCIENCE (NURSING) PROGRAM

Applications are invited for one probationary tenure-track position, pending budget approval, beginning September 1998. Salary and rank will be commensurate with qualifications and experience.

St. Francis Xavier University offers a four-year, integrated, undergraduate B.Sc.N. program; a part-time, post-diploma baccalaureate program by distance education; and an innovative certificate program in continuing care which focuses on community-based practice via distance education for post-RN students.

Initial teaching responsibilities will be with the on-campus B.Sc.N. program. Opportunity is also available for teaching in the distance-education programs.

Minimum academic preparation and qualifications include a Master's degree in nursing, a doctorate in nursing, teaching experience at the undergraduate level, a strong practice focus in maternal/child nursing, evidence of research and scholarly productivity, and eligibility for registration with the Registered Nurses Association of Nova Scotia.

The applications deadline is when the position is filled. Applicants must submit a cover letter, a curriculum vitae, a copy of current registration, and the names of three referees, including most recent employer, to:

Dr. Angela Gillis, Chair

Department of Nursing, St. Francis Xavier University

Box 5000, Antigonish, Nova Scotia B2G 2W5

Fax (902) 867-2322

In accordance with Canadian immigration requirements, priority will be given to Canadian citizens and permanent residents of Canada. St. Francis Xavier University is committed to employment equity.

The University of Hong Kong

DEPARTMENT OF NURSING STUDIES

Associate Professor

Applications are invited for appointment as Associate Professor (RF-97/98-27: 3 posts), tenable from 1 July 1998 or as soon as possible thereafter. Applicants should have a PhD in nursing or a related discipline.

Assistant Professor

Applications are invited for appointment as Assistant Professor (RF-97/98-38: 5 posts), tenable from 1 August 1998 or as soon as possible thereafter. A PhD in nursing or a related discipline is preferred; a Master's degree in nursing is required.

For both posts appointment will initially be made on a three-year fixed-term basis, with a possibility of renewal. Applicants should be licensed to practise, or be eligible for licensure, with the Nursing Board of Hong Kong. They should also have classroom and clinical teaching experience in tertiary institutions, knowledge of curriculum development, and a program of research reflected by publications in refereed journals. Preference will be given to those with expertise in the areas of maternal-child health, women's health, nursing care of adults with acute and chronic illnesses, community health nursing and the behavioural and social sciences. Fluency in both English and Chinese is desirable.

Annual salary (attracting 15% [taxable] terminal gratuity) for an Assistant Professor (in the grade of Lecturer) is on an 11-point scale, for Associate Professor (in the grade of Senior Lecturer) on a 9-point scale, with starting salary depending on qualifications and experience. Assistant Professor* (in the grade of Lecturer): HK\$522,780 – HK \$873,360 (approx. C\$97,736 – C\$163,278; Canadian dollar equivalent as at 2 February 1998).

*An appointee with an annual salary at HK\$698,520 (approx. C\$130,589) or above may be considered for the award of the title of Associate Professor; Associate Professor (in the grade of Senior Lecturer): HK\$812,220 – HK \$1,091,100 (approx. C\$149,001 – C\$200,173; Canadian dollar equivalent as at 2 February 1998).

At current rates, salaries tax will not exceed 15% of gross income. Leave, medical benefits, an allowance for children's education in Hong Kong, and, in most cases, a financial subsidy for private tenancy are provided, the last at a charge of a percentage of salary, currently 7.5%. Further particulars and application forms can be obtained at <http://www.hku.hk>; or from the Appointments Unit, Registry, The University of Hong Kong, Hong Kong, Fax (852) 2540 6735 or 2559 2058; Email: APPTUNIT@REG.HKU. HK.

Closing date: 15 April 1998

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The University of Manitoba

DEAN, FACULTY OF NURSING

The University of Manitoba invites applications and nominations for the position of Dean, Faculty of Nursing. The Faculty of Nursing offers programs leading to Bachelor and Master of Nursing degrees. In Manitoba the B.N. degree is the entry to professional practice, and the University is the sole provider of this degree. The Faculty has a complement of 74 academic staff and 27 support staff, and enrolments of 526 full-time and 301 part-time undergraduate students and 16 full-time and 58 part-time graduate students. The Faculty supports an active research environment through the Manitoba Nursing Research Institute and other institutes of the University and through collaborative arrangements with health-care agencies. During the tenure of the Deanship, it is anticipated that the Faculty of Nursing will be provided with new physical facilities.

Candidates must have a clear commitment to and vision for nursing education and research. A doctoral degree in nursing or a related discipline and professional registration or eligibility for registration under the Manitoba Association of Registered Nurses are required. Demonstrable ability to provide leadership and effective administration in the context of post-secondary education and the evolving Canadian health-care system is an asset. Ability to work collaboratively with other institutions, including hospitals, colleges and universities, government agencies, and community groups such as First Nations, is essential.

The appointment will commence on July 1, 1998, or as soon thereafter as may be mutually agreed, and normally is for a period of 5 to 7 years. Under University policy reappointment is possible.

The University of Manitoba encourages applications from qualified men and women, including members of visible minorities, Aboriginal peoples, and persons with disabilities. Priority consideration will be given to Canadian citizens and permanent residents of Canada.

Applications (with the names of three referees) and nominations will be received until April 15, 1998, and should be forwarded to:

Dr. James S. Gardner
Vice-President (Academic) and Provost
and Chair, Advisory Committee for the
Appointment of the Dean of the Faculty of Nursing
Room 202 Administration Building
The University of Manitoba
Winnipeg, Manitoba R3T 2N2
(204) 474-9444

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: Three double-spaced typewritten copies of the manuscript on 8 1/2" x 11" paper are required. Articles may be written in French or English. Authors are requested not to put their name in the body of the text, which will be submitted for blind review. Only unpublished manuscripts are accepted. A written statement assigning copyright of the manuscript to the *Canadian Journal of Nursing Research* must accompany all submissions to the journal. Manuscripts are sent to: The Editor, *Canadian Journal of Nursing Research*, School of Nursing, McGill University, 3506 University Street, Montreal, QC H3A 2A7.

Manuscripts

All manuscripts must follow the fourth edition of the *Publication Manual of the American Psychological Association*. Research articles must follow the APA format 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. Do not use footnotes.

Title page: This should include author name(s), degrees, position, information on financial assistance, acknowledgements, requests for reprints, address, and present affiliation.

Abstract: Research articles must include a summary of 100–150 words containing information on 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 a summary of the argument.

Text: The text should not exceed 15 double-spaced typed pages. References, tables, and figures should follow the text.

References: The references are listed in alphabetical order, double-spaced, and placed immediately following the text. Author names and journal citations must be spelled out in full.

Tables and figures: Tables and figures should appear only when absolutely necessary. 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.

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.

La *Revue canadienne de recherche en sciences infirmières* paraît quatre fois par année. Son mandat est de publier la recherche en sciences infirmières qui a trait au développement des connaissances dans la discipline et l'analyse de la mise en pratique de ces connaissances. La revue accepte également des articles de recherche reliés à l'éducation, à l'histoire de même que des articles reliés à la méthodologie, la théorie et l'analyse critique qui permettent le développement des sciences infirmières. Des lettres et commentaires sur des articles publiés sont également encouragés.

Modalités : Les textes doivent être soumis en trois exemplaires, être dactylographiés à double interligne sur des feuilles 216mm x 279 mm et être adressés à la rédactrice en chef, à la *Revue canadienne de recherche en sciences infirmières*, Université McGill, École des sciences infirmières, 3506 rue Université, Montréal, QC, H3A 2A7. Il est entendu que les articles soumis n'ont pas été simultanément présentés à d'autres revues. Veuillez également inclure lors de la soumission, une déclaration de propriété et de cession de droits d'auteurs. Finalement, afin de garder l'anonymat lors du processus de révision, veuillez ne pas inclure les noms des auteurs dans le texte.

Manuscrits

La présentation du manuscrit doit respecter les normes du *Publication Manual of the American Psychological Association*, 4^{ème} édition, 1994. Particulièrement, les figures, tableaux, illustrations et références doivent suivre ces normes de présentation. Il est suggéré de ne pas utiliser de notes au bas de la page.

Page titre : Pour assurer la lecture anonyme des textes soumis, seule la page titre du manuscrit comprendra le nom, l'adresse et l'affiliation de(s) auteur(s), les diplômes obtenus ainsi que l'aide financière reçue, les remerciements et une demande de copies.

Résumé : Un résumé en anglais et en français d'environ 100 à 150 mots chacun doit précéder le texte. Ce résumé devrait comprendre l'objectif, la méthode, les résultats et les retombées de la recherche. Les manuscrits qui concernent la théorie et les analyses critiques doivent inclure une identification des objectifs principaux, le cadre conceptuel utilisé pour l'analyse des données et un résumé de la discussion. La qualité du français est primordiale; le style doit être clair concis et doit éviter un langage sexiste ou discriminatoire.

Texte : La longueur totale d'un manuscrit incluant les tableaux, les figures et les références, ne doit pas dépasser 15 pages, dactylographiées à double interligne. Les articles peuvent être rédigés soit en anglais ou en français.

Références : Les références doivent paraître en ordre alphabétique, à double interligne et faire suite au texte. Les noms des auteurs de même que les citations de revues doivent être écrites au long.

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