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

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Les nouveaux défis de la recherche et de la pratique infirmières en santé mentale

Nicole Ricard, Ph.D.

Au début de l’année 1999, les infirmières ont appris le départ d’une grande pionnière et d’un leader inestimable en nursing psychiatrique, madame Hildegard Peplau, Ph.D. Au cours des cinquante dernières années, madame Peplau a contribué de façon magistrale à l’établissement des assises et à l’avancement des soins en santé mentale et en psychiatrie. Visionnaire, elle a été l’une des premières infirmières à élaborer un modèle conceptuel en sciences infirmières et à créer un programme de formation pour les infirmières cliniciennes spécialisées en santé mentale, innovation qui aura certainement fourni l’impulsion nécessaire au développement de la pratique avancée en sciences infirmières. Je voudrais donc avant tout, dans ce numéro consacré à la santé mentale, rendre hommage à cette infirmière qui a tracé la voie pour les infirmières cliniciennes, éducatrices ou chercheuses. Son départ peut évoquer la nostalgie d’une certaine époque mais aussi constituer une occasion de réaffirmer la contribution fondamentale des infirmières et d’anticiper avec optimisme leur rôle futur dans l’amélioration des soins en santé mentale.

Au cours des vingt dernières années, une multitude de facteurs ont influencé le développement de la recherche en santé mentale et en sciences infirmières. Tout d’abord, des progrès considérables ont été réalisés dans la compréhension des mécanismes génétiques et neurochimiques des troubles mentaux graves, influençant considérablement les modes de traitement, la trajectoire d’évolution de ces troubles, et les besoins de suivi et de réadaptation des personnes atteintes de troubles graves et persistants. Dans le domaine psychosocial, les recherches ont également permis de développer une compréhension beaucoup plus dynamique des facteurs qui contribuent à augmenter ou à moduler la vulnérabilité des personnes au développement d’un problème de santé.
mentale, ainsi que des facteurs susceptibles d’influencer l’évolution de certains troubles mentaux et la réadaptation. Par ailleurs, les pressions inhérentes aux impératifs économiques et une préoccupation constante pour la recherche d’efficience et d’efficacité sont venues remettre en question les modèles traditionnels de prestation des soins, influençant ainsi la durée, les lieux de traitement ainsi que les diverses approches de soins. Cependant, il faut reconnaître que ces progrès ne se sont pas nécessairement traduits par une amélioration de la santé mentale des populations. En effet, comme le souligne un rapport de l’Organisation Mondiale de la Santé (1995), même si la santé physique s’est améliorée à l’échelle mondiale, l’état de santé mentale n’a pas changé. Au contraire, on observe une détérioration puisque plusieurs problèmes tels l’alcoolisme, les toxicomanies, la violence, le suicide touchent maintenant autant les sociétés pauvres que les plus riches. La prévalence des problèmes de santé mentale et leur complexité croissante exigent des services nombreux, diversifiés, complémentaires, accessibles et adaptés aux nouvelles problématiques. Toutefois, il est reconnu que, contrairement au domaine des soins physiques, la majorité des personnes qui présentent des problèmes de santé mentale ne consultent pas, soit en raison de la méconnaissance ou de l’inefficacité des services. (Dorvil, Guttman, Ricard et Villeneuve, 1997)

Ces divers constats interpellent tant les infirmières cliniciennes, éducatrices et chercheuses. Ils les confrontent à de nouveaux défis et les obligent à réévaluer sérieusement les priorités de recherche infirmière en santé mentale et le type de contribution que la discipline peut apporter aux soins, actuellement en pleine transformation. Or, cette réflexion est déjà en cours et, comme le démontre le texte de Chaifetz et Ricard, il y a de plus en plus de données empiriques et cliniques nous incitant à développer une véritable orientation biopsychosociale dans les soins en santé mentale, à repenser les fondements de la pratique avancée et l’orientation des curriculum au niveau des études supérieures. Les difficultés du système de soins actuel à répondre de façon efficace aux nouvelles problématiques de santé physique et aux besoins complexes des personnes atteintes de troubles graves et persistants exigent le développement de compétences nouvelles et élargies chez les infirmières en santé mentale. L’orientation et la formation des infirmières en pratique avancée doit être repensée, mais sans entrer dans ce débat contre productif sur les rôles respectifs des infirmières cliniciennes spécialisées et infirmières praticiennes. Il importe de développer un modèle de pratique avancée intégrant diverses compétences du domaine de la santé mentale et des soins de première ligne.
Cette formation devrait permettre aux infirmières d’être davantage reconnues parmi les divers professionnels comme intervenantes de première ligne efficaces, efficientes et capables d’assurer un leadership dans le domaine du soin et du suivi des clientèles qui ont des problèmes de santé mentale.

Les enjeux liés au développement et à l’adoption d’une véritable perspective biopsychosociale de l’infirmière dans l’équipe de santé mentale ont guidé les travaux de Hawkins, Veeder et Pearce qui, dans leur volume, intègrent des dimensions biopsychosociales et systémiques pour développer un modèle de collaboration entre infirmières et travailleurs sociaux. Or, Bonin, dans la critique de ce volume, constate que les auteurs font une réflexion intéressante en tenant compte de l’historique de cette collaboration et des nouveaux rôles à assumer dans le contexte des transformations actuelles du système de santé. Toutefois, l’opérationnalisation du modèle qu’ils proposent semble inciter les infirmières à s’orienter davantage vers le biosocial et à limiter leurs interventions pour ce qui est du domaine psychologique. On constate donc que le développement et l’opérationnalisation d’une véritable perspective biopsychosociale dans les soins en santé mentale représente un défi qui exige de dépasser les schémas habituels de référence qui ont, jusqu’ici, déterminé le partage des rôles et responsabilités des professionnels. Il ne s’agit pas tant de se répartir entre les professionnels le bio, le psycho ou le social que de déterminer la façon spécifique avec laquelle les infirmières ou les autres professionnels abordent ces dimensions et les intègrent à leurs interventions ou préoccupations de recherche.

Dans cette perspective, il est de plus en plus reconnu que les infirmières ont un rôle important dans la mise en place des conditions qui assurent la réussite des progrès réalisés au plan des traitements psychopharmacologiques et des programmes de maintien des malades dans la communauté. Parmi ces conditions, l’assiduité à la médication prend toute son importance en raison du contexte de suivi à long terme et de chronicité qui caractérise certaines maladies mentales. L’article de Bonin traite de cette problématique et, à partir du modèle conceptuel préventif des croyances en matières de santé de Pender, permet de cibler des caractéristiques de la clientèle et des facteurs psychosociaux auxquels les infirmières doivent être vigilantes pour faciliter l’assiduité chez leur client et réduire les risques de rechute. Cette étude apporte une excellente contribution à la recherche en sciences infirmières en raison de ses forces méthodologiques, notamment au plan de la taille et des caractéristiques de l’échantillon et de la diversité des mesures pour
évaluer l’assiduité. L’auteur attire notre attention sur le fait que les barrières perçues s’avèrent un prédicteur puissant de la non assiduité et devraient interpeller les décideurs politiques dans un contexte où de nouveaux programmes gouvernementaux tel celui de l’assurance médicamente au Québec contribuent justement à augmenter ces barrières.

L’évolution des connaissances sur l’étiologie organique des troubles mentaux a aussi modifié considérablement nos modes d’intervention auprès des familles. En effet, après avoir été culpabilisées pour la maladie mentale de leur proche, les familles sont davantage considérées comme des partenaires dans le soin ; de plus en plus de programmes de psycho-éducation leur sont offerts et s’avèrent efficaces. Toutefois, les premiers programmes de psycho-éducation avaient pour objectif premier de prévenir la rechute du malade et s’intéressaient peu au bien-être de la famille. Actuellement, des programmes récents, développés par des infirmières, ciblent davantage les facteurs qui influencent la santé de la famille et ses forces pour l’aider à développer des stratégies de coping permettant de faire face plus efficacement aux exigences de leur rôle d’aidant naturel (family caregiver). En ce sens, l’innovation décrite par Baker dans « From Chaos to Order » apporte une contribution originale au développement d’une intervention infirmière novatrice auprès d’un groupe de parents qui ont la difficile tâche de composer quotidiennement avec un enfant qui présente un déficit de l’attention et de l’hyperactivité (attention-deficit hyperactivity disorder). S’inspirant d’un cadre théorique en sciences infirmières, les objectifs de ce programme visant l’empowerment sont très bien ciblés pour aider ces parents à développer ou consolider leurs compétences dans la gestion des comportements difficiles de leur enfant, et pour améliorer leur interaction avec ce dernier. Ce programme comporte sans doute un potentiel de prévention tant auprès des parents que de l’enfant qu’il y aurait lieu d’évaluer systématiquement dans le futur.

Les données des enquêtes épidémiologiques sur la santé mentale des populations révèlent que les personnes les plus touchées par l’augmentation des problèmes de santé mentale sont les jeunes de 15 à 24 ans (Bellerose, Lavallée et Camirand, 1994). Plusieurs facteurs sociaux contribuent à expliquer l’augmentation de ces problèmes : le peu de perspective d’avenir, la pauvreté, la précarité et la violence. La recension des écrits de Dahinten reflète bien comment la recherche en sciences infirmières peut apporter une meilleure compréhension à l’influence de certains déterminants socio-environnementaux sur la santé des jeunes. L’auteure démontre que le phénomène du harcèlement sexuel à l’ado-
lescence est fréquent mais banalisé, peu établi et qu’il peut constituer une menace importante à la santé mentale des femmes. En s’inspirant du cadre théorique de stress-coping, l’auteure propose un modèle conceptuel qui tient compte de la complexité et de l’interaction des divers facteurs à retenir dans le développement de devis de recherche. L’étude de l’impact de ce phénomène, non seulement sur les résultats de santé (health outcomes), mais aussi sur les comportements de santé, constitue un apport spécifique et particulièrement pertinent de la recherche en sciences infirmières. Enfin, l’auteure invite les infirmières en santé scolaire à élargir leur perspective et à se préoccuper davantage de l’influence des facteurs psychosociaux sur la santé des adolescents.

On ne peut s’empêcher de faire des liens entre les préoccupations de recherche décrites dans l’article de Dahinten et la recherche qualitative menée par Gallop, Engels, DiNunzio et Napravnik. Ces deux textes font ressortir comment le harcèlement sexuel et la violence font partie d’un même continuum, et influencent la santé mentale des femmes. Cette recherche qualitative apporte une contribution exceptionnelle au présent numéro en expliquant clairement comment la qualité de l’environnement de soins peut contribuer à réactiver les expériences traumatisantes de ces femmes. Cette étude constitue un excellent prototype de recherche clinique dont la pertinence et la richesse des données devraient avoir des implications immédiates pour l’amélioration des pratiques de soins. En effet, les résultats illustrent que, malgré leur importance, les valeurs et les principes de la relation thérapeutique et le rôle fondamental des infirmières dans l’organisation du milieu thérapeutique ne semblent pas toujours intégrés au prètiques quotidiennes des infirmières. Ces résultats conduisent les auteurs à proposer diverses explications dont le manque de contrôle et de pouvoir des infirmières sur la modification de leurs pratiques de soins. On peut aussi se demander si, à un niveau plus général, les milieux de soins ont été suffisamment vigilants à préserver les acquis du nursing psychiatrique. Les valeurs humanistes et l’engagement des infirmières sont-elles des ressources inépuisables, capables de résister à des contextes de plus en plus stressants, exigeants et moins valorisants? Comment les administrations dans les divers milieux de soins facilitent-elles le développement professionnel des infirmières et assurent-elles le soutien nécessaire pour faire face aux stressesurs occupationnels de plus en plus nombreux? Ces questions concernent directement la santé mentale des infirmières ainsi que les stratégies à déployer pour soutenir les infirmières qui interviennent auprès des personnes les plus vulnérables et les plus en besoin.
Enfin, plus que jamais, la santé mentale des Canadiens et la qualité des services psychiatriques sont au centre des préoccupations des décideurs politiques. Les gouvernements provinciaux et fédéral et les organismes subventionnaires sont prêts à consentir les efforts nécessaires pour identifier systématiquement les pratiques les plus efficaces et efficientes en santé mentale. Ces orientations fournissent donc actuellement l’impulsion nécessaire à un développement accru de la recherche sur les services de santé mentale. Dans cette perspective, les sciences infirmières sont actuellement très bien placées comme partenaire privilégié pour participer au développement de ce secteur de recherche.

En somme, les priorités actuellement accordées à la recherche sur les services en santé mentale auront certainement un impact important sur le développement futur de la recherche infirmière dans ce domaine. Toutefois, il est aussi important que les infirmières chercheuses influencent ces tendances et déterminent elles-mêmes leurs priorités de recherche. Le champs de la santé mentale et des soins psychiatriques est si large qu’il peut facilement conduire à l’éparpillement des efforts de recherche et nuire au développement d’un corps de connaissances utiles à l’avancement des pratiques des soins en santé mentale et en soins psychiatriques. Aussi, faudrait-il que les infirmières chercheuses se concertent davantage pour développer un réseau de recherche, identifier leurs priorités et consolider les partenariats déjà établis avec les milieux de pratique, notamment avec les infirmières en pratique avancée.

Références


Nicole Ricard, Ph.D., est professeure titulaire à la Faculté des sciences infirmières de l'Université de Montréal. Madame Ricard est chercheuse régulière au Centre de Recherche Fernand-Séguin, affilié à l'Hôpital Louis-H. Lafontaine. Ses recherches portent sur la famille et le suivi intensif dans la communauté de personnes atteintes de troubles graves et persistants. Elle est membre du Comité de Santé mentale du Québec.
The New Challenges of Mental Health Nursing Research and Practice

Nicole Ricard

Early in 1999, the nursing community learned of the passing of Dr. Hildegard Peplau, a great pioneer and an invaluable leader in psychiatric nursing. For the past 50 years Dr. Peplau has been instrumental in establishing benchmarks and furthering mental health and psychiatric care. A visionary, she was one of the first nurses to develop a conceptual model in nursing and to create a training program for nurse clinicians specializing in mental health, an innovation that spurred the development of advanced nursing practice. In this issue dedicated to mental health, I would like to pay tribute to this nurse who paved the way for all nurse clinicians, teachers, and researchers. While her passing may evoke nostalgia for a bygone era, it also offers us an opportunity to reaffirm the fundamental contribution of the nursing profession and to look forward with optimism to the role it will play in the field of mental health.

Many factors have influenced the development, in the past 20 years, of research in mental health and nursing. Considerable progress has been made in understanding the genetic and neurochemical mechanisms of serious psychiatric disorders, significantly affecting treatment methods, the progression of the disorder, and the need for follow-up and rehabilitation of people with serious and persistent mental disorders. Psychosocial research has enhanced our understanding of the factors that predispose individuals to, or protect them against, mental illness, as well as the factors that influence rehabilitation and the progression of certain disorders. Also, economic pressures and a constant focus on efficiency and effectiveness have called into question traditional models of health-care delivery, thus affecting the duration and location of treatment and various approaches to health care. However, such progress has not necessarily translated into better mental health for the population. A 1995 World Health Organization report (WHO,
1995) points out that although physical health has improved on a worldwide scale, the state of mental health remains unchanged. In fact, it appears to be deteriorating, since alcoholism, drug addiction, violence, and suicide now affect poor and rich societies alike. The prevalence and increasing complexity of mental health problems call for a host of diverse, complementary, and accessible services. It is a known fact that, unlike the situation with physical care, most individuals with mental illness do not consult mental health professionals, either because they are unaware of the services available or because these services are ineffective (Dorvil, Guttman, Ricard, & Villeneuve, 1997).

These various facts are of interest to nurse clinicians, teachers, and researchers. They raise new challenges and call for a serious re-assessment of nursing research priorities in mental health and the type of contribution the discipline can make to treatment, which is currently undergoing sweeping changes. This reflection is already underway, and, as Chafetz and Ricard show, a preponderance of empirical and clinical data prompt us to develop a biopsychosocial orientation in mental health care, to rethink the fundamentals of advanced nursing practice and the orientation of the nursing curriculum at the graduate level. The current inability of the health-care system to effectively respond to new physical health problems, and the complex needs of individuals with persistent major problems, require that nurses in the field of mental health strengthen their present skills and develop new ones. Although the orientation and training of nurses in advanced practice merit re-evaluation, this exercise should not be turned into a counter-productive debate on the respective roles of specialized nurse clinicians and nurse practitioners. It is important that we develop an advanced nursing model that integrates various mental health and first-line treatment skills. Such training should raise the profile of nurses, among the various professional groups, as effective, efficient first-line practitioners capable of assuming leadership in the care and follow-up of a clientele with mental illness.

Issues related to the development and adoption of a biopsychosocial perspective by nurses on the mental health team have guided the work of Hawkins, Veeder, and Pearce, who integrate biopsychosocial and systemic dimensions to develop a collaborative model for nurses and social workers. In his review of this work, Bonin notes that the authors offer an interesting perspective that takes into consideration the background of the collaborative team and the new roles engendered by the current restructuring of the health-care system. He points out, however, that this model seems to encourage nurses to favour the biosocial aspects while limiting their psychological interventions.
Clearly, the development and implementation of a truly biopsychosocial approach to mental health care requires us to go beyond the frames of reference that have determined the division of professional roles and responsibilities. It is a question less of dividing bio-, psycho-, and socio- dimensions among the professions than of determining how nurses and other professionals should approach and integrate these dimensions into their interventions or research.

It is increasingly acknowledged that nurses play an important role in creating the conditions for the success of psychopharmacological treatments and programs for keeping the mentally ill in the community. Among these conditions, medication compliance is paramount because of the long-term follow-up involved and the chronic nature of some mental illnesses. Bonin addresses this issue and, based on Pender's preventive health beliefs model, targets the patient characteristics and psychosocial factors that nurses must take into account in order to facilitate medication compliance and reduce the risk of relapse. This study makes a tremendous contribution to nursing research because of its rigorous methodology, particularly with respect to the size and characteristics of the sample and the diversity of measures used to assess compliance. He calls our attention to the fact that perceived obstacles are strong predictors of non-compliance; this should be of interest to policy-makers in a context where new government programs, such as the Quebec drug insurance plan, serve to increase these obstacles.

The advancement of knowledge regarding the organic etiology of mental disorders has also influenced the types of interventions that are made with families. In fact, having once been blamed for the mental illness of their relatives, family members are now increasingly viewed as partners in care; a variety of psycho-education programs are being offered to them and are proving effective. The first of these programs focused on relapse prevention rather than on the family's well-being. Current programs developed by nurses focus on factors that influence the family's health and draw on its strengths to help it develop coping strategies to more effectively meet its caregiver role. The innovation described by Baker in "From Chaos to Order" makes an original contribution by developing a nursing intervention with a group of parents faced with the difficult task of dealing, on a daily basis, with a child with attention-deficit hyperactivity disorder. The goals of this empowerment-focused program, which is inspired by a theoretical nursing framework, are to help the parents develop or consolidate the skills required to manage the behaviour of their child and improve their interaction with the child. This program clearly has a preventive poten-
tial with respect to both the child and the parents, and it merits a systematic evaluation.

Epidemiological studies reveal that the greatest increase in mental illness has occurred in the 15–24-year-old age group (Bellerose, Lavalée, & Camirand, 1994). Several social factors help explain this statistic: poverty, insecurity, violence, and a bleak outlook for the future. A review of Dahinten’s work clearly shows how nursing research can provide a better understanding of the influence of certain socio-environmental determinants on the health of adolescents and young adults. The author explains that the sexual harassment of adolescents, though common, is trivialized and hardly studied, and poses a major threat to women’s mental health. The author proposes, based on the stress-coping theoretical framework, a conceptual model that takes into account the complexity and interaction of various factors that should be considered in developing research proposals. The study of the impact of this phenomenon, on health behaviours as well as health outcomes, constitutes a particularly relevant contribution to nursing research. The author invites all nurses working in the field of school health to broaden their outlook and pay more attention to the influence of psychosocial factors on adolescent health.

One cannot avoid making links between the research concerns described in Dahinten’s article and the qualitative research conducted by Gallop, Engels, DiNunzio, and Napravnik. Both works show that sexual harassment and violence are on the same continuum and influence women’s mental health. This qualitative research explains how the care environment may help to reactivate the traumatic experiences of these women, and it is an exceptional contribution to this issue of the Journal. It provides an excellent prototype for clinical research, in which the relevance and wealth of data should have immediate implications for improving nursing practices. In fact, the results illustrate that, despite their importance, the values and principles of the therapeutic relationship, and the fundamental role of nurses in the organization of the therapeutic milieu, are not always integrated into nurses’ daily practices. The authors offer various explanations, including nurses’ lack of control and lack of power to change their care-giving practices. In a more general sense, one could ask whether the health-care milieu has been sufficiently vigilant in preserving psychiatric nursing skills. Are humanist values and nurses’ commitment inexhaustible resources, capable of enduring situations that are increasingly stressful, demanding, and unrewarding? These questions directly concern nurses’ mental health, as well as the strategies to be deployed to support nurses who intervene with the most vulnerable and needy.
More than ever before, the mental health of Canadians and the quality of psychiatric services available are a major concern for policymakers. Provincial and federal governments and granting agencies are prepared to do whatever is necessary to systematically identify more effective and efficient mental health practices. These orientations provide the impetus for increased research in mental health services. Nursing is currently very well positioned to become the partner of choice in developing this area.

In summary, current research priorities in mental health services will have a significant impact on the development of nursing research in this field. It is important for research nurses to influence these trends and establish their own research priorities. Mental health and psychiatric care are such broad fields that efforts could easily become scattered and thwart the development of a body of knowledge for advanced practice. Nurse researchers must make a concerted effort to develop a research network, identify their priorities, and consolidate existing partnerships with practice milieux, specifically with nurses in advanced practice.

References


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Discourse

The Biopsychosocial Perspective in Psychiatric Nursing: Myth or Future Reality?

Linda Chafetz and Nicole Ricard

As psychiatric nurses enter the new century, we can reflect on some important achievements, including establishment of an advanced-practice-nursing role within mental health services and development of a broad range of skills that enhance our contributions to the care of severely mentally ill adults. Changes in psychiatric nursing practice are informed by the dramatic advances that have occurred in psychiatric treatment over the past decades. In the realm of psychopharmacology, "third generation" medications offer a range of safer and more tolerable alternatives for care than older agents. In the psychosocial arena, clinical research has identified conditions that increase vulnerability to acute psychotic illness as well as protective factors that prevent or delay relapse and promote coping and social function. These new understandings have provided the impetus for innovative programs (such as family psycho-education or intensive case management) demonstrated to be efficacious under the strict conditions of clinical trials (Lehman, Steinwachs, et al., 1998). Without trivializing the continuing impact of

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severe mental disorders, it is probably fair to say that, because of access to appropriate care, many severely mentally ill adults can now anticipate more satisfying, “normal” lives with reasonable control over their symptoms.

This has important ramifications for mental health providers, who can move beyond a preoccupation with relapse prevention and reduced re-admission to hospital. As our treatment expectations evolve, we can also focus on broader quality-of-life issues that affect the well-being of patients and their families (Ricard, Bonin, & Ézer, 1999). The term quality of life has crept into our lexicon, sometimes without very clear definition. Generally, it refers to both objective and subjective appraisals of living conditions across domains such as housing, income, occupational activities, social relationships, and general health. The implicit assumption is that these are the areas that make life worth living. Many rehabilitation programs target quality-of-life outcomes—for example, cooperative housing or supported employment programs. However, the domain of general health status has received relatively superficial attention, on the part of researchers as much as mental health clinicians.

This phenomenon is astounding for several reasons. First of all, it seems to underplay the well-known effects of major mental disorders on physical function, including appetite, sleep and wakefulness, energy level, and motor behaviour. Also, it fails to acknowledge the centrality of medication in the lives of the mentally ill. Mentally ill adults live with complex regimens that have powerful effects on the body. Even “novel” agents touted because of favourable side-effect profiles can contribute to very serious obesity and to the associated problems of cardiovascular diseases and new-onset diabetes (Casey, 1999). Finally, severe mental illness sometimes leads to lifestyle risk factors such as smoking, poor diet, sedentary lifestyle, and substance abuse. These contribute to a variety of chronic illnesses, including cardiovascular diseases (Hayward, 1995). As people age, they may experience the impact of these health risks as well as other chronic medical problems.

The mentally ill homeless represent the extreme case, at risk for all the problems associated with unsafe living conditions and extreme poverty. These include respiratory infections, problems related to hygiene and nutrition, injuries, and exposure to diseases such as tuberculosis (White, Tulsky, Dawson, Zolopa, & Moss, 1997; Zolopa et al., 1994). Substance-use disorders often coincide with severe mental illness, adding to the risk of medical problems. In addition to some of the well-known effects of long-term alcohol abuse or dependence, drug use appears to incidence the risk of HIV/AIDS among the mentally ill in
some settings (Cournos et al., 1994; Empfield et al., 1993; Susser et al., 1996). In sum, psychiatric illness, its treatment, and associated lifestyle factors as “patienthood” can contribute to medical morbidity and mortality (Jeste, Gladso, Lindamer, & Lacro, 1996; Simpson & Tsuang, 1996). This point is brought home forcefully in a recent report in the British Journal of Psychiatry (Harris & Barraclough, 1998). The authors point out that, given the improvements in psychiatric treatment, it is time to critically examine the issue of physical illness among the mentally ill. Their meta-analysis of 152 English-language reports published between 1966 and 1995 identifies deaths from both “unnatural” (suicide and other violence) and “natural” (medical) causes. Based on these data, they identify “excess mortality” among the mentally ill, or their risk of dying from a specific cause compared to expected mortality among similar age groups in relevant countries. The highest rates occur among groups with eating disorders and substance abuse. However, the rates in schizophrenia are significantly higher than those in comparison samples, and, while many excess deaths reflect suicides, 62% are due to medical illness. For all affective disorders, the figure is 45% (major depression alone did not produce statistically significant findings). These figures provide stark documentation of health risks among the mentally ill, independent of factors such as suicide. They are probably also conservative, since they describe samples with single diagnoses rather than the extensive comorbidity that we observe today. For example, some of the cases with schizophrenia lived in institutions that controlled diet and restricted access to cigarettes.

It seems apparent that severely mentally ill adults require access to the appropriate general health services that can address their particular profile of needs. However, the mental health clinicians who provide their ongoing care frequently come from social-rehabilitation backgrounds and have limited knowledge of general health care. At best, they depend on referrals to community medical providers. Certain patients, because of their symptoms or their cognitive or functional deficits, may not be able to negotiate appointments, to clearly express their complaints, or to tolerate stressful interview and examination procedures. Failure to complete an appointment, communication difficulties, or interpersonal withdrawal may be misunderstood and mislabelled as “non-compliance” and “poor motivation for treatment.” Further, even the most interpersonally sensitive primary care providers may lack knowledge about psychiatric regimens that should be considered in a total plan of care.

It will be difficult to improve this situation in a climate of cost containment, with its emphasis on brief treatment of acute psychiatric
problems and rapid return to the community. Resources seem to be limited for health maintenance, promotion, and prevention among mentally ill adults. Moreover, whether they receive care in an institutional or a community setting, these patients are followed by highly specialized teams lacking the preparation and experience to link their psychosocial approach with the primary care that takes the complex needs of this population into account.

As nurses, when we search for solutions our tendency is to promote psychiatric nurses within the mental health teams, extolling them as the only mental health professionals with a truly biopsychosocial tradition and orientation. However, we should look very critically at these kinds of beliefs and assumptions. True, psychiatric nurses in traditional settings have long been responsible for the physical well-being of their patients and for a holistic view of self-care. However, advanced-practice nurses such as Clinical Nurse Specialists have sometimes abandoned the traditional nursing focus on almost exclusive adoption of psychotherapeutic treatment models. This narrow focus may have actually impeded efforts to define advanced-practice psychiatric nursing and to develop our role among the mental health disciplines (McBride, 1990; McEnany, 1991).

Today, a certain amount of progress has occurred with general recognition of the neurobiological bases of mental illness and the importance of biological treatments. In fact, psychiatric nurses have become highly competent in the management of psychotropic regimens, while responding effectively to the psychosocial needs of severely mentally ill adults. Nevertheless, it is important to ask if this neurobiological sophistication is sufficient. A genuine biopsychosocial perspective for care of the mentally ill should be much broader and should encompass the effects of psychiatric illness on every dimension of the individual’s health, and not psychological function alone. This means that the patient should be able to find comprehensive services within the same program: services for health maintenance and promotion as well as treatments directed at psychiatric illness and at psychosocial rehabilitation.

Such an orientation would obviously require psychiatric nurses to develop new kinds of clinical expertise. One option would be development of graduate nursing programs to prepare advanced-practice psychiatric nurses with skills in the domain of primary care. Is it possible to develop and combine these two domains? Is there a danger of promoting primary care competencies at the price of psychiatric skills? Would this broad and comprehensive type of education be so demand-
ing in terms of course work as to erode the clinical teaching that should produce therapeutic use of self and psychotherapeutic competencies? All of these outcomes are possible.

However, if we continue to frame our discussion in terms of these kinds of questions, we reinforce the body/mind dichotomy that has thus far obstructed development of holistic nursing models for severely mentally ill adults. It is vital to think, instead, in terms of constructing new nursing models for the management of severe mental illness, ones that respond to new understandings about the clinical complexity of our patients as well as the forces shaping new and emerging systems of health care.

In the United States, Delaney, Chisholm, Clement, and Merwin (1999) report a growing trend towards integration of physical assessment, pathophysiology, and pharmacology in graduate education in psychiatric nursing. A number of universities have established "psychiatric nurse practitioner" programs to combine psychiatric and primary care. These include the University of California at San Francisco (Chafetz & Collins-Bride, 1997), the University of Pittsburgh (Dyer, Hammill, Regan-Kubinski, Yurick, & Kober, 1997), and the University of South Carolina at Columbia (Williams et al., 1998). These experiences can certainly enrich discussion in the Canadian context, where in many provinces there is an increasing focus on development of advanced-practice nursing, such as projects by the Canadian Nurses Association (1999) and the Canadian Association of University Schools of Nursing (Giovanetti, Stuart, Tenove, & vanden Berg, 1996) that should lead to proposals for a framework of reference as well as recommendations for educational and research programs.

It is becoming evident that these kinds of programs can produce a new kind of advanced-practice psychiatric nurse who would make a unique contribution to the care of severely mentally ill adults and heighten the visibility of nursing within health-care systems. However, it is too early to determine the impact of their contributions on the health of severely mentally ill adults. Despite beliefs about the importance of a biopsychosocial perspective, its impact remains an empirical question. The evaluation of these innovations will constitute a turning point for the development of advanced-practice nursing. This is a time of exceptional opportunity for nurse researchers, who should be able to consolidate their resources and develop well-designed studies on outcomes of advanced nursing practice. These studies might be able to provide solid evidence of the ways in which we can improve the health
of severely mentally ill adults and the ways in which wellness can enhance the quality of their lives.

References


Déterminants psychosociaux de l’assiduité au lithium chez des clients présentant un trouble bipolaire

Jean-Pierre Bonin

Physical, cognitive, and social factors play a central role in the lithium compliance of people with bipolar disorder. However, studies provide only a partial understanding of this phenomenon and there is currently no nursing model that takes into consideration a combination of factors. This study, based on Pender’s preventive health beliefs model, was intended to identify the psychosocial determinants of lithium compliance. A random sample (n = 149) of outpatients at a large Montreal psychiatric hospital was used to measure lithium compliance on the basis of 5 criteria: compliance according to the nurse and according to the patient, appointment compliance, and compliance according to two criteria related to hyperuricemia. Polytomous logistic regression analyses were computed by regressing a composite of these criteria on sociodemographic variables and on the variables of the Pender model: susceptibility, seriousness, control over health, motivation to be healthy, perceived benefits and obstacles, and triggering factors. It appears that being female, being elderly, living with a partner, and perceived treatment benefits and obstacles are determining factors in lithium compliance. These results are all the more important in light of Quebec’s newly implemented drug insurance plan, which could increase the obstacles to medication. Nurses will have to be increasingly vigilant with respect to these new obstacles and will have to adjust their interventions accordingly.

Chez les personnes atteintes d’un trouble bipolaire, plusieurs facteurs d’ordre physique, cognitif et social joueraient un rôle particulier dans l’assiduité au lithium. Cependant, les études n’offrent qu’une compréhension partielle de ces facteurs et aucun modèle en sciences infirmières n’a étudié ce phénomène de façon à prendre en compte un ensemble de facteurs. En s’inspirant du modèle préventif des croyances en matière de santé de Pender (1982), la présente étude vise à identifier les déterminants psychosociaux de l’assiduité au lithium. Cette étude a été menée auprès d’un échantillon probabiliste (n = 149) de clients fréquentant les cliniques externes d’un grand hôpital psychiatrique de Montréal. L’assiduité au lithium était mesurée à partir de cinq critères : l’assiduité selon l’infirmière, selon le client, l’assiduité aux rendez-vous, et l’assiduité selon deux critères reliés aux litièmes. Des analyses de régression logistiques polytomées ont été réalisées en regroupant un composite de ces critères sur des variables sociodémographiques et sur les variables du modèle de Pender, soit la susceptibilité, la gravité, le contrôle sur la santé, la motivation à la santé, les bénéfices et les barrières perçus, et les éléments générateurs.

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d'action. Il ressort que le sexe féminin, l'âge plus élevé, le fait d'être en couple, ainsi que les barrières et les bénéfices perçus face au traitement, sont les déterminants significativement reliés à l'assiduité au lithium. Ces résultats sont d'autant plus importants du fait qu'un nouveau régime d'assurance-médicaments vient d'être mis en place au Québec et risque d'augmenter les barrières à la médication. Il importe que les infirmières soient doucement vigilantes face à ces barrières qui s'ajoutent à celles déjà existantes et ajustent leurs interventions.

Introduction

Dans son plan de transformation des services en santé mentale, le Ministère de la santé et des services sociaux du Québec (MSSS, 1996) se donne comme priorités de transférer certaines ressources vers la communauté et de privilégier des types de services comme le suivi intensif dans le milieu. Toutefois, même si ce type de programme a démontré son efficacité, il semble que l'assiduité à la médication psychotropique serait le principal facteur relié à l'amélioration des personnes atteintes de troubles mentaux bénéficiant d'un suivi intensif dans la communauté (Dixon, Weiden, Torres et Lehman, 1997). Les infirmières dans ce programme de suivi jouent un rôle important quant au soutien quotidien de la clientèle, notamment en ce qui a trait à l'adoption de comportements de santé et l'adhésion au régime thérapeutique. Elles jouent donc un rôle important de soutien et d'éducation, entre autres auprès des personnes atteintes d'un trouble bipolaire. Chez cette clientèle, plusieurs facteurs d'ordre physique, cognitif et social joueraient un rôle particulier dans l'assiduité au lithium. Cependant, les études n'offrent qu'une compréhension partielle de ces facteurs et aucun modèle en sciences infirmières n'a étudié ce phénomène de façon à prendre en compte un ensemble de facteurs. La présente étude vise à identifier les facteurs reliés à l'assiduité au lithium à l'aide du modèle préventif des croyances en matière de santé de Pender (1982)1.

Troubles bipolaires, assiduité au traitement et difficultés de mesure

Le trouble affectif bipolaire est souvent identifié comme un des troubles mentaux graves et persistants et l'on estime sa prévalence à vie entre 0,3 à 1,5 % de la population (Weissman, Bland et Canino, 1996). La personne atteinte, en plus de devoir accepter sa maladie, est contrainte à un régime thérapeutique à long terme qui a fait ses preuves dans la régulation des symptômes et la prévention des rechutes, mais qui n'est

1 La présente étude utilise le modèle préventif de Pender (1982), à ne pas confondre avec le modèle de promotion de la santé Pender souvent utilisé en sciences infirmières

La principale conséquence de la non-assiduité à la médication est l'hospitalisation, qui signifie des coûts financiers et sociaux considérables. Une étude de Keck, McElroy, Strakowski, Bourne et West (1996) a démontré que 64 % des clients réadmis en psychiatrie n'avaient pas été assidus à leur traitement au cours du mois précédent. Green (1988) rapporte que parmi la population des clients souvent hospitalisés, le facteur le plus prévalent (92 % des cas) est la non-assiduité à la médication, suivi de près par la non-assiduité aux rendez-vous (76 %). Dans une révision de différentes études, Cochran (1986) estime qu'entre 9 et 57 % des patients traités au lithium éprouvent des problèmes à suivre l'ordonnance de façon assidue et que les taux les plus élevés sont probablement les plus justes.

Une des embûches inhérentes aux études sur l'assiduité au traitement réside dans la difficulté de la mesurer de façon adéquate (Cramer et Rosenheck, 1998). Les méthodes utilisées pour mesurer l'assiduité se divisent en deux catégories : directes et indirectes. Les méthodes directes, telle la lithémie, sont essentielles pour une mesure précise, mais présentent des difficultés relatives à la mesure elle-même (sensibilité et spécificité) et des difficultés pour définir ou classifier les clients assidus et non-assidus (Sackett et Snow, 1976). Parmi les méthodes indirectes, l'entrevue, qui consiste à demander au client s'il a bien suivi les recommandations thérapeutiques, est la méthode la plus simple et la plus largement employée. Toutefois, la validité de cette méthode soulève des doutes. Ainsi, Becker (1985) rappelle que si quelques études ont démontré une assiduité surestimée par le client, plusieurs autres ont établi une corrélation entre l'assiduité rapportée par le client et la mesure directe. Une étude récente réalisée auprès d'un vaste échantillon rapporte que les patients se considèrent généralement plus assidus que ne l'évalue leur médecin traitant (Valenstein, Barry, Blow, Copeland et Ullman, 1998). Par contre, Roth (1987) note que les médecins tendent à surévaluer l'assiduité de leurs clients ; il soutient par ailleurs que lorsque le client affirme ne pas prendre sa médication, des mesures directes corroborent généralement cette assertion. Dans un autre contexte, soit auprès de clients suivis en hémodialyse, Cummings, Becker et Kirsch (1982) ont démontré que l'évaluation de l'infirmière était la plus fiable en ce qui a trait à l'assiduité à la médication. Pour
contrer les difficultés inhérentes à la mesure de l’assiduité, Hays et Di Matteo (1987) ont conclu que plusieurs méthodes devraient être utilisées conjointement de façon à minimiser les erreurs de mesure.

Les facteurs liés à l’assiduité au lithium

Quelques études ont mis en évidence les raisons de la non-assiduité au lithium et la raison principale invoquée serait la présence d’effets secondaires : l’incoodination, la paresthésie, la sensibilité diminuée et les tremblements (Nilsson et Axelsson, 1989). Par ailleurs, Gidin, Cochran et Jamison (1989) ont constaté que les problèmes cognitifs (p. ex. difficultés de concentration) et le gain de poids constituaient les effets les plus dérangeants chez les patients traités au lithium.

Selon Lenzi, Lazzerini, Placidi, Cassano et Akiskal (1989), il est difficile d’identifier les prédicteurs de non-assiduité, laquelle résulterait d’une interaction complexe de facteurs tels l’âge, le sexe, le statut civil, la condition sociale, le type et la sévérité de la maladie, la longueur des intervalles entre les rechutes, l’environnement thérapeutique et les caractéristiques de la médication en elle-même. Frank, Prien, Kupfer et Albert (1985) ont déclaré que les clients plus âgés, mariés, et plus scolarisés étaient plus assidus au lithium, ainsi que ceux ayant démontré une bonne assiduité dans le passé. Selon Becker (1985), la famille peut apporter de l’assistance et de l’encouragement, tout en améliorant la supervision. Cependant, cet auteur rapporte que l’individu est constamment exposé, via les médias, à des controverses remettant en cause les médicaments et les services de santé, lesquelles controverses influencent l’assiduité du client.


L’assiduité au lithium s’avère donc reliée à plusieurs facteurs : sociaux, psychologiques, physiologiques, cognitifs et situationnels. Cependant, l’articulation et l’identification de ces variables dans un
Les modèles théoriques

Plusieurs modèles théoriques ont tenté d’expliquer l’assiduité au traitement pharmacologique avec plus ou moins de succès. Le modèle des croyances en matière de santé (Rosenstock, 1974) s’est avéré efficace dans plusieurs études pour prédire l’assiduité à d’autres types de médication et il intègre plusieurs variables se retrouvant dans les autres modèles (Cohen, 1979) (Figure 1). Ce modèle a été développé au début des années 1950 pour proposer un cadre de référence permettant d’explorer pourquoi certaines personnes adoptaient des comportements pour protéger leur santé alors que d’autres ne le faisaient pas (Pender, 1987). Selon Rosenstock (1974), le modèle propose que la probabilité qu’une personne entreprenne des actions relativement à sa santé est déterminée par sa disposition à prendre une action (readiness) et par l’évaluation des coûts versus les bénéfices perçus de ladite action. Certains facteurs dits modifiants influencent les perceptions de l’individu. Ces facteurs sont : les variables démographiques, interpersonnelles et situationnelles. Les perceptions de l’individu sont : la perception de la susceptibilité, de la menace et de la sévérité de la maladie, ainsi que des bénéfices et des barrières face à l’action de santé. La susceptibilité perçue consiste en la probabilité estimée par l’individu de développer une maladie ou de faire une rechute. La sévérité perçue évoque la reconnaissance par l’individu du sérieux de la maladie ou de la rechute, ou comment il compare son problème de santé à d’autres. Les deux variables précédentes (susceptibilité et sévérité) réunies constituent la menace perçue par la maladie et celle-ci dépendrait en partie des connaissances sur la maladie (Rosenstock, 1974). Les bénéfices perçus réfèrent à la croyance de l’individu que le régime thérapeutique proposé guérira ou contrôlera la maladie. Les coûts ou barrières perçues incluent les coûts financiers et les inconvénients du traitement, tels la douleur, la stigmatisation, ou les effets secondaires possibles. Pender (1982) a proposé d’inclure les variables de lieu de contrôle et de motivation envers les comportements de santé. Le modèle préventif des croyances en matière de santé de Pender se veut donc un cadre conceptuel adéquat pour articuler les différentes variables identifiées dans les écrits comme étant reliées à l’assiduité au lithium.
Figure 1 Modèle préventif des croyances en matière de santé de Pender (1982)

Facteurs de motivation
- Variables sociodémographiques :
  - Genre (féminin = +)
  - Âge (+)
  - Statut civil (couple = +)

Perceptions individuelles
- Importance de la santé (motivation) (+)
- Contrôle perçu sur la santé (Contrôle interne +)
- Perception de la gravité de la maladie (+)
- Perception de la susceptibilité à la maladie (+)
- Perception des barrières à l'adoption du comportement de santé (-)
- Perception des bénéfices à l'adoption du comportement de santé (+)

Probabilité d'action
- éléments générateurs d'action (+)

Assiduité au lithium

Note : (+) et (-) indiquent les sens des hypothèses.
Ce modèle a été utilisé entre autres par Connely (1984) qui a tenté en vain d’établir des corrélation significatives entre l’assiduité au lithium et les éléments du modèle original des croyances en matière de santé. Celle-ci recommandait d’utiliser un instrument validé pour mesurer les croyances en matière de santé et un échantillon plus large. Récemment, Budd, Hugues et Smith (1996), de même que Nageotte, Sullivan, Duan et Camp (1997) l’ont utilisé pour expliquer l’assiduité à la médication chez des personnes atteintes de schizophrénie; la sévérité, la susceptibilité à la maladie et les bénéfices perçus ont été identifiés comme reliés à l’assiduité à la médication. Cependant, ces études incluaient totalement ou partiellement l’assiduité à des neuroleptiques de longue action (dépôt), ce qui représente une autre problématique.

But
La présente étude a pour but d’identifier, à l’aide du modèle préventif de Pender (1982), les déterminants psychosociaux de l’assiduité au lithium chez des personnes atteintes de troubles bipolaires (Figure 1).

Méthode

Milieu et échantillon
Cette recherche a été effectuée dans un centre hospitalier psychiatrique de Montréal, auquel sont affiliées six cliniques externes couvrant chacune un secteur de l’est de la ville, ainsi qu’une clinique centrale de lithium. Le projet a été accepté par le comité d’éthique de ce centre hospitalier. Un échantillon probabiliste en grappe comptant 150 sujets souffrant d’un trouble affectif bipolaire a été formé à partir de la clientèle des différentes cliniques. L’échantillon a été construit en compilant, à l’aide du logiciel SPSS pour Windows, un échantillon aléatoire de journaux nous permettant d’atteindre le nombre de sujets désirés. À cet effet, un relevé de tous les clients s’étant présentés dans les différentes cliniques au cours des quatre semaines précédentes avait été produit afin de connaître le nombre de sujets potentiels. Les critères d’inclusion étaient les suivants : 1) le trouble bipolaire devait être le diagnostic psychiatrique primaire, tel que stipulé au dossier du client; 2) les clients devaient avoir été traité au lithium depuis au moins un an; 3) leur état devait être considéré comme stable par l’infirmière de la clinique concernée; 4) les sujets devaient avoir entre 18 et 70 ans et pouvoir lire et comprendre le français.
Déroulement de l’étude

Le chercheur et une collègue infirmière se sont présentés à des cliniques et à des jours déterminés aléatoirement et ont invité tous les clients présents répondant aux critères d’inclusion à remplir un questionnaire. Le projet avait préalablement été présenté et expliqué au client qui devait signer la formule de consentement. Au total, 150 des 153 personnes rencontrées ont accepté de remplir le questionnaire ; les personnes ayant refusé disaient ne pas avoir le temps (2 personnes) ou ne pas se sentir assez bien pour parler d’un vécu personnel (1 personne). Un questionnaire a été rejeté lors de l’examen préliminaire des données.

Instruments de mesure

Évaluation de l’assiduité au lithium. L’assiduité a été évaluée de cinq façons. Premièrement, les clients et leur infirmière étaient invités à coter l’assiduité au traitement sur une échelle de Likert de 1 (« très assidu ») à 5 (« pas du tout assidu »). Puis, l’assiduité était évaluée selon les lithémies et ce, de deux façons. Ainsi, le sujet devait présenter un taux de lithium sanguin entre 0,5 et 1,5 mEq/L lors des lithémies effectuées au cours de l’année précédant l’entrevue et ce taux devait présenter une stabilité, c.-à-d. n’afficher aucune variation de plus de ±0,15 mEq/L, afin d’être considéré comme assidu. Les clients dont la lithémie variait de façon injustifiée et ceux dont le taux se situait hors de la norme thérapeutique étaient considérés comme non-assidus. Enfin, nous avons évalué l’assiduité aux rendez-vous : le client qui se présentait à plus de 75 % des rendez-vous était considéré comme très assidu au traitement (cote=1) et les autres, moins assidus (cote=0). Ces données provenaient de la clinique de lithium où étaient notés les rendez-vous prévus et ceux que le client avait manqué.

Puisque les différentes mesures d’assiduité se sont avérées peu concordantes– seules les deux mesures de lithémies présentaient un kappa significatif (k=0,76 ; p<0,05) – un composite de ces scores tenant compte de ces mesures a été créé de la façon suivante. D’abord, chacune des mesures a été dichotomisée. Par exemple, une personne qui avait une cote de 5 (« parfaitement assidue ») selon l’évaluation de l’infirmière, se voyait attribuer la cote de 1 et la cote de 0 était attribuée aux autres. Le même processus était appliqué aux autres mesures. Ensuite, le composite variant de 0 à 5 était formé en additionnant les scores d’assiduité dichotomisés.

Mesure des concepts du modèle. La mesure des concepts relatifs au modèle de Pender (Figure 1) a été réalisée à l’aide d’une version modi-
Déterminants psychosociaux de l’assiduité au lithium

fiée du questionnaire de Champion (1984) afin d’inclure des questions pertinentes à l’assiduité au lithium. Trente-quatre des 39 items créés par Champion ont été ainsi adaptés : la susceptibilité (4 items), la gravité (11 items), les bénéfices (4 items), les barrières perçus (8 items), et la motivation à la santé (7 items) ; les items retirés ne pouvaient s’appliquer à la présente problématique. Ces échelles de type Likert offrent cinq choix, de fortement en accord (5 points) à fortement en désaccord (1 point), et les scores de chaque item sont additionnés pour former un score global pour chaque concept. Les analyses de consistance interne pour l’instrument original révèlent des coefficients alpha de Cronbach variant de 0,60 à 0,78. Une série de 11 items provenant du Health Locus of Control Scale (HLC) (Wallston, Wallston, Kaplan et Maides, 1976) a été ajoutée au questionnaire de Champion afin de mesurer le contrôle perçu sur la santé. Cet instrument a été utilisé dans maintes recherches, dont celle de Pender (1987). Les analyses de fidéïté pour cette sous-échelle ont démontré un alpha de Cronbach de 0,76. De plus, une série d’items ont été traduits et adaptés de Kelly, Mamon et Scott (1987) afin de mesurer les éléments générateurs d’action, soit une liste de symptômes possibles pouvant jouer un rôle dans l’assiduité chez une personne psychotique. Certains items ont été enlevés ou modifiés afin de correspondre à des éléments susceptibles d’être retrouvés chez des clients souffrant de maladie affective bipolaire. Les coefficients alpha de Cronbach des différentes échelles pour la présente étude varient de 0,66 (susceptibilité perçue) à 0,85 (barrières perçues).

Validation des instruments. La traduction et la validité de contenu des instruments a d’abord été vérifiée par un statisticien, un psychiatre et une psychologue bilingue. La compréhension a été vérifiée à l’aide d’un prêtre effectué auprès des 30 premiers sujets de la recherche ; quelques items ont été légèrement modifiés pour faciliter la compréhension.

Procédures statistiques

Les données ont été analysées à l’aide des logiciels SPSS v. 9 pour Windows et SAS v. 6,03 pour Windows. Des corrélations simples ont d’abord été réalisées entre les variables du modèle et le composite d’assiduité. Puis, des analyses de régression logistique polytomée ont été réalisées avec le composite d’assiduité décrit plus haut comme variable dépendante. Les variables sociodémographiques (sexe, âge et statut civil) et les variables du modèle (susceptibilité, gravité, motivation, bénéfices, barrières, contrôle et éléments générateurs d’action) sont les variables indépendantes retenues (Figure 1). Puisque Hosmer et Lemeshow (1989) estiment que le chi-carré de Wald rejette souvent des variables
qui pourraient être significatives, surtout lorsque l'échantillon dépasse 100 sujets, le seuil de signification pour cette statistique a été fixé à 0,10.

Résultats

L'échantillon se compose de 54,4 % de femmes, la moyenne d'âge des répondants étant de 47,3 (E.T. :12,11). Près de 45 % des répondants vivent en couple, la majorité ont complété au moins des études de niveau secondaire, et plus du tiers de l'échantillon rapporte que leur source principale de revenus est générée par un emploi. Près de 30 % des sujets de l'échantillon ont été hospitalisés plus de cinq fois en psychiatrie et 13,6 % ne l'ont jamais été ; les personnes rencontrées prenaient toutes du lithium depuis plus d'un an.

Tel que décrit précédemment, l'évaluation de l'assiduité au lithium a été réalisée par plusieurs mesures concomitantes. Ainsi, 68,9 % des patients ont répondu avoir respecté la prescription à la lettre et 27,0 % ont dit avoir suivi la prescription la plupart du temps, tout en omettant une ou plusieurs doses ; l'évaluation des infirmières présente des proportions semblables (63,2 % parfaitement assidus), bien que le pourcentage d'accord ne soit que de 50,7 % entre ces mesures. Quant aux données objectives, 87,2 % des patients ont été présents à plus de 75 % de leurs rendez-vous. Pour les lithémies, 93,2 % des sujets ont maintenu un taux de lithium à l'intérieur des normes et 89,9 % ont présenté des lithémies qui ne variaient pas de plus de 0,15 mEq/L au cours de l'année précédente. Enfin, 30,9 % des clients ont obtenu la cote de 5 pour le composite ; 44,3 % la cote de 4 ; 15,3 % la cote de 3 ; et le reste 2 ou moins.

Le tableau 1 présente les résultats de l'analyse de régression logistique polytomée du composite d'assiduité sur les variables sociodémographiques et les variables du modèle de Pender. Il ressort que le modèle d'analyse démontre un degré d'ajustement assez élevé, soit un pseudo R2 de Nagelkerke (1991) de 0,45 et un coefficient de vraisemblance de 290,25 (chi-carré=78,03 ; df=40, p<0,000). Le test de ratio de vraisemblance (likelihood ratio test) permet de vérifier la différence de coefficients de vraisemblance entre le modèle final et un modèle réduit, ce dernier étant formé en omettant l'effet d'une variable du modèle final. L'hypothèse nulle considérerait l'effet de tous les paramètres égal à zéro. À la lumière de ce tableau, nous pouvons constater que plusieurs variables, prises individuellement, apportent une contribution significative au modèle, soit : le sexe et l'âge du répondant, les barrières perçues, les bénéfices perçus et les éléments générateurs d'action. Cette étape a été suivie d'une étape multifactorielle (Tableau 2), où les
<table>
<thead>
<tr>
<th>Source</th>
<th>-2 log likelihood du modèle réduit</th>
<th>dl</th>
<th>Chi-carré</th>
<th>Sign.</th>
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</tr>
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<tr>
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<tr>
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</tr>
</tbody>
</table>

R² de Nagelkerke : 0,45
-2 Log likelihood : 290,25 (chi-carré=78,03 ; dl=40, p<0,000).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estime du paramètre</th>
<th>Erreur standard</th>
<th>Wald Chi-carré</th>
<th>Sign. Chi-carré</th>
<th>Ratio de cotes</th>
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 données ont été entrées ensemble dans la régression polytomée (méthode enter). À cette étape, on constate que les variables significativement reliées à l’assiduité sont : le fait d’être de sexe féminin (R.C. = 1,96 ; p < 0,05), l’âge plus élevé (R.C. = 1,04 ; p < 0,01), le fait d’être en couple (R.C. = 1,73 ; p = 0,10), les barrières (R.C. = 0,67 ; p < 0,10) et les bénéfices perçus (R.C. = 1,79 ; p < 0,01).

Discussion

L’échantillon de la présente étude était constitué de 149 sujets souffrant de trouble affectif bipolaire, rencontrés aux différentes cliniques externes et à la clinique de lithium d’un grand centre hospitalier de la région de Montréal, lequel dessert une population de 340 000 personnes. À notre connaissance, peu de recherches ont pu rassembler un échantillon de cette taille et possédant le même diagnostic, soit celui de trouble affectif bipolaire. En effet, seules l’étude de Frank et al. (1985) (n=216) et celle de Tramoni, Dufour, Azorin et Tatossian (1992) (n=205) portaient sur plus de sujets. Cependant, dans ces études, les sujets ne prenaient pas tous du lithium ou ne souffraient pas tous d’un trouble affectif bipolaire. Également, la présente recherche a été faite à partir d’un échantillon probabiliste, soit un échantillon en grappe de jour-nuit. Cette technique a permis de constituer un échantillon qui nous apparaît assez représentatif.

Par ailleurs, nous avons observé une plus forte proportion de patients assidus que dans les études recensées ; cette caractéristique peut avoir restreint la variation entre les sujets et limiter l’identification de certaines. Notons cependant que la présente étude est la seule, à notre connaissance, qui utilise cinq critères d’assiduité, ce qui renforce la précision de la mesure. Par ailleurs, lors de recherches récentes effectuées aux mêmes cliniques externes que la présente recherche, Ricard et al. (Ricard et Fortin, 1993 ; Ricard, Fortin et Bonin, 1995) ont retrouvé des proportions de 81,0 % et 81,5 % de sujets très assidus, tel qu’évalué par le soignant naturel du malade souffrant de maladie affective bipolaire. Ces dernières données, recueillies auprès de vastes échantillons (N=359 ; N=200) démontrent que les personnes fréquentant ces services semblent très assidues.

Dans la présente recherche, le sexe, l’âge et la situation de famille se sont avérés significativement reliées à l’assiduité au lithium. Ces résultats concordent avec ceux de plusieurs autres recherches (Wilder, Plutchik et Conte, 1977 ; Maajbjerg, Aagaard et Vestergaard, 1988 ; Frank et al., 1985 ; Connely, Davenport et Nurnberger ; 1982 ; Kucera-Bozarth, Beck et Lyss, 1984). Il importe donc que les infirmières
Détecteurs psychosociaux de l’assiduité au lithium

œuvrant auprès de personnes atteintes de troubles bipolaires gardent à l’esprit les caractéristiques sociodémographiques des personnes qui risquent, plus que les autres, de ne pas rester assidues à leur médication. Elles doivent porter une attention particulière, lors de leur enseignement et de leur soutien, aux clients de sexe masculin, aux plus jeunes, ainsi que ceux qui ne sont pas en couple. Nageotte et al. (1997) suggèrent des actions qui aident à améliorer l’assiduité au traitement : apport de renseignements sur la maladie, utilisation de rappels fréquents, renforcement positif des comportements d’assiduité et implication du soutien social pour le traitement. Les infirmières peuvent intégrer ces interventions dans leurs tâches auprès de cette clientèle.

La présente recherche identifie comme prédicteurs reliés au modèle de Pender les barrières, les bénéfices et les éléments générateurs d’action. Or, une revue des études sur le modèle (Janz et Becker, 1984) a identifié les barrières perçues comme le prédicteur le plus puissant tandis que les bénéfices perçus se classaient au deuxième rang. Notons que deux études ayant utilisé le questionnaire de Champion (Champion, 1984 ; Wyper, 1990) ont aussi isolé les barrières comme étant liées à l’auto-examen des seins. Ces résultats suggèrent que les infirmières doivent vérifier la perception de leurs clients face aux difficultés de prendre leurs médicaments : Comment la prise de lithium s’intègre-t-elle dans la routine quotidienne ? Comment le client sera perçu par ses proches et ses pairs s’il prend du lithium ? D’autre part, il faut renforcer les bénéfices de la médication, tels l’événement de la rechute et de l’hospitalisation, et le fait de pouvoir continuer ses activités quotidiennes.

Enfin, puisque les barrières se sont avérées un prédicteur important de l’assiduité au lithium, il faut noter que cette étude a été réalisée avant la mise sur pied d’un programme d’assurance-médicament au Québec. Ce programme entraîne chez certains clients des déboursés supplémentaires ce qui, selon certains témoignages de clients et reportages dans les médias, entraînerait une baisse d’assiduité au traitement. Il importe donc que les infirmières soient doublement vigilantes face aux coûts, à titre de nouvelles barrières. Les infirmières œuvrant dans la communauté sont les mieux placées pour vérifier les perceptions de leurs clients face à la médication et au traitement. Elles peuvent et doivent prendre des ententes avec des personnes du réseau social du client, de la famille au pharmacien du coin, afin de favoriser l’assiduité de la personne souffrant de troubles bipolaires. Les infirmières à l’interviennent doivent poursuivre la relation thérapeutique et utiliser le temps d’hospitalisation pour transmettre au client l’importance de bien suivre leur traitement, même lorsque le client vit des tensions ou ressent des
effets secondaires. Enfin, les infirmières n’ont qu’à continuer leur travail d’enseignement et d’encouragement auprès du client pour qu’il puisse se prendre en charge sur le plan de sa santé.

Références


Déterminants psychosociaux de l’assiduité au lithium


**Remerciements**

L’auteur tient à remercier Nicole Ricard pour son soutien inestimable et son encouragement au cours des différentes étapes du mémoire de maîtrise ayant mené à cet article.
Peer Sexual Harassment: A Barrier to the Health of Adolescent Females?

V. Susan Dahinten

La question du harcèlement sexuel au travail et à l’université a suscité une attention croissante au fil des ans, mais l’on s’est trop peu préoccupé chez les infirmières de cette question en ce qui concerne la santé des adolescentes. La notion de harcèlement sexuel englobe un large éventail de comportements offensifs et sexistes qui contribuent à créer un environnement hostile pour les victimes. Bien que la recherche sur ce sujet demeure limitée et peu rigoureuse, les résultats préliminaires, de même que les conclusions tirées de la documentation sur le harcèlement au travail et l’adaptation au stress, suggèrent que le harcèlement sexuel exercé par les pairs peut avoir des répercussions sur la santé physique et mentale des jeunes femmes, sur leur comportement en matière de santé et sur leurs éventuels rapports affectifs. L’auteur recommande que de plus amples recherches soient entreprises sur le sujet, et que les outils conceptuels choisis pour ce faire soient extrait des écrits traitant de l’adaptation et du stress transactionnels.

Despite increasing societal concern about sexual harassment in the workplace and in academia, to date sexual harassment has been neglected by nurses as a health issue among adolescents. Sexual harassment includes a wide range of unwelcome sexually oriented and gender-offensive behaviours that contribute to a hostile environment. Although the research is limited and lacking in rigour, early findings, along with evidence abstracted from the workplace-harassment and stress and coping literature, suggest that peer sexual harassment may adversely affect young women's mental and physical health, health-related behaviours, and future relationships. The author makes recommendations for further sexual-harassment research, specific to the adolescent population, based on a conceptual framework derived from the transactional stress and coping literature.

Although sexual harassment is increasingly recognized as part of the continuum of violence against women, to date it has been neglected by nurses and other health-care providers as a health issue among adolescents. This is in contrast to increased societal concern about sexual harassment in the workplace and in universities and colleges, as well as the emerging concern of educators about the harassment of adolescents. Even with the recognition of adolescents as an at-risk group in terms of mental-health status and health behaviours, and with increasing attention being directed to the broad determinants of their health, the sexual

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harassment of adolescents has received virtually no attention in the adolescent-health or school-health literature. For example, a computerized search of the CINAHL and Medline databases located only two studies pertaining to the sexual harassment of adolescents (Bagley, Bolitho, & Bertrand, 1997; Roscoe, Strouse, & Goodwin, 1994), and only one of these was concerned with health outcomes (Bagley et al.). In startling contrast, abundant attention has been directed towards the sexual harassment of health-care professionals.

The research that has been done on the sexual harassment of adolescents has emerged from the fields of education and psychology, and although it is still in the nascent stage, findings indicate that student-on-student — or peer — sexual harassment is both widespread and pernicious, at least for female adolescents. This should not be surprising given that the American Psychiatric Association recognizes sexual harassment in the workplace as a significant stressor in the lives of women (as cited in Koss et al., 1994) and given the abundant evidence linking psychosocial stressors with negative physical, psychological, and behavioural health outcomes in the adult population. Although adolescence is generally conceived of as a particularly healthy time of life, it is known that adolescents engage in serious health-risk behaviours (which have implications for long-term lifestyle and health outcomes) and suffer high rates of psychological disturbance (e.g., depression), possibly in response to the stressors in their lives. Stress is a meaningful construct for nursing because of its well-documented association with illness and other negative health outcomes. Stress and coping theory is, therefore, an appropriate conceptual framework to bring to the study of sexual harassment and adolescent health. The purpose of this paper, then, is to review the early work on sexual harassment among adolescents, and to abstract issues from the workplace-harassment and stress and coping literature that may guide future research into the health effects of harassment in the adolescent population.

Legal and Social Definitions of Sexual Harassment

Discussions of sexual harassment are complicated by the lack of a single, unambiguous definition. Sexual harassment was originally thought to refer only to situations in which women are threatened with loss of employment or career advancement as a means of extorting their sexual cooperation (Koss et al., 1994), and as such requires an imbalance of power and abuse of authority. Now, however, sexual harassment is seen as including “any type of unwelcome conduct directed toward an employee or student because of his or her gender” (Strauss, 1992, p. 5).
Sexual harassment is considered a form of discrimination by the Canadian Human Rights Commission (1991) and the United States Civil Rights Act of 1964 (as cited in Koss et al., 1994). There are two broad categories of sexual harassment, both of which are illegal. Sexually coercive behaviour, with its threatened consequences for a person’s employment or academic status, is referred to as *quid pro quo* harassment. The other category of harassment behaviour, which is more relevant to a discussion of adolescent peer sexual harassment, is termed *hostile environment*. Hostile-environment sexual harassment refers to any verbal or physical behaviour that creates an intimidating, hostile, or offensive environment, thus interfering with “a student’s ability to learn” (Paludi, 1997, p. 226) or “right to receive an equal educational opportunity” (Stein, 1995, p. 148). Legal rulings in Canada and the United States have indicated that the hostile-environment category of harassment includes negative and degrading comments about a person’s gender or gender-related attributes. These sex-related but not specifically sexual behaviours are termed *gender harassment* (Koss et al.).

As suggested above, sexual harassment involves a wide range of behaviours ranging from unwelcome sexual references and sexist comments to unwelcome sexual advances and forms of sexual imposition or physical contact that may cross over into the legal definition of sexual assault. Spreading sexual rumours; pulling someone’s clothes off; making sexual gestures; touching, pinching, or grabbing; or rating someone on his or her attractiveness or sexual skills are all harassment behaviours. And although the behaviours may be defined by the perpetrator as harmless flirting or merely a joke, both legal and behavioural definitions of sexual harassment acknowledge the phenomenal experience of the recipient. It is “the impact of the behaviour, not the intent” (Paludi, 1997, p. 227) that is most critical in determining whether sexual harassment has occurred. Moreover, we now recognize that females may perpetrate sexual harassment against males, and that same-sex harassment is also possible.

**The Scope of Peer Sexual Harassment**

There is little published research on the prevalence and incidence of sexual harassment in the adolescent population. The best information, albeit American-based, comes from the Hostile Hallways study commissioned by the American Association of University Women Educational Foundation [AAUW], (1993), which drew on a stratified and ethnically representative random sample of 1,600 students in grades 8 through 11 in 79 secondary schools across the US. Although
the response rate is not identified, the researchers claim that the findings are generalizable throughout the US, with a 95% confidence level. The key findings, which pertain only to school-related experiences during school-related times, are as follows.

Sexual harassment is a common experience among high-school girls, 85% of whom reported being victimized by sexual harassment. Although the incidence of sexual harassment was not clearly defined, 31% reported that they were “often” the target of sexual harassment in school. The ambiguity of the word “often” points to the need for researchers to gather more precise frequency data when surveying adolescents about sexual-harassment victimization. The most common experience was non-physical harassment, including sexual comments, jokes, gestures, and looks. However, 65% of the girls reported being touched, grabbed, or pinched in a sexual way, and 13% had been forced to do something sexual other than kissing. Although the questionnaire included 14 items addressing both physical and non-physical harassment behaviours, gender harassment was not addressed except for one item about being called gay or lesbian. It is possible that prevalence and incidence rates would have been even higher had the full spectrum of sexual harassment been addressed. By far the largest proportion of the harassment experienced in school came from other students rather than teachers or other staff, and it was a public (not secret) occurrence: 86% of the female victims reported being harassed by their peers, whereas 25% reported being harassed by school staff; and they reported experiencing harassment in the hallway (73%), in the classroom (65%), on school grounds (48%), and in the cafeteria (34%). Indeed, Stein (1995) refers to sexual harassment in schools as “the public performance of gendered violence” (p. 145). (The term gendered violence is used in feminist literature to direct attention to the role of gender and its social construction as underlying features of male violence against women.)

Additional support for these findings comes from the 1992 mail-in survey conducted by the Wellesley College Center for Research on Women through Seventeen magazine (Stein, Marshall, & Tropp, 1993) and a more recent study of 700 New Jersey high-school students (Trigg & Wittenstrom, 1996), which used a modified version of the AAUW (1993) questionnaire. Particularly significant findings of the Seventeen study were that 39% of the girls and young women \((n = 4,200\), aged 9–19) reported being harasssed at school on a daily basis throughout the prior year and that sexual harassment apparently extends into the elementary-school system. The similarities in findings are striking despite differences in sampling. The school response rate for the New Jersey study was only 30%, with the resultant sample over-representing racial
diversity and the middle-class strata but under-representing eighth-graders. Respondents to the Seventeen study were disproportionately Caucasian (89%), with the majority being in the 12- to 16-year-old age group. No similar research has been published for Canadian adolescents, although researchers in the field of education (e.g., Larkin, 1994) have conducted qualitative studies on the experience and meaning of sexual harassment.

Harassment of Boys

The above focus on the sexual harassment of girls and young women is not meant to imply that boys and young men are not also harassed. Indeed, statistics from both the AAUW (1993) study and the New Jersey study (Trigg & Wittenstrom, 1996) show a fairly narrow gender gap in terms of ever being harassed, although the frequency is far less for boys (i.e., roughly the same proportion of girls and boys are harassed at some point in their lives, but a girl is harassed many more times during her life than is a boy). In addition, findings from both of these studies strongly suggest that the educational and emotional experiences of harassment are qualitatively different for boys. For example, a much lower percentage of the boys who were harassed reported changing their behaviour or wanting to stay home from school in response to the harassment. In the New Jersey study, 52% of the girls, but only 19% of the boys, who had been harassed said that they were somewhat or very upset by the experience.

Challenges of Recognition and Measurement

The measurement of sexual harassment is complicated by definitional issues and the sheer prevalence of the problem. Research findings suggest that, unless there has been some physical assault, most students in higher education and women in the workplace do not classify their experiences as sexual harassment despite their feelings of distress and the fact that the behaviour meets legal definitions of harassment (Fitzgerald, 1990; Paludi, 1997). Another challenge in recognizing and addressing sexual harassment among adolescents is what may be termed the paradox of its prevalence. As argued by other feminist researchers (e.g., Halson, 1989; Jones, 1985; Larkin, 1994), sexual harassment is so common that it has been normalized by young women, who often simply accept the behaviours and resulting distress as an inevitable part of being female. This normalization is reinforced by the way in which the behaviours have been tolerated and interpreted by
others as natural expressions of masculinity and by its exclusion from surveys and discussions of school violence (Larkin).

Sexual-harassment research with the adolescent population may be further complicated by variation in the forms of harassment behaviours that are experienced, and their outcomes, relative to age, developmental stage, gender, and other sociodemographic characteristics. The available data suggest that harassment is experienced across a wide age range (AAUW, 1993), with some disturbingly adult-like sexualized behaviours occurring even in the elementary grades (Stein et al., 1993). In the AAUW study, 32% of respondents who had been harassed reported that their first harassment experience occurred prior to Grade 7, with 10% of the Hispanic girls being harassed prior to Grade 3, but the forms of harassment were not delineated. There is also some evidence that males are more likely to experience gender harassment (e.g., being called gay), to experience same-sex harassment, and to be more disturbed by such behaviours (Trigg & Wittenstrom, 1996).

Health Consequences of Sexual Harassment

Whereas there has been little research on the prevalence and incidence of sexual harassment in the adolescent population, even less work has been conducted on outcomes. Outcome data for adult victims of workplace harassment is somewhat less scarce, but until recently has tended to be limited to descriptive and anecdotal accounts from self-identified victims or clinical accounts reported by health-care professionals (Dansky & Kilpatrick, 1997; Lenhart, 1996). Nonetheless, the data that do exist suggest that sexual harassment poses a significant threat, both directly and indirectly, to women’s health and well-being.

Adult victims of sexual harassment report a variety of somatic complaints, including headaches, fatigue, sleep disturbances, gastrointestinal disorders, weight fluctuations, back pain, and jaw tightness and other forms of muscular tension, along with increases in the frequency of respiratory and urinary tract infections. They also report a range of emotional effects, including anger, anxiety, depression, and an increased fear of rape and other crime, as well as changes in self-perception such as decreased self-esteem and self-confidence (Dansky & Kilpatrick, 1997; Lenhart, 1996). In one of the few more rigorous studies, Dansky and Kilpatrick used hierarchical multiple logistic regression analysis with a randomized sample of 3,000 American women to demonstrate that women with a history of sexual-harassment victimization were 1.2 times more likely than non-victims to be currently suffering depression. Schneider, Swan, and Fitzgerald (in
press) were similarly able to discriminate between groups of women who had and had not been harassed, on the basis of their psychological status. No similarly rigorous study was found with respect to physical-health outcomes.

Outcome data from the three adolescent surveys cited earlier (AAUW, 1993; Stein et al., 1993; Trigg & Wittenstrom, 1996), and the qualitative work by Larkin (1994) in Canada and Halson (1989) in the United Kingdom, are congruent with the psychological outcomes reported for workplace harassment. In the AAUW study, 43% of the girls who had experienced harassment reported feeling less confident about themselves, 39% reported feeling afraid or scared, and 25% reported that the harassment left them feeling confused about who they were. One young woman in Larkin’s study described her response as, “I feel bad about my body and I wish that I was a boy” (p. 109). Although it seems likely that the different developmental tasks of childhood and adolescence may be differentially affected by harassment in its various forms, this is an area that has not yet been explored in the literature.

The Stress-Health Relationship

Further evidence of the potentially harmful effects of sexual harassment may be abstracted from the stress and coping literature. Despite some inconsistent findings and the challenge in establishing definitive causal relations, investigation into stress-health relationships has yielded provocative results for a wide range of health effects, including immune-system functioning, infectious disease, the course of chronic disease, and somatic complaints (Barr, Boyce, & Zeltzer, 1996). Research has also demonstrated significant relationships between stress and health-risk behaviours such as tobacco or alcohol use (e.g., Wills & Filer, 1996), although the relationship to health-protective behaviours has been less well tested and remains uncertain. If sexual harassment does have similar behavioural effects, adolescents may be at particular risk for developing harmful long-term lifestyle patterns due to their critical stage of development.

Psychosocial stressors are generally categorized as either acute life events (e.g., death of a sibling), daily hassles (e.g., arguments with siblings), or chronic strains (e.g., living in poverty) (Aldwin, 1994), although the effects of magnitude and chronicity are not yet well understood. Nonetheless, what is particularly relevant to the study of sexual harassment is that each type of stress has been found to be predictive of somatic and mental-health complaints (Aldwin; Thoits, 1995). Thus, the
construction of sexual harassment as including a wide range of offensive behaviours, from the more serious single incidents to the less offensive but much more frequent behaviours, is congruent with the theoretical approaches and empirical findings of other stress research. Still controversial, however, is the uncertain duration of stress effects (Aldwin; Thoits), with its critical implications for research design and selection of outcome measures.

There are other dilemmas remaining that offer important lessons for future harassment research. For despite the abundant evidence of a broad range of health effects, and our nascent understanding of the psychobiological pathways, stress-health research findings have yielded relatively small effect sizes, with substantial variation among individuals; and it now seems well established that stress is not a simple construct but, rather, a complex, transactional process involving multidimensional situational stressors, subjective appraisal, coping behaviours, and the interplay of other personal resources (Aldwin, 1994; Barr et al., 1996; Thoits, 1995). Social support has been the most frequently studied coping resource, and although it has been found to be positively associated with better physical and mental health, it remains uncertain whether social resources exert their effects directly, indirectly, or through a combination of pathways. Furthermore, though it has been demonstrated that people tend to use multiple coping strategies in the same stress situation, little is known about the efficacy of the different forms of coping (Thoits).

The above results suggest the importance of including subjective appraisal into any measure of stress (e.g., by requiring each respondent to rate the severity or undesirability of each stressor experienced) and assessing coping strategies along with personal characteristics that may influence the stress experience, while paying theoretical and methodological attention to the differences between mediating and moderating variables (see Barr et al., 1996). Given that the three phases of adolescence (early, middle, and late) are purported to have distinct characteristics (Crockett & Petersen, 1993), with mid-adolescence being characterized as having a peer orientation, it seems important to consider both age and developmental issues that may relate to the adolescent’s vulnerability or resilience to various stressors. A conceptual approach to the study of sexual harassment, grounded in a transactional theory of stress and coping (Lazarus & Folkman, 1984), is proposed in Figure 1. This approach directs attention to: (a) possible interaction effects (e.g., appraisal of the event being moderated by a coping resource such as self-esteem), (b) the direct and indirect pathways by which health may be affected, and (c) the phenomenon of comorbidity. The latter refers to
multiple health outcomes that may coexist or exert interaction effects (e.g., physical health effects or behavioural outcomes may be mediated by the emotional effects of harassment). Such an approach would help move sexual-harassment research with adolescents beyond simple correlational surveys and atheoretical descriptive analyses to better capture the dynamic nature of the stress phenomena and reduce the difficulties of causal inference.

**Figure 1 Conceptual Approach to Sexual Harassment Health Outcomes Research**

**Indirect Health Effects through Educational Outcomes**

Sexual harassment may affect health indirectly. Studies of sexual harassment among adolescents provide compelling evidence of serious educational consequences, including attention difficulties, decreased class participation, and absenteeism (AAUW, 1993; Larkin, 1994). According to Strauss (1993), such reactions and avoidance behaviours on the part of the victims "may result in lost education opportunities, which in turn decreases career options and economic potential" (p. 31). Given our emerging understanding of the relationships between socioeconomic factors and health, this presents yet another potential pathway for negative health outcomes, with particularly long-term implications.

Perhaps a more critical issue is the possibility that peer sexual harassment among adolescents may contribute to sexual and physical violence in future intimate relationships. Because high schools play such an important role in gender socialization, Stein and others argue that if sexual harassment is left unchecked the schools may function as training grounds for violence — places where girls "are trained to accept battering and assault" and boys "receive permission, even training, to become batterers" (Stein, 1995, p. 148; see also Jones, 1985; Larkin, 1994).
The Challenge to Nurses

Expanding definitions of health are challenging nurses, especially those concerned with community or school health (Broering, 1993). No longer is it adequate to focus on immunization schedules, medication protocols, or vision screening to the exclusion of a concern for mental health, social health, or psychosocial barriers to learning. In addition, both nursing and the health-promotion movement have moved beyond a focus on the individual to an approach that incorporates socio-environmental determinants of health. These changes render it appropriate for nurses to be concerned with social problems that may underlie their clients' psychological disturbances, somatic complaints, or health-compromising behaviours, and with the social construction of gender and gender-related behaviours that may influence the health of adolescents.

In addition to the need to develop a more precise knowledge of the incidence of peer sexual harassment among adolescents in Canada, other research objectives worth pursuing include gaining an understanding of: (a) the meaning of harassment behaviours to adolescents; (b) personal resources that may impact their appraisal of harassment behaviours, choice of coping responses, and their outcomes; (c) the short- and long-term effectiveness of various responses to the harasser (e.g., avoidance or confrontation) and other coping strategies; (d) the impact of institutional factors on the incidence and outcomes of harassment; and (e) gender and developmental differences in adolescents' sexual-harassment experiences. Both qualitative research and more rigorous and analytically complex quantitative approaches are called for.

The above knowledge would assist the nurse, as a member of the school health team, to influence policy-development and prevention efforts by sensitizing schools to the scope of sexual harassment and its health-related sequelae. Such knowledge would also provide a foundation for the development of more appropriate nursing interventions for adolescent harassment victims, interventions that may pertain to cognitive reappraisal, the development of more successful responses to harassment, or more healthful ways of coping with emotional distress than coping strategies that may compromise their health. Knowledge of the links between sexual harassment and health behaviours would also serve more general health-promotion efforts. When causal linkages are demonstrated between psychosocial stressors (some of which arise from social inequities) and health-compromising behaviours, the harmful behaviours become much more of a collective social issue and less a marker of individual failure. Such findings could, therefore, be influential in prioritizing health problems and interventions directed at
youth and might be used to influence intersectoral health-promotion efforts.

References


Acknowledgements

The author gratefully acknowledges the financial assistance of the British Columbia Health Research Foundation studentship program and the constructive comments of Professor Elaine Carty (University of British Columbia) on a prior version of this manuscript.

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Abused Women’s Concerns about Safety and the Therapeutic Environment during Psychiatric Hospitalization

Ruth Gallop, Susan Engels, Rosanna DiNunzio, and Sonia Napravnik

The purposes of this study were to identify the concerns of women who have a history of abuse regarding safety and the inpatient environment during psychiatric hospitalization, and to identify environmental changes they would like to see. A qualitative design was used to explore the women’s concerns through semi-structured interviews. Instruments
measuring sexual and physical abuse were administered. Of the 20 women recruited from 3 hospitals, 18 reported a history of sexual and/or physical abuse. One investigator interviewed the participants and one acted as recorder. After each interview, a list of identified concerns was generated; these concerns were raised in the next interview if not spontaneously brought up by the participant. Seventeen women reported feeling unsafe in mixed-gender units and said they would prefer segregated areas for programming and meals; 16 expressed concerns about nighttime routines and the traditional practices of restricting medications and contact with staff at night; 15 considered primary nursing extremely important to feeling understood and safe. The participants said they wanted to be heard and to be included in decision-making.

Despite clinicians’ increasing awareness of the psychological and pathophysiological sequelae of child abuse, women with a history of abuse present an enormous challenge for clinical management in ensuring that hospitalization does not reinforce their sense of powerlessness and of being silenced. There is limited literature examining the experience of hospitalization for women with a history of abuse. What little literature does exist highlights hospitalization as a significant risk for evoking feelings of powerlessness and of being silenced (Doob, 1992; Firsten, 1991; Urbancic, 1992). The present study was an attempt to identify ways in which the clinical environment can be modified to increase women’s sense of safety and of maintaining control.

Clinical reports and research studies of the past few years have reported that approximately two thirds of female psychiatric patients have a history of childhood physical and/or sexual abuse (Beck & van der Kolk, 1987; Briere & Zaidi, 1989; Bryer, Nelson, Miller, & Krol, 1987; Chu & Dill, 1990; Firsten, 1991). Firsten reports that 83% of a sample of Canadian women hospitalized in a large urban psychiatric hospital reported either physical or sexual abuse in childhood and/or adulthood. The broad psychological sequelae of abuse can include feelings of betrayal or powerlessness, lack of trust, need to avoid close/intimate relationships, and lowered self-esteem (Briere, 1992; Herman, 1992). These feelings can lead to a view of the world as a hostile environment (Briere).

Background

A history of abuse can influence expression of psychopathology, length of hospitalization, and clinical outcomes (Carmen, Rieker, & Mills, 1984; Goff, Brotman, Kindlon, Waites, & Amico, 1991). Strong association has been observed between a history of abuse and specific psychiatric disorders such as dissociative identity disorder, post-traumatic stress disorder, and borderline personality disorder (Herman, Perry, & van der Kolk, 1989; Sansomnet-Hayden, Haley, Marriage, & Fine, 1987; Westen,
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Ludolph, Misle, Ruffins, & Block, 1990). Greater frequency and severity of depression and psychotic symptoms have been reported for hospitalized women with a history of abuse than for those without a history of abuse (Hall, Sachs, Rayens, & Lutenbacher, 1993; Muenzenmaier, Meyer, Struening, & Ferber, 1993). Increased alcohol and drug abuse have been reported among sexual-abuse victims (Beck & van der Kolk, 1987; Briere & Zaidi, 1989; Herman, 1986; Margo & McLees, 1991; Pribor & Dinwiddie, 1992). Suicidal ideation, suicide attempts, and self-mutilation have also been found to be associated with sexual abuse (Briere & Zaidi; Romans, Martin, Anderson, Herbinson, & Mullen, 1995). A positive relationship has been demonstrated between the severity of abuse (in terms of form, duration, and closeness of relationship) and self-harm behaviours (Briere, 1992).

Some authors have drawn parallels between the experience of psychiatric hospitalization, designed to help the client during a state of acute crisis, and the experience of trauma. As early as 1984, Mills, Rieker, and Carmen found that abuse victims, particularly women, experienced longer hospital stays than other clients and that abuse victims were more likely to use self-harm as a means of coping with anger. Authors such as Fromuth and Burkhart (1992) question whether there can be a "benign" psychiatric hospitalization for women with a history of abuse. They argue that the experience of psychiatric hospitalization shares with abuse the themes of stigmatization, betrayal, and powerlessness. Harris (1994) speaks to the need, among women with a history of sexual abuse, for hospitalization that is carefully planned, voluntary (when possible), and under the control of the client. She suggests that alternatives to traditional hospitalization be explored and that efforts be made to reframe the hospital as a place where one goes when in need of safety rather than where one goes when out of control. Cohen (1994) uses Herman's (1992) model of captivity, in which fear is produced by the unpredictable violence and "capricious" application of rules, to argue that psychiatric hospitalization with its locked units, isolation from familiar people, use of restraint, and violence can produce a form of captivity trauma. A moving article by Jennings (1994) uses the 17 years of mental health records of her sexually abused daughter to document the system's failure to help. Not only was the abuse ignored during her daughter's hospitalization, but, according to Jennings, many common hospital practices can lead to a form of institutional retraumatization for the client.

Recent surveys with psychiatric nurses indicate that nurses fear they lack the skills to assess a history of abuse in an appropriate and sensitive manner and to respond or counsel appropriately when
women disclose a history of abuse (Gallop, McCay, Austin, Bayer, & Peternelj-Taylor, 1998; Gallop, McKeever, Toner, Lancee, & Lueck, 1995). It would seem that what is required is a therapeutic environment that attends to the abuse without fostering the silencing of women concerning their experiences or inviting potentially harmful abreaction or regression. Unfortunately, the inpatient setting with its acutely ill patient population and structure can actually increase feelings of powerlessness and anxiety in abused women. This may lead, in turn, to a loss of behavioural control with increased suicide attempts and self-harm behaviours.

Often the response to self-harm behaviours and loss of behavioural control is increased use of such interventions as chemical and physical restraints, which can be experienced as a re-enactment of the abuse, perpetuating the sense of betrayal, insecurity, and powerlessness so central to the experience of women with a history of abuse (Gallop, McCay, Guha, & Khan, in press). The therapeutic milieu should be sensitive to the needs of women who have been abused, with inpatient programs that negotiate proactive interventions with the women, enabling them to attend to their need for safety and containment. Kirby, Chu, and Dill (1993) consider acknowledgement, security, and containment as essential features of the first phase of dealing with trauma and with ongoing issues in the treatment of trauma.

Purpose

This paper addresses two research questions: What are the concerns of abused women regarding their safety and their experience of hospitalization? How would these women like to see these concerns addressed? The ultimate objective of the study was to develop clinical guidelines to ensure that, from the beginning of psychiatric hospitalization, key issues and identified concerns of abused women regarding safety and control are used in shaping the therapeutic environment and the responses of clinicians.

Methods and Procedures

The study was conducted in two phases. In phase one, women admitted to acute-care inpatient units were interviewed to identify their safety concerns. These findings are described in this paper. In phase two, the concerns identified by the women were discussed in focus groups of nurses and other clinicians in the study units to determine how this information might be used to modify unit policy and practice. Phase two is not covered in this paper.
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Overview

The study relied on qualitative methodology. In phase one, women's perceptions of safety during hospitalization were explored through semi-structured face-to-face interviews. One of the investigators conducted the interviews while another took detailed verbatim notes.

Participants

Data were collected at three inpatient sites, selected to represent the variation in acute-care psychiatric facilities available to clients: an acute-care unit of a large urban teaching hospital, an acute-care unit of an urban psychiatric teaching hospital, and an acute-care unit of a community hospital. Every woman admitted to either of the three sites was eligible to participate if she could understand and communicate clearly in English and provide informed consent.

Twenty-one women agreed to participate. At two sites, no woman was excluded by the nurses from eligibility and no woman declined to be approached. At the third site, approximately six women were considered too ill to participate. All women who heard the study description agreed to participate; however, one woman was always too tired or unwell at scheduled times and therefore did not participate in data collection. Data were collected over a 5-month period.

Originally, the researchers had planned to interview women until there were at least 20 with a history of childhood physical and/or sexual abuse and 20 without a history of abuse, in order to see if safety concerns differed for abused and non-abused women. However, of the first 20 women interviewed, only two did not report a history of childhood abuse. The researchers believed it would be very difficult to obtain a sample of 20 non-abused women and were reluctant to invite women to hear about a study, then reject them because they had a history of abuse. When 20 interviews had been conducted, the research team agreed that no new information was being obtained and the topic was saturated. In the interests of consistency, the interview data for the two women who did not have a history of abuse are not reported, even though their concerns were similar to those of the abused women.

Interviews

Semi-structured interviews were used to gather information. The interview commenced with an open-ended question/comment such as: We are interested in knowing what you think we can do to help you feel safe in this setting. If a woman did not spontaneously bring up concerns
identified during previous interviews, she was asked if she had any thoughts about specific concerns identified by others: male clients; room location; nighttime issues; participation in decision-making; nature of contacts she found helpful. For each concern identified, the interviewer sought clarification as to how the client would like staff to respond to that concern.

**History of sexual abuse.** The investigators made the decision to inquire about a history of physical and/or sexual abuse, given the increasing evidence that many hospitalized women do have such a history. If during the semi-structured interview the woman disclosed a history of abuse, the researcher asked her permission to inquire in more detail about it. A brief questionnaire was developed by the authors for this purpose. The women were given the option of refusing to answer any question, and it was made clear that such refusal did not imply a history of abuse. No woman refused to answer these questions.

**History of physical abuse.** The Physical Abuse Research Schedule (a sub-schedule of the Child Maltreatment Interview Schedule [Briere, 1992]) includes three basic questions about physical abuse occurring before the age of 17 (during the years when the typical shared parent-child living arrangement is most prevalent). Measures of physical abuse are usually defined as punishment that results in marks, bruises, breaks in skin, or injury warranting medical attention (Weaver & Clum, 1996). The Briere schedule captures these requirements and has been used extensively.

**Data Analysis**

Data analysis used the following process for identifying issues of concern consistent with the techniques for inductive analysis described by Huberman and Miles (1994). After each interview, the data were analyzed for emergent concerns. After the participant had listed her concerns and possible solutions, the interviewer asked about areas not mentioned but identified by other participants. Following completion of all interviews, the members of the research team individually examined the concerns identified (e.g., concerns about male patients). The researchers counted the number of times a concern was expressed. They then met and discussed each area in order to reach consensus on the nature of the concerns. All the researchers were psychiatric nurses, and one senior student had also been involved in research in this area for 2 years; therefore, care was taken to ensure that personal biases were not inserted into the data and that the reported concerns reflected the actual content of the data.
Results

Participants

Twenty women participated in the study. Interviews ranged in length from 15 to 60 minutes. Women ranged in age from 20 to 61 years, with a mean age of 36.8 years. Eighteen women had completed high school; 12 women reported being educated beyond high school. For six women this was the first admission; 10 women reported at least four previous admissions. Twelve women had a primary diagnosis of depression, five bipolar disorder, two dissociate identity disorder, and one schizophrenia.

Sixteen women reported a history of childhood sexual abuse; of these, nine also reported a history of childhood physical abuse. One woman reported a history of childhood physical abuse without childhood sexual abuse. No women reported being in an abusive relationship currently, although one woman did state that she had just left an abusive relationship. Four women reported both adult sexual abuse and adult physical abuse, four reported adult sexual abuse, and four reported adult physical abuse. Only two women did not report some form of abuse as a child or as an adult.

Concerns

The abused women reported many concerns about safety and other elements of hospitalization, and they made many suggestions. Collectively the comments reveal, from the women's perspective, how the therapeutic milieu should be shaped.

Three major areas of concern are discussed: male patients, night issues, and nursing issues. The quotes offered below are taken verbatim from the record of each interview. The numbers in brackets are participant code numbers.

Male patients. Seventeen women raised concerns about male patients. The women spoke of their fear of men, and most stated that they would have preferred an all-female unit or at least a unit with segregated spaces and programming.

Having an all female floor would be better, or at least have men on one side of the floor and women on the other. [07]

Having a floor with only ladies on it would be better. [03]

Concerns reflected a preference for not only separate bedrooms but also separate dining and other communal areas.
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When you are in with men — I am not thinking about myself as a sexual object, I would wander for breakfast in my bathrobe — I questioned what message am I giving? [19]

Eating lunch alone versus with male patients is an important choice. [02]

The women gave a number of reasons for feeling unsafe or wanting segregated areas. For many, the wish for segregation was related to the threat of violence and sexual assault.

Having male patient screaming next room [is] scary. [02]

Older male patients — it was adults who abused me, so it feels unsafe when the males walk by my room and say something — it scares me — I can’t sit in same room with them. [20]

Being in same room with these men, like dining area, meeting area etc. is scary better to be able to eat in room if afraid. [04]

Just because of my history I don’t trust males. [16]

They described feeling unsafe with men wearing pyjamas or underclothing in public areas of the unit (dining room, corridors).

Making male patient wear clothes or gown or something that covers them. [03]

Guys walking around in their underwear, they should be covered up. [05]

Profane language caused particular concern for several of the women.

It frightens me when men use bad language. [04]

Night issues. Nighttime clearly presented difficulties for many of the women. Sixteen participants discussed specific concerns, which can be clustered into four subcategories: lights; doors; routine checks and interventions; and staff availability.

Most of the women felt safer and more secure knowing that there were routine night checks, but they found the use of a flashlight intrusive, frightening, and disruptive to their sleep. They expressed a preference for softer lights that could be left on all night, affording visibility within their bedrooms. This issue was related to fear of both nighttime and having a man next door or nearby. The women found it especially distressing to have a flashlight shone in their faces during night rounds, although in general these routine night checks promoted their sense of safety.

Afraid in hospital when light is off in room, helpful to have a choice to have light on/off. [03]

Light on at night so you can see whole room. [02]
The night rounds are good, although the flashlight startles me. [07]

A number of women spoke about bedroom doors being open or closed at night. Some preferred the doors kept open, while others preferred them shut. In general, their concerns reflected a fear of someone wandering into their room at night while they slept.

At night it is good to have door closed, safer so people don’t wander in. [05]

Prefer to have the door closed so that I wake up if someone comes in. [09]

Feel safer with door open with a little light, helps nurses not to wake you up and if someone comes in I can see them, but if they open and close the door I can’t see them. [04]

Routine night checks made many women feel more secure, both because it ensured their safety and because it indicated the availability of staff.

Short frequent contact at night to make sure I was OK at night, really made me feel safe. [18]

Night checks make me feel safe. [16]

Need to have staff around who know what you are up to — how you are doing — put pins in my wrist one night but the staff did not know because they did not come around. [14]

Many of the women felt that there was a need for more therapeutic interventions at night and that staff was inaccessible during the night shift.

Having staff available to talk to is important to help me feel safe [at night]. [05]

Helped me feel safe when nurse asked if she could sit with me because I couldn’t sleep, the nurse was very empathic and sat with me, I really appreciated talking with her. [04]

Night is the hardest time, the staff is usually unknown to me, and they do not seem to care, they do not introduce themselves to you at night, they don’t even look at you, they seem very unapproachable. [07]

They spoke of the need to have a place to go, such as a lounge, when they couldn’t sleep and having medication available if they needed it.

Have panic attacks only at night. [01]

Having to stay in your room 11-7 when you can’t sleep is unsafe. [05]

Having a place to go at night is good and having medication available when I need it is also good, watching TV helps me at night. [07]
Smoking privileges at night nearby are important — hard because you need to have a cigarette because you are upset and it is late at night and now you are going out on your own — it is dangerous for me. [14]

Not having meds after one o'clock to sleep intimidated me and I felt bad, one night I woke up around 3 and asked for meds to help me sleep but nurse said she could not give them to me after 1 am — this was terrible, the nurse intimidated me. [15]

Nursing issues. All of the women described the qualities and skills that nurses should possess. Fifteen participants spoke about the importance of a primary nursing relationship in ensuring consistency of care, caregiver, and coordination of care, and thus their own sense of safety, comfort, and empowerment. Central to their sense of safety was the ability to develop a trusting relationship with their primary nurse.

Closely related to primary nursing was staff skill perceived as important in this milieu. Sixteen women spoke about staff skill. Their sense of safety and comfort was influenced by the skill of the staff, primarily because it was manifested in superior coordination and interventions. Skill covered experience, knowledge, treatments, and medications; knowledge of the individual patient — including keeping up to date with any changes; spending time getting to know the patients; initiating contact; and professionalism.

The following comments illustrate the importance they attached to primary nursing.

When you feel connected with someone you don't feel so alone and vulnerable, you know you will not lose control, therefore important to have primary nurse. [05]

The bond created with a primary nurse makes you feel safer — they are working with you, they know you and understand what is wrong. [14]

Primary nursing is important because you have someone to turn to that you have gotten to know and who knows you — you can divulge more, you don't have to start from the beginning all over again, it is like climbing stairs. [11]

A problem identified by the women was the feeling of being ignored by and unconnected to nursing personnel other than their own nurse. They found this especially difficult when the primary nurse was not there, such as at night.

Having primary nurse is good but if a nurse is not your primary they don't even smile at you, I know they are understaffed but that does not mean they cannot be friendly when they walk past you. It would be nice if they came to talk to you if they had time even if they are not your nurse. [07]
Many of the women found that experienced staff made them feel safe. However, they believed that experience was not as important as caring, empathy, and compassion.

Having experienced staff is one of the most important things, they have confidence in their skills, it is reassuring when they say “I have seen this before.” [06]

Not being task oriented — more important to have a nurse who actually cares rather than one who has been there for 25 years — she has seen it so many times but couldn’t care less about you. [14]

Participants said it was important that staff be knowledgeable and informed about their problems, treatments, and medication; otherwise, they felt unsafe and afraid. The women also spoke about the importance of staff sharing this knowledge with them.

Expert nurses tell you each time what medication they are giving you and why; they are informed and educated, putting time and effort into the moment of giving you medication is almost like bonding. [08]

The nurses, they are the ones who are really with the patients; they see the progress of the patient; it is important they know what is happening with you. [07]

Many women said it was important for staff to initiate contact, because it showed that staff both cared about them and understood their condition well enough to know when an intervention was needed.

I would like the caregivers to interact with me at times, I cannot always articulate it. [19]

Important to not feel like you are imposing, better for the nurse to initiate the contact. [11]

The women said it was important that staff remain professional — leaving their personal issues at home, maintaining confidentiality, and making and keeping appointments.

When the nurses are here they don’t bring their personal lives in here, they do not bring their personal problems in here, they are professional — I know they have their own problems but when they are here they concentrate on mine. [06]

Confidentiality — I’m worried professionals may go home and tell their families about some of my horror stories. [20]

The participants also felt it was important to their sense of safety to have staff available to help them cope with their symptoms.

Knowing that people are around because I’m suicidal, so that people are here to stop me from harming myself. [16]
I panic sometimes, it was good when I panicked once and they stepped in and sat with me and ensured I did not harm myself. [14]

For nine participants, the gender of staff was an issue. For three of these women, the concern centred on bodily touching.

[02] Like female nurses as opposed to men, do not trust male nurses.

People should have a choice in not having a male nurse — I am disabled and having a male nurse is hard to preserve my dignity. [09]

They (the staff) were searching me, but I am Muslim and should not be touched or looked at naked by men — but they did not seem to care. [12]

All the participants spoke about the wish to be more informed about unit policy and practices and to be consulted about treatment decisions. There was an overall sense in the interviews that the women wanted to be considered integral to planning care, although some women recognized that at the time of admission they may not have been well enough to participate.

Nursing care plan drawn up and being involved in that is important — could not do it when came in because I was too depressed but it was good that when I was feeling better my primary nurse went over it with me again; important that nurses step in when I cannot. [10]

I am supposed to tell them if I want to hurt myself — but this is hard to do, I would feel safer if there was another plan in place also; for example, they should assess the contract frequently so that it changes as I change and to be on guard for when I may not able to control myself. [14]

Not surprisingly, many women cited knowing what to expect as contributing to their feeling in control and empowered. Given the centrality of a sense of powerlessness, betrayal, and insecurity in the experience of abused women, anything that helps them feel in control and secure is important.

Getting some preparation and being involved with treatment helps me feel safe — shows they are listening. [17]

People should ask you what helps you feel safe prior to admission or tell you conditions on the floor prior to admission so you can prepare yourself. [02]

Information giving — telling me how they will treat me and how my treatment will treat me — what the treatment plans are or including me in treatment plans makes me feel safe because I know I’m listened to. [16]

The women wished to have choices and to have input concerning their medications. Choices included being free to come to the hospital to feel safe. Harris (1994) cites this as an important issue — rather than
coming to hospital because one is out of control — for women with a history of trauma. For 16 of the participants, being consulted meant being believed and taken seriously; otherwise, they felt unsafe, not listened to/validated, humiliated, and treated inhumanly. These themes are similar to concerns expressed by participants in a recent study by Gallop et al. (in press).

Being treated as a person, having choices in care as important. [02]

Having a choice to come into hospital — that they will let me in when I need it — helps me feel safe. [17]

One night a nurse told me just to forget my family because I have problems with them, I was so insulted, I got angry for the first time — so his unempathic response made me feel unsafe for the first time — “don’t tell me how to feel.” [17]

On the other hand, when the participants sensed that the nurses took their job seriously and cared for the patients they felt more secure and comfortable. They felt safer when the staff respected them, took them seriously, believed them, listened to them, and showed genuine concern.

A listening and compassionate air cannot be replaced by medication. [08]

I just feel safe when I have nice people around me — professionals who know how to respect and talk to me, act like they care then I feel safe in the environment. [20]

Additional Observations

Twelve of the participants reported that having women’s groups on the floors would contribute to their feeling of safety in hospital. Women’s groups were seen as an opportunity to share experiences, as helping to promote feelings of safety, and as private places where women could comfortably and openly discuss distressing and personal issues.

Being told I have to go to group therapy makes me feel unsafe because there are males there, I don’t even have male visitors. [20]

Discussion

The participants in this study suggested environmental changes to limit their exposure to male patients, to provide them with more options in managing nighttime difficulties, and to facilitate their active participation in all aspects of treatment planning and the therapeutic relationship. Concerns about male patients may be related to the state of hyperarousal and chronic fear evident in trauma survivors (van der Kolk et
al., 1996). In addition, women who have experienced childhood sexual and/or physical abuse are at significantly greater risk of adult victimization, and concerns about males may be a reflection of this reality in the lives of the participants (Briere, 1992).

The participants wanted a fuller range of treatment options made available to them at night, to alleviate their fears and enhance their sense of safety and containment. Some of the suggested modifications were: having staff available to speak with or simply to be present during difficult times in the night; access to the television lounge or other communal space; smoking privileges; and medications regardless of the hour. These recommendations are not surprising given that trauma survivors frequently experience a chronic state of hyper-vigilance and a related inability to rest (van der Kolk, 1994). In addition, sleep disturbance, such as difficulty falling asleep, frequent waking in the night, and early waking, are common. Nightmares and flashbacks may be experienced, and panic may be greater at night.

The participants wished to be involved in the planning of their care and in decision-making. They discussed characteristics of the nursing staff essential to establishing this type of collaborative relationship. Their need to be involved may be related to the chronic feelings of powerlessness engendered in women who have experienced abuse. The need to exert control in the outside world is paramount to a woman’s sense of safety given that the world may have been internalized as a hostile place (Herman, 1992). The repeated call by these women for qualities in nurses that foster a sense of safety reflects the traumatic experiences that leave women feeling socially vulnerable and make it exceedingly difficult to establish trust.

The participants identified the important role of nursing. When the characteristics of primary nursing, willingness to make contact, professionalism, and knowledgeability were lacking they felt insecure and anxious. All of the participants acknowledged concerns about their lack of involvement in treatment planning and described aspects of their care that seemed to fall short of what are essential elements of nursing.

For decades, the nursing profession has espoused a participatory decision-making framework and advocated for client-centred care focused on the needs of each individual patient. In addition, there is an extensive nursing literature on the centrality of empathy and interpersonal process in mental-health nursing (Gallop, 1997). Despite these espoused and documented nursing values and the literature on trauma,
these participants cited many examples of nurses forsaking these values and failing to apply their trauma knowledge. The study sites still practised what might be ingrained and traditional night routines. The premise that nighttime is reserved for sleeping and daytime for programming seems to be the basis for these practices. The nighttime practices of "lights out," unavailability of sedation after 1:00 am, restriction of lounges, and minimal nursing contact all support the assumption that patients must sleep at night so that they can participate fully in treatment during the day. The historically rooted night routines and traditional restrictions continue to be applied even though nurses should know that an estimated two thirds of women admitted to their unit have experienced trauma and may suffer from distressing symptoms such as flashbacks and panic, which are often heightened at night. It may be that what nurses have come to know experientially over years of practice takes precedence over newly acquired theoretical and empirically based knowledge.

Another factor contributing to an apparent lack of integration of trauma knowledge into unit practices may be a weariness on the part of nurses resulting from failed attempts to effect change. Nursing, a predominately female profession, functions in a system that has historically provided its practitioners with little control over intervention and change. Nurses may feel much as the women in this study did — silenced and powerless to change the system. Changing unit practices and policies requires the support of colleagues and administrators. Silencing can occur in many ways. Mohr (1995) describes the team meeting in psychiatric units as a pleasing myth of egalitarianism and democratic principles. Mohr claims that in reality it is strictly hierarchical and led by the psychiatric expert; nursing input is valued only to the extent that it reinforces the scientific model. Because nurses and physicians may speak different languages at the meetings, the nurse may feel both unheard and silenced (Gallop, 1997). Frequently, medical staff speak the language of science — positivist; signs, symptoms, diagnoses — nurses, the language of feelings, context, and process. Lack of response to nurses' language conveys the message that their input is of no consequence. Senior nursing administrators may also contribute to the silencing of nurses. Roberts (1983) describes nurses as an oppressed group and nurse administrators as identifying with the oppressor (i.e., physicians) in order to exercise power over the front-line clinicians. Hence the struggle to bring about changes that may be valued as important by both nurses and clients, but not by the power groups, can become a fruitless and frustrating experience.
Conclusion

The concerns of women with a history of abuse can be addressed by modifications in unit and nursing practices. If nurses acquire the ability to comfort clients who have experienced abuse, recognize the high rate of abuse in the lives of psychiatric clients, and believe they have the authority and support to proceed with change, they will be able to provide safe and empowering environments.

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**Acknowledgements**

This research was funded by a grant from the Women’s Health Bureau, Ontario Ministry of Health.

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Innovative New Program

From Chaos to Order: A Nursing-Based Psycho-Education Program for Parents of Children with Attention-Deficit Hyperactivity Disorder

Cynthia Baker

Un programme psychopédagogique destiné aux parents d’enfants atteints de trouble d’hyperactivité avec déficit de l’attention (THADA) est décrit dans l’article qui suit. Cette stratégie d’intervention est fondée sur la théorie infirmière intitulée Modelage és imitation de rôles, élaborée par Erickson, Tomlin et Swain, dans le but d’aider les gens à gérer les éléments de stress en favorisant le développement de connaissances et de ressources menant à l’autonomisation et en promouvant des actions autonomisantes. Les composantes clés du programme mettent l’accent sur la reconnaissance et la gestion de comportements récurrents, le développement de connaissances provenant de ressources internes et externes et la mise en évidence des forces des participants et de leurs enfants atteints de THADA.

A psycho-education program for parents of children with attention-deficit hyperactivity disorder (ADHD) is described. This intervention strategy is based on the nursing theory of Modeling and Role Modeling developed by Erickson, Tomlin, and Swain to help people cope with stressors by facilitating the development of self-care knowledge and self-care resources, and by promoting self-care action. Key components of the program are an emphasis on pattern recognition and pattern management, the fostering of insider and outsider knowledge, and an emphasis on the strengths of participants and of their children with ADHD.

Psycho-education, introduced to prevent relapse among individuals with schizophrenia, has proved to be immensely effective in improving the illness course of this disorder (De Jesus Mari, 1994). This success has inspired the development of a psycho-education program for another population, the parents of children with attention-deficit hyperactivity disorder (ADHD). This program, named From Chaos to Order, is based

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on a self-care nursing theory developed by Erickson, Tomlin, and Swain (1988). The rationale, the underlying framework, and a brief overview of the program are presented below.

**Rationale**

The symptoms of ADHD cause a considerable amount of family stress and account for numerous referrals to child mental-health services (Jensen, Martin, & Cantwell, 1997). They are also associated with an increased risk for other psychiatric problems such as conduct disorder and depression (Jensen et al.). The major treatment modality has been stimulant medications. Despite clear evidence of short-term therapeutic effects, however, long-term benefits have not been demonstrated. Furthermore, stimulant medications appear to have weak effects on secondary emotional deficits (Richter et al., 1995). Parenting programs developed by psychologists have been a complementary intervention. Although helpful in providing training in child behaviour modification, they are highly didactic and target specific, currently evident behaviours (Cousins & Weiss, 1993). ADHD, however, is a chronic disorder often persisting throughout adulthood. Its impact is heterogeneous and varies over time. Moreover, the parents being trained are also liable to have some traits associated with ADHD because of a strong genetic contribution to the disorder (Richter et al.). These considerations indicated the need for a parent-focused intervention with a broader and more holistic therapeutic agenda than skill-training.

Psycho-education incorporates an educative function, which, in contrast to training, fosters an ability to create and exercise new options (Bevis & Watson, 1989). Also, psycho-education offers social support. Numerous studies have demonstrated that this improves coping, moderates the impact of stressors, and promotes self-care (Stewart, 1993).

**Guiding Framework**

The theory of modelling and role-modelling (Erickson et al., 1988) that guided the development of the program holds that self-care involves three interacting components. Self-care knowledge refers to personal knowledge. Self-care resources are the internal and external factors available to an individual for contending with stressors. Finally, self-care action refers to behaviours that result in the development and utilization of self-care knowledge and resources to maintain or attain optimum functioning. The program was conceived as an intervention
to develop participants' self-care knowledge and self-care resources in order to help them cope effectively with stressors related to parenting a child with ADHD.

Facilitating self-care begins with modelling, the effort to understand clients' perspectives of their situation. Although a group intervention limits the extent to which each participant's unique perspective may be grasped, the facilitator seeks to understand participants' frames of reference through an interactive format. Modelling is followed by role-modelling, the process of helping clients to develop personal knowledge and self-care resources to contend with stressors through self-care action. At the heart of role-modelling are interventions that create trust, promote control, encourage a positive orientation, and facilitate goal-setting. Interventions with these ends in view are, therefore, integrated throughout the program.

Description

From Chaos to Order is a community-based program sponsored by the Moncton branch of the Canadian Mental Health Association and supported by the New Brunswick Department of Health and Community Services. Its ultimate aim is to improve outcomes among children with ADHD. Short-term objectives target parents' understanding of ADHD, their emotional adaptation to the stress imposed by it, and their management of problematic behaviours associated with it.

Structure and Organization

From eight to 10 participants meet with a facilitator for 2 hours once a week over a period of 8 weeks. Classes include didactically presented information supported by handouts, themes for discussion, group brainstorming activities, and experiential exercises. At the end of each class (except the last), participants are given a homework activity in order to adapt information discussed in light of their particular situation and needs.

Content

The informational content of the program is shaped by the notion of patterns, the concepts of insider and outsider knowledge, and an emphasis on strengths. Core symptoms of ADHD tend to be reflected in re
curring behavioural patterns and often trigger recurring sequences of interpersonal interactions with others. Participants are therefore invited to order the chaos caused by ADHD, by seeing and making sense of patterns and deliberately trying to manage or alter problematic patterns. A repertoire of strategies for managing problematic patterns is presented. It is called M&M&M, which stands for minimizing symptoms, maximizing health, and modifying the environment. Minimizing symptoms focuses directly on problematic behaviours and on the child’s self-esteem. Maximizing health, which is concerned with holistic functioning, uses strategies for managing family stress and promoting the child’s health in order to reduce symptoms. Finally, modifying the environment involves strategies for creating an environment around the child that will compensate for the core symptoms of ADHD.

The program is intended to foster two types of knowledge. Insider knowledge, a concept developed for the program, refers to an understanding of ADHD and its management that is grounded in the lived experience of people who have it or who parent a child with it. Outsider knowledge, in contrast, refers to empirically obtained information about ADHD. Insider knowledge is a component of self-care knowledge and an essential complement to outsider knowledge in managing patterns of behaviour associated with ADHD. Personal expertise developed from experience is considered invaluable. Participants are encouraged to identify, develop, and share personally discovered insights and management techniques. Outsider knowledge is considered a potential self-care resource if incorporated into an individual’s self-care knowledge. Learning activities therefore encourage participants to personalize outsider information about ADHD and to integrate it into their own frames of reference.

Finally, the program is intended to be empowering, and class content emphasizes the strengths associated with the core symptoms of ADHD. It also focuses on the potential of the participants to compensate for the limitations that result from the disorder. The program highlights the strengths of the participants and of their child with ADHD.

**Summary and Conclusion**

In summary, From Chaos to Order is a community-based intervention strategy oriented by a nursing framework. It promotes self-care among parents of children with ADHD by emphasizing patterns of behaviour and patterns of responses to these behaviours. It fosters the development and use of both insider and outsider knowledge in managing problematic patterns.
References


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Mother-Loss: Recreating Relationship and Meaning

Pamela J. Dietrich, Carol L. McWilliam, Susan F. Ralyea, and Ann T. Schweitzer

The purpose of this investigation was to describe adult women’s experiences in losing their mother. Using an interpretive phenomenological frame of inquiry, 5 women were purposively selected to share their loss experience. Memories of the mother-daughter relationship were explored, and the meanings the daughters attached to their loss described, in written narratives, 2 in-depth interviews, and 1 group session. Seven themes emerged: Recalling, Holding On, Saying Goodbye, Longings of the Heart, Shifting Patterns of Relationship, Recreating the Dialogue, and Honouring Our Mothers/Ourselves. The loss of one’s mother represents the loss of one’s first intimate relationship, a relationship that has a unique meaning for daughters because their personal development is profoundly and
uniquely shaped by it. This potentially pervasive and transforming life experience is best understood from an in-depth exploration and understanding of the nature of the mother-daughter relationship. Nurses who come to understand the dynamic interaction of grief and development through women's experience of mother-loss can more successfully offer their presence, their understanding of the complexity of the mother-daughter relationship, and their skills in bereavement care to facilitate healing and to promote health and personal growth.

While nurses are educated to provide bereavement care, the subject of how best to work with adult women who are in a lifelong process of grieving the loss of their mother has not been investigated. The potential impact of this unique experience of loss can be understood only from the literature on the significance of the mother-daughter relationship and the adult bereavement experience in general. The purpose of this inquiry was to directly explore the long-term experiences of women grieving the loss of their mother.

**Background**

To understand a woman's experience of mother-loss one must first understand the nature of the mother-daughter relationship. Theories and research on this relationship have identified several characteristics that distinguish it from those of all other family dyads. Chodorow (1978) maintains that when the mother is the early and primary source of caregiving she becomes the primary source of attachment and identification for her children. Chodorow asserts that the important developmental processes of separation and individuation occur differently for boys and girls, given their different realities in a predominantly patriarchal society. There are fewer societal expectations for daughters than for sons to separate from their mothers (Chodorow; Flax, 1981). Separation is defined here as the establishment of a person's firm sense of differentiation, of possessing one's own physical and mental boundaries; individuation refers to the range of characteristics, skills, and personality traits unique to a person (Chodorow). In a society that equates maturation with autonomy, many contend that attributes unique to the mother-daughter relationship may develop through the process of identification, including conflict, the undermining of individuation, and the perpetuation of same-gender intergenerational patterning. Boyd's (1989, 1990) research provides some, albeit limited, empirical support for a model of mother-daughter identification in which attachment and conflict are central features of the relationship.

In the context of the same-sex dyad in which identification continues throughout life, women are more likely than men to maintain aspects of their primary relationship with their mother. This does not
mean that they are unable to individuate; the process is wrought with complexity. Gilligan (1982) suggests that for girls and women, issues of feminine identity do not depend on the achievement of separation from their mother or the progress of individuation. Rather, as a result of identifying with their mother, women learn to value and preserve their other relationships.

Fischer (1981) reports that as a daughter moves into adulthood, she and her mother re-evaluate each other, redefining and renegotiating their relative status and role within the parent-child dyad. Thompson and Walker’s (1984) research reveals differences between younger and older mother-daughter dyads with respect to bonding and aid patterns. Younger daughters reported greater attachment, having just moved through a period of high emotional involvement, than older daughters. Davis and Corson Jones (1992), however, show that a daughter’s attachment to her mother and her level of self-differentiation are not causally related, which supports the view that differentiation of self and attachment are distinct variables in personality development.

The literature documents several factors that undoubtedly influence the mother-daughter relationship. From psychoanalytic theory and more recent feminist research, we know that the aforementioned processes of attachment, identification, separation, and individuation all ultimately impact on the adult mother-daughter relationship. Social learning theory contends that modelling results in similar sex-role behaviours in mothers and daughters (Weitzman, 1984), adding to our understanding of the contextual factors that influence this relationship. Clearly, how these factors have influenced the evolution of the adult mother-daughter relationship will, in turn, influence all dimensions of that relationship, including the experience of mother-loss.

To date, investigations of relationship loss have focused on the experience of spouses, children, and parents. It is often assumed that losing a parent during adulthood is a normative life event for which one prepares over a lifetime and therefore is less difficult to bear than losing a spouse (Bass, Noelker, Townsend, & Demling, 1990; Owen, Fulton, & Markuson, 1982; Sanders, 1980). However, a growing body of research has identified immediate outcomes of an adult’s loss of a parent, including: a sense of trauma and devastation (Kahrl, 1988); depression (Vargas, Loya, & Hodde-Vargas, 1989); feelings of guilt, regret, and anticipatory grief; changes in other family relationships; lifestyle changes (Kerr, 1994); and poor health, remorse, and removal of a final psychological buffer against one’s own mortality (Perkins & Harris, 1990).
In addition, studies of young women experiencing parental loss have identified intrusive thoughts, images of the deceased, periods of impaired concentration, and varying degrees of somatic and psychological disruption (Galloway, 1990; Malinak, Hoyt, & Patterson, 1979). Kahrl (1988) reports that middle-aged women continued to feel traumatized and devastated 2 years after the death of their mother, and were surprised by the depth of their pain and grief. King (1993), in an analysis of adult women who had been their mother’s caregiver, found patterns of grieving for changes in and fantasies about the relationship, loss of the daughter role, and loss of a future mother-daughter relationship. Matthisen (1989) found that adult women who placed their mothers in nursing homes experienced conflicts in balancing their own needs with those of their mother and grieved similar losses.

Questions about the duration of grief and the nature of symptoms have been central to the studies conducted to date. The findings provide some insight into the nature of the loss experience for adults after the death of a parent. However, the subjective mother-loss experience of women has not been described in depth within nursing. The purpose of this inquiry was to examine the phenomenon in some detail. The specific research questions were:

1. How do adult women experience the loss of their mother?
2. What meanings do they attach to the loss of their lifelong relationship with their mother?

Methodology

Phenomenological methodology was used to engage participants in reflection and explication of their experience of mother-loss (van Manen, 1990).

Sample

In order to achieve maximum variation in age, marital status, parity, and time elapsed since the mother’s death, a purposive sample of five women was selected from among respondents to an advertisement. The nature of this sample made possible an in-depth exploration of five unique stories of loss. The following profiles of the participants (using self-selected pseudonyms) describe the sample.

Avesia was a 56-year-old married professional woman with two grown children. Six years prior to the study, her mother had died of a heart attack at the age of 81 while Avesia was living in another country.
The qualities of their relationship included an emphasis on family history and tradition through storytelling and travel, with Avesia adopting her mother’s childrearing values and beliefs and following in her mother’s career path.

Barb, a 31-year-old university student, was married with a 17-month-old son. Her mother was 67 years old when she died of cancer, during the very hours when Barb was in labour and childbirth. Barb had grown up in a large family in which her mother functioned for many years as a single parent, expecting self-control and independence from her daughter. Barb described their relationship as distant and uncommunicative, although she began to grow close to her mother as she cared for her during her illness.

Cathy was a 44-year-old single woman living alone and working in a service industry. Her mother had died of cancer 11 years previously. Cathy was living with her mother at the time of her death. She had been highly dependent on her mother since the age of 18 when she began to experience multiple health challenges as a result of an accident. Their relationship evolved into one of friendship and mutual nurturing, with Cathy growing more independent throughout her mother’s final years.

Fiona was a professional woman in her 50s. Her mother had died of a heart attack at the age of 63, in a distant city, 20 years earlier. At that time Fiona and her husband were raising their young children. She described an abusive childhood and a strained mother-daughter relationship during her adulthood.

Jackie, a 44-year-old married woman, was the mother of four young children; her mother, a woman in her 80s, had died of cancer 2 months previously. Jackie had been a significant, nurturing presence during her mother’s 17-year illness. She had been living in a distant city for the last 5 years of her mother’s life.

Data Collection

Participants engaged in a process of dialogue that included written narratives on their relationship with their mother, two in-depth individual interviews ranging from 60 to 90 minutes, and a final group interview.

Prior to the first interview, participants were given a blank journal and asked to describe their relationship with their mother through narrative, poetry, photographs, and/or letters. Four of the five participants responded with narratives varying in length from two to 10 pages.
These were used as the first set of data, forming the basis for further exploration in the first interview.

Written consent was obtained. All interviews, which were videotaped, began with an open-ended, non-directive invitation for the participant to expand upon her narrative and to comment on her feelings, actions, and interactions with others during the course of her loss experience. For example, Avesia's journal entry included many powerful comments about her mother's care and support:

I remember feeling really important standing on a stool beside her helping to make cookies...she even used to play dolls with me.

This narrative became an important piece of data for exploration and elaboration whereby the interviewer could respond with:

You have described many examples of the ways in which your mother was a supportive influence in your life...tell me more about the ways in which your mother nurtured you as a young girl...

To facilitate dialogue, the interviewer used reflection, occasional self-disclosure, or brief descriptions of other women's experiences. The interviewer also asked, "What is life like for you now, without your mother's living presence?" The second interview was used to further explore and validate themes. All discussions were geared to the needs of the participants, whose well-being was the foremost concern (Munhall, 1988).

After all the interviews had been completed, a group session, also videotaped, permitted collective validation of the researcher's observations, interpretations, and descriptions. Participants were encouraged to elaborate on their experiences, challenge and/or validate the researcher's interpretations, summarize common themes, and comment on their role as participant in the research. These strategies are consistent with feminist narrative research, which strives to achieve the best possible account of collective experiences while honouring participants' unique stories (Benner, 1994; Hall & Stevens, 1991; Reissman, 1994; Russel, 1987; Webb, 1992).

Data Analysis

Interpretive analysis was used to study each case separately, beginning with the individual's narrative. Themes identified in the narrative were used to develop questions for the first interview. Data from each interview were then analyzed for themes under two broad categories: relationship with mother and experience of loss. During the second inter-
view, initial interpretations were clarified, themes explored in greater depth, and a more comprehensive understanding of the participant’s experience of loss elicited (Benner, 1994). Videotaping for subsequent review served to facilitate recollection and understanding of various significant moments in the interview. Thematic analysis across cases revealed commonalities of experience from one case to the next, permitting development of composite representations. Participants reviewed and validated their stories and initial data sets, prior to the group interview, and selected pseudonyms for presentation of their stories of relationship and loss. This combination of informal and formal participant validation served to promote authenticity (Sandelowski, 1993).

Findings

Participants experienced the loss of their mothers holistically, linking thoughts, feelings, and enactments of the mother-daughter relationship that extended from birth, through life, death, and beyond. Seven themes emerged from the data, as revealed in their stories.

Recalling

This theme set the context for women to uncover the nature of the primary attachment and affiliation with their mother, described specifically as mother’s caring and struggles of relationship.

Mother’s caring. Participants’ recollections and knowledge of how they were mothered from birth through to the time of their mother’s death provided poignant evidence of how the loss of their mother represented loss of their first relationship of caring, and thus loss of support, nurturing, protection, and security.

My mom listened, and accepted, unconditionally...encouraged us to do whatever we wanted...she was really motherly.... This support helped me through exams, difficult teaching situations, my sons’ minor illnesses and [my] marriage.

I went through a miscarriage and she was there for me and she really [crying]...she took me to the hospital.... And she really did care and went out of her way...you’re always like a little kid when it comes to your mom.

Struggles of relationship. Participants also recalled conflicts and concerns that reflected a tension between continuing the mother’s role of caregiving and changing the mother-daughter affiliation from a parent-child relationship to an adult-adult one. For example, Cathy’s
recolletion of her mother’s caring was also experienced as a barrier to her individuation:

Mom protected me so much I felt smothered and I couldn’t do anything about it.... My mom sheltered and protected me too much, held me back.

Fiona’s lifelong sense of hurt and abandonment was mixed with a strong need to seek her mother’s approval:

I never felt as if I did anything that pleased her...sometimes I think I could say I hated her, you know, I could feel that...but then I really wanted her approval. I remember feeling that. I really wanted her to say that I’d done something well.

The process of recalling the mother-daughter relationship during the grieving process thus revealed powerful and frequently discordant interpersonal dynamics that were essential to understanding the experience of loss.

**Holding On**

The experience of mother-loss was also permeated with a tendency to “hold on” (Chodorow, 1978). This appeared to be a component of the process of separation, one that took place gradually over time — interspersed with “letting go” (Chodorow) — and beginning as the inevitability of the mother’s death became apparent. As Barb described it:

...her mental capacities were failing, I had to do more for her.... I wanted her to look after me. I wanted my mother to help me throughout my pregnancy, I wanted her encouragement and advice.

Jackie held on to the relationship by continuing in her role as nurturer and enveloping herself in her mother’s scent:

[A]fter she died] I didn’t really want to leave her there but after I’d followed through with funeral home “pick up” arrangements and getting the ring...I was the one doing the matter of fact things the way Mom and I handled her cancer...got her clothes picked out and looked after what Dad would wear for the funeral. Mom knew I would be the one to do these things [crying].... I slept with her nightie on that night because it still had her “smell” on it.

**Saying Goodbye**

Participants ultimately experienced the “letting go” (Chodorow, 1978) dimension of their loss through “saying goodbye.” Jackie reflected:
...she breathed her last and I took her hand and said, "You're not alone" [sobbing]... We [she and her mother] were holding hands.... It was very peaceful to see her finished — finished with all that hard work.

For four of the women the funeral became an important part of the loss experience. Symbolic ways of saying goodbye provided comfort and relief.

Avesia: My sister and I placed the ashes in the grave. And it was just a really comforting feeling, it was sort of, "This is the last thing we can do for you," and it was really nice.

Longings of the Heart

Participants' descriptions of their loss experience over time included an uncovering of aspects of the mother-daughter relationship that they wished had been different. The diversity of these women's experiences of longing were represented in the sub-themes needing to know more, regretting, and missing her. These sub-themes reflected various dimensions of the mother-daughter relationship-building process, including elements of attachment, role identification, individuation, and same-gender intergenerational patterning.

Needing to know more. Avesia expressed a strong need to go back to the very beginning of her relationship with her mother, reflecting the central theme of her unique story of loss, in which she experienced a sense of abandonment:

I wanted to find out as much about my mom as I could.... During our last visit together I had a lump in my throat for a long time and I couldn't ask her, but I wanted to ask her, "Mom, what was it like when I was born?" But I couldn't, because I would have started to cry.... And I would like to know more about what it was like for her actually growing up.... I had a strong sense of abandonment.

Regretting. The collective experience of regret was clearly represented by Barb's longing to express her appreciation for her mother at a time when she herself was immersed in being a mother, an experience she had hoped to share with her mother.

I feel regret because I didn't like to listen to her advice. I thought that I knew it all. I didn't give her credit for her knowledge and experience. I wish...and regret not thanking her or telling her that I appreciated her concern for me. After becoming a mother myself, I now realize what sacrifices my mother had made for me.
Missing her. Avesia’s identification and affiliation with her mother was apparent in her longing to speak with her, in her missing the powerful primary relationship.

I think you have this connection with your mother that you don’t have with your father. I mean, even though I realized that I bonded with my father...I think your mother is still closer.... What I miss most is being able to just talk with her.

While participants reported that the day-to-day outward expressions of grief had, over time, changed to some extent, the longing remained. The intense need for attachment and affiliation with their mothers persisted long after the immediate sense of loss had faded away.

Shifting Patterns of Relationship

All participants identified, in the loss experience, changes in their relationships with significant others. The women assumed aspects of their mother’s former role with others, and others in turn dealt with their loss by responding accordingly to the surviving daughter. Family members grew closer to or more distant from each other throughout the grieving process. The experiences of relationship changes were captured in three sub-themes: dealing with magnified conflicts, taking care of others, and setting own needs aside. Participants described how others expected them to get on with life, which led them to the final sub-theme, gaining support.

Dealing with magnified conflicts. This theme described longstanding family issues. For example, Barb initially resented the expectation that she would, in her mother’s absence, assume the leadership role in the family, yet this was a role her mother would have expected of her.

It was just really my sister and I that kind of took over and helped my dad...they [her brothers] just couldn’t handle the situation...we get very upset at that sometimes because we feel like we’re doing all the family arranging...and they just kind of show up.

Cathy’s longstanding conflict with her siblings grew intense and disruptive as they settled their mother’s estate:

She was hoping her death would bring my brother and sister and I closer...it has made us even further apart....

Taking care of others. This sub-theme described the burden of becoming caregiver to a surviving parent and siblings. Jackie’s reflections are representative:
I had all this to do before I left, to make sure I got this will straightened out. I also had to get all the paperwork for my dad so he wouldn't have to worry. My other sister is doing well but I didn't know how much stress she could handle...

Setting own needs aside. This sub-theme described the outcome of managing the multiple tasks involved in caring for a surviving parent, mothering one’s own children, and returning to work. Barb’s experience had a direct effect on her relationship with her infant son, leading her to set her needs aside in order to manage. Her experience illustrates that of the women collectively:

I can remember when he [her son] was born and...I just couldn’t allow myself to like him...just real detachment there...I just didn’t want to get myself close to him because I was afraid that something would happen...I just had to put it aside...because people expect you to just get back into things....You had things to do and I’d do them...didn’t have time to talk with anyone about my needs.

Gaining support. This sub-theme described the ways in which the women received support from others:

Fiona: My other aunt...now is like a mother to me and like a grandmother to my children.

Avesia: One reason that I am able to work through it is that he [her husband] is able to be supportive now, where he wasn’t when my mother died...didn’t want me to talk about it....

Barb: It’s nice that she [her sister] has gone through motherhood and had two children and has lots of advice for me...we’ve really become closer [crying].

Jackie: The nurse put her arm around me as Mom passed away...and they stayed with us....They gave us our space and yet stayed....They went through it with us.

A re-patterning occurred in the lives of the women as they experienced and confronted conflicts, assumed multiple caregiving roles (similar in some cases to the roles their mothers had assumed), and, in order to manage multiple roles, set their own needs aside, gaining support from others in various ways. Integral to the collective experiences of gaining support were shifting relationships with family and friends or new associations with professionals that reminded them of their mother’s caregiving role in the mother-daughter relationship.
Recreating the Dialogue

The five participants portrayed the experience of mother-loss as one of maintaining affiliation; they perceived their mother's continued presence in their lives, reflecting the powerful spiritual dimension and intimacy of the mother-daughter relationship. The women spoke about physical sensations, hearing their mother's voice, and spontaneously "speaking with" their mother, either out loud or in their thoughts. Four sub-themes capture the diversity of participants' experiences of recreating their affiliation with their mother: sensing her presence, being like mother, keeping remembrances, and exploring family history and tradition.

Sensing her presence. The nature of their mother's continued presence closely resembled the nature of the mother-daughter relationship. For example, the ongoing "dialogue" that connected Cathy with her mother was represented by Cathy's identification with her mother's role as a seamstress, and manifested in her calling out to her mother for support:

I hear her voice: "If you don't do it [sew] with the utmost care and precision, you'll never be happy with the item you are creating"...

When I'm stuck sewing, and I'm working it out...I'm going, "Mom, what am I doing wrong?" and then I calm down and everything goes like clockwork.... So she is there.

Barb's longing to affiliate with her mother in her own new motherhood role was expressed through her awareness of her mother's presence, guiding her in caring for her infant:

I remember being totally exhausted one night, and I was sleeping and the baby was crying and all of a sudden I felt...somebody tugging my shoulder, like "Wake up. Wake up." And I opened my eyes and there was this figure...bending over and trying to wake me up, and it pointed toward the baby's room.... And I just said, "Oh, it's Mom."

Fiona's fear of her mother was expressed very powerfully:

I had this experience of smelling her perfume...this really strong sense came over me...similar to that experience I had when I heard her calling my name...this is her presence.

Being like mother. The women identified with their mothers. For example, Jackie identified physical features and character traits that she and her mother shared, while Fiona feared at times that she might repeat similar patterns of interaction with her own children:
Jackie: I look down and see my mother’s hands [holding out her hands and crying]. Only hers were longer — mine are fat. But when they’re working [long pause] they’re her working hands, you know [crying].

Fiona: I catch myself sometimes, being my mother. And I find that very disturbing...why did I do that, why did I say that?...

**Keeping remembrances.** The women used tangible remembrances to keep their mothers near.

Barb: I wear this [necklace] practically all the time. I hardly ever take it off...

**Exploring family history and tradition.** This sub-theme was most powerfully illustrated in Avesia’s reference to snowdrops and travelling to her mother’s homeland, reminding her of and affirming the mother-daughter bond.

Snowdrops have come to symbolize my mom for me...when we got back after her memorial service the snowdrops were out.... We’ve planted snowdrops in our back yard now... Here was a whole country of soft-spoken, old-fashioned people just like my mother...it was exactly as my mom had described it and I recognized my great-grandparents’ house.... I had a lump in my throat the whole time...we climbed to the top of Blarney Castle so my dad could kiss the Blarney stone...a family tradition.

A strong sense of continued need for identification with and attachment to their mother was apparent in the stories. This might be viewed as an important part of the process of individuation for adult daughters whose mothers have died.

**Honouring Our Mothers/Ourselves**

The participants’ insights reflected the ways in which they had found meaning in and learned from their experience of loss. They described having come to more deeply appreciate their mothers’ lives and at the same time undergoing a personal transformation as they developed new perspectives on their own lives as women. This final theme may be described as the process of finding positive, enduring meaning in the mother-daughter relationship, through honouring the unique value of their mothers and themselves. Two sub-themes were apparent: giving voice to her story and celebrating change.

**Giving voice to her story** described the ways in which participants gained a more intimate awareness of their mothers’ hardships, vulnerabilities, and resiliency, and a deeper appreciation for their mothers as women. Fiona, for example, grew aware of her mother’s hardships, and
this enabled Fiona to move forward in her own life, having gained strength and a capacity for healthier relationships.

I know she had a lot of needs.... And I feel badly that I didn't really ever know her...my life is so opposite — it's like night and day to what hers was. My relationship with my kids and my husband and all of us together, like it's just so, so different. In some ways maybe I have her to thank for that because maybe I learned how I didn't want it to be.

Barb expressed her appreciation for her mother as she learned about some of the challenges of raising children:

After becoming a mother myself, I now realize what sacrifices my mother had made for me and my brothers and sisters.... I can see that now...she was a very strong person, very hard-working and independent.

Celebrating change. This sub-theme described how participants transformed the experience of loss into one of honour and celebration; contained within their stories were statements of acceptance, resolution, hope, positive change, and self-transcendence.

Fiona: I make a conscious effort to try and do things differently because I can remember the pain that I felt as a child and as a young adult in my relationship with my mother, and...I just didn't want to have that kind of a relationship with my own family...

Barb: Really, I've learned a lot since then you know.... I seem to take her advice more seriously now....There's lots to be said for your own experience.... I used to take life for granted...not now.

Cathy: I have more control over myself now.... At one time I couldn't do any of this...so why not take this course [dress-making]! It will keep me busy and it will update my diploma...she would sure be pleased with what I accomplished.

Jackie: ...the whole process up to this day is helping me work through things...even to look into other things in my life...you're stopping and evaluating what you're doing...and if I should be changing...I'm thinking more of living for today.

Ayesha: So there are resolved issues and they feel more comfortable...and what it does is you gain understanding. It's very healing.

The women in this investigation had apparently achieved more mature individuation, coming to appreciate their own lives and to see the possibility of enjoying life in the present. They had expanded their relationships with others, while maintaining a sense of connectedness through an awareness of their mother's abiding presence in their lives. They used fond memories and both tangible and symbolic remembrances of their mother to maintain intergenerational identification and attachment in the mother-daughter relationship. Simultaneously,
however, as they gained new insights and knowledge of their mother as an inner presence in their lives, they had come to terms with their loss and were able to draw upon their mother’s life to find and celebrate new meanings and directions in their lives.

Discussion

The findings of this study reveal the relevance of relationship in women’s experience of mother-loss. For the participants, the experience entailed recreating the relationship by recalling their mother’s care and merging past and present — or their childhood and adulthood experiences. While for these women the loss constituted the painful removal of their role as child, the experiences they recalled as part of the grieving process were those of daughter; these memories served to either reconnect them to the experience or force them to work through the more negative aspects of the recollections. This recreation of the relationship facilitated the evolution of the grief process into a state of further personal individuation in an enduring connectedness that honoured both mother and self.

Defining self in connection with and separate from others has been a focus of feminist research. In their early work, Gilligan (1982) and Chodorow (1978) contended that the feminine personality is defined in relation to others — particularly the mother. More recently, researchers have demonstrated the ability of women to be both connected to and separate from others, depending on their role in the relationship. In Attanucci’s (1988) study of women’s descriptions of self, women described relationships that much more closely characterized interdependence than autonomy or separation. The participants in this study described their relationship with their mother as ongoing, extending beyond role identification, similarities, and differences.

While the literature indicates that daughters often sustain, well into their 40s, a sense of their function as “child” in the mother-daughter relationship (Fischer, 1986), the findings of this study suggest that for adult women the grieving process intensifies the experience and, perhaps, hastens resolution of the conflict associated with the role of child in the adult mother-daughter relationship. A similar phenomenon is identified by Fischer (1986), who found that daughters intensely engaged both instrumentally and emotionally in mother-daughter relationships, by virtue of assuming the caregiver role of “mutual mothering” (p. 195–196), and similarly conveyed a sense of “holding on” while simultaneously allowing the relationship to evolve. This powerful connection between loss and development has been identified by theorists.
Gilligan (1982) notes the value of preserving the relationship, and Caffarella and Olson (1993), summarizing the work of several theorists, observe that individuation must be accompanied by feelings of connectedness and affiliation in order for development to occur. Gleason’s (1991) research into the mother-daughter relationship supports this stance, the author noting that all experiences must be accepted as reflecting core aspects of women’s development, and not labelled as pathological or dysfunctional. Judith Viorst (1986) describes this link between loss and development:

The road to human development is paved with renunciation. Throughout our life we grow by giving up. We give up some of our deepest attachment to others. We give up certain cherished parts of ourselves. We must confront, in the dreams we dream as well as in our intimate relationships, all that we never will have and never will be. (p. 16)

The findings of this study add significantly to Bowlby’s (1973) work on attachment and grief theory. The nature of attachment and relationship varied among the participants in this study, in keeping with the complexities unique to their relationships. Bowlby’s model of grief, characterized by a set of stages including shock, protest, apathy, despair, and detachment, arose from his theory of childhood attachment. His model characterizes grief as a process in which detachment is an essential step in reorganizing one’s life, allowing one to form new attachments in the absence of the deceased. Themes of abandonment and processes of detachment were observed as part of the grief response for some of the women in this study. However, Bowlby’s theory, like other traditional grief and loss theories, limits one’s experiences to a single reality or set of stages. Such theories do not sufficiently explain the subtle experiences of loss, which continue over time, as illuminated by this study in which the women recreated and transcended their relationships with their mother. Consistent with the findings of several researchers (Galloway, 1990; Kahl, 1988; Kerr, 1994; King, 1993), this study found that the women experienced a sense of trauma and devastation, images of the deceased, grieving the loss of the daughter role, feelings of regret, anticipatory grief, and shifts in family relationships. Beyond that, however, the experience of grief was marked by the significance the loss of the mother-daughter relationship had in the women’s own experience of development.

The findings of this study strongly support more recent views of grief. Kaplan’s (1995) interpretation of loss and grieving expands upon earlier attachment theory by viewing loss as an emotional process embodying the vitality of the human spirit, rather than death, with its connotations of decay, finality, and terminated relationships. Kaplan
suggests that individuals form attachments through human dialogue — in the intimacy between parent and child — and that once they have entered into that dialogue they cannot live without it. The findings of this study support Kaplan's view that mourning entails not only detachment and a gradual letting go of the deceased, but also a powerful affirmation of attachments. Since the mother-daughter relationship involves two women whose identities and life experiences tend to be strongly linked, mother-loss may include a subtle sense of self-loss that is not easy for women to articulate or understand. As the women in this study responded to their loss by recalling their mother's care and their relationship struggles, and as they experienced a strong sense of longing and changes in their other relationships, they recreated a semblance of their relationship with their primary caregiver — their mother. The formation of their mother as an ongoing presence in their lives constituted the full work of mourning as the women rebuilt their inner worlds and continued on with their own development as women.

Implications for Nursing

Nurses caring for women experiencing mother-loss face a multifaceted challenge. Theories used to guide nursing care for the grieving person focus narrowly on working through the loss. While approaches to care that reject assumptions about "normal," time-limited grieving have gained widespread acceptance in clinical practice (Carter, 1989; Edmonds & Hooker, 1992; Harvey, 1996; Joffrion & Douglas, 1994; Kaplan, 1995; Solari-Twadell, Schmidt Bunkers, Wang, & Snyder, 1995), attention to interactions specific to the mother-daughter relationship has been lacking.

To maximize their care of adult women who have lost their mother, nurses must reframe their supportive care to help the bereaved woman resolve the loss of a relationship that uniquely challenges her own self-image and development. Furthermore, nurses must extend their efforts beyond supportive care, to health promotion. These nursing efforts are inextricably linked; specific elements of nursing intervention may simultaneously embrace both facets of care if framed and undertaken within this more holistic understanding of the woman's experience of mother-loss.

Care might begin with helping the woman to explore the links between the experience of loss and the nature of her lifelong relationship with her mother. The nurse must explore patterns of mother-daughter relationship in the context of the woman's life, helping her to understand the influences that have contributed to her unique sense of
loss. This requires fully eliciting the woman's story while making her aware that dealing with this particular loss has implications for her own sense of self. For example, nurses might help women who have had conflictual or abusive mother-daughter relationships to understand and normalize their feelings of anger and detachment as a legitimate way of resolving a negative relationship rather than seeing them as merely a phase of grieving. Women may need frequent opportunities to discuss their feelings and to understand that themes of abandonment may date to their early childhood. Women who have experienced a negative mother-daughter relationship may remain hopeful throughout their lives that positive attachment will occur (Kaplan, 1995). For these women, mother-loss not only represents the loss of hope for the relationship, but also affords them a chance to learn and grow, fostering more positive roles and relationships. Other women, by contrast, may need to work through positive aspects of the relationship that they have internalized as reflecting an extension of their mothers in themselves. Regardless of her particular experience, every woman who has lost her mother will need help in resolving the role conflict associated with being her mother's child versus being an adult and an individuated extension of her mother.

By responding to a range and depth of feelings, nursing can promote health and healing, helping each woman to understand both the nature of her relationship with her mother and the links between personal growth, development, and health. The first step is helping the woman to view health as part of her consciousness (Newman, 1986) and health promotion as her own personal resource for everyday living (Ford Gilboe, 1994; McWilliam, 1993; McWilliam, Stewart, Brown, Desai, & Coderre, 1996). Helping women to achieve greater individuation by better understanding themselves in the context of their mother-daughter relationship is the essence of comprehensive health promotion in the context of this grief experience.

Interventions to facilitate this development can take place in the context of a long-term therapeutic relationship in either a community or a clinical setting. More immediate needs may be seen around the time of the death as the woman attempts to hold on to the relationship, immersing herself in the role of caregiver. A woman who was not present for her mother's death may benefit from a description of the measures used to comfort and support her mother. Focusing on the multiple roles that daughters often assume and encouraging self-care activities will facilitate the grieving process. By recognizing the tendency of some women to set their own needs aside, nurses can facilitate healing and promote health; they might encourage the woman to
address her loss, to talk about what life has been like for her. Nurses can also refer women to community support groups where they will be able to share their stories of relationship and loss. Symbolic “goodbyes” can be used to facilitate a “letting go” of the mother’s physical being. By presenting the phenomenon of sensing the mother’s presence as a valid response to the loss, nurses can facilitate the process of recreating the relationship as an inner presence. Finally, giving voice to her mother’s life story may reveal new strengths and insights in a woman’s own development. The Appendix consists of a summary of proposed theme-related nursing interventions.

Conclusion

The findings of this study illuminate both the scope and the breadth of nursing opportunities in caring for women grieving the loss of their mother. Integral to the profession’s commitment to caring are concepts and skills that describe the ways in which nurses care for people experiencing significant loss. “Presence,” a concept that represents the ways in which nurses attend to the fundamental need for human contact in health and illness situations, reflects purposeful action, meaningful dialogue, and a spiritual dimension of care (Allanach & Golden, 1988; Benner, 1984; Benner & Wrubel, 1989; Brown, 1986; Chinn, 1991; Cohen, Hausner, & Johnson, 1994; Dietrich, 1994; Eakes, 1993; Montgomery, 1992, 1993; Pederson, 1993; Samarel, 1991; Swansen, 1993). A nurse’s presence in caring for women experiencing mother-loss must extend beyond anticipating and attending to the loss and being there for the death; it must encompass an understanding of the mother-daughter relationship and facilitate discussion of what losing, resolving, and recreating that relationship mean to the woman. The nurse’s presence extends to working with the woman over time as she explores personal development in response to the loss. The findings of this study support the essential health-promoting functions of exploring the nature of the mother-daughter relationship and helping the woman to resolve and recreate the mother-daughter connection, thereby transforming the loss into an experience of personal growth.

These findings challenge nursing researchers to consider further inquiry in the area of loss and bereavement. A clear limitation of this study was the cultural homogeneity of the participants, all of them belonging to a culture in which open discussion of grief and loss was the norm. Investigations of the loss experience for women whose mothers died during their infancy, childhood, or adolescence would also further inform nursing practice. Given this study’s illumination of
the ongoing nature of loss, researchers might examine the experiences of one or two women over an extended period, in search of patterns and transitions. Exploring the experiences of nurses who have cared for women throughout their loss would further explicate how practice might be refined. Clearly, if nurses are to fully develop their role in caring for women, much is to be learned from understanding the depth and breadth of mother-loss as an enduring experience of recreating relationship and meaning.

References


# Appendix  A Nurse's Presence with Women

## Grieving the Loss of Their Mother

### Being There: The Time of Initial Loss
- Attend to daughters as caregivers who have personal needs, and set aside time to discuss these needs.
- Facilitate communication between mother and daughter and convey your availability.
- Anticipate daughter’s need to intensify involvement with mother; she may not wish to leave bedside.
- Anticipate mother’s disengagement and support daughter through this process.
- Survey daughter’s need for respite care, acknowledging her multiple duties at work and at home.
- Care for mother and inform daughter of events; offer insights into her mother’s experience.
- When daughter is not present for mother’s death, offer to tell her about her mother’s passing.

### Responding to the Immediate and Ongoing Grief
- Consider ways in which we encounter women’s stories of loss: as caregivers at their mother’s bedside, in the community, during women’s contact with the health-care system.
- Provide opportunities for women to tell their stories of loss and legitimize their grief experience as one that extends beyond the loss of an individual to one of loss of a primary relationship involving one’s own self.
- Acknowledge the potential depth of loss; do not dismiss the loss as a life-course event.
- Explore shifts in other significant relationships.
- Link women to community supports and counselling resources according to their expressed needs.

### Exploring the Nature of the Mother-Daughter Relationship
- Set aside assumptions about the nature of the mother-daughter relationship and explore the nature of attachment and affiliation.
- Recognize that the experience of loss is embedded in the nature of the relationship and is shaped by family context, new relationships, and changes in women’s role in society.
- Consider developmental and contextual issues when helping women to find meaning in their experience, and explore the meaning of the loss in their larger life context.
- Determine the inextricable links between the identities of mother and daughter.
- Explore the nature of longing and lost hope in the mother-daughter relationship.
Helping Women to Recreate the Dialogue of the Mother-Daughter Relationship

- Explore how women conceptualize the finality of their mother’s death.
- Normalize and legitimize their experiences of sensing the mother’s presence as spiritual connections are explored.
- Help women to incorporate these experiences when forming an “inner presence” of their mother.
- Encourage women to comment on mother-daughter similarities and differences.
- Encourage women to retain and initiate rituals of remembrance.
- Keep in mind that disclosure of painful memories may require the skilled and supportive presence of a caring other over time.
- Create an environment of support and acceptance, and facilitate links with other women.

Transforming the Loss

- Engage women in reminiscence about the joys and sorrows in the relationship.
- Encourage women to tell their mother’s stories and make links with their grief experience.
- Explore aspects of loss that are positive, that tell the women something about their mothers and themselves throughout the loss; determine changes they would like to see in their own lives.
- Acknowledge the potential that exists for women to broaden their definition and sense of self as women.
- Celebrate women’s capacity to separate themselves from, yet remain connected with, their mothers and significant others.
- Identify the potential for honouring their mothers and themselves as women.
- Offer support for women to embrace new directions in their lives.
- Encourage women to reach out to each other.
- Consider specific strategies such as support circles, guided imagery, prayer, art therapy, and narrative writing about their experiences of relationship and loss.
Measuring the Care Needs of Mothers of Children with Cancer: Development of the FIN-PED

E. Marilyn Goodyear Whiteley, Linda J. Kristjanson, Lesley F. Degner, Rochelle Yanofsky, and Bryan Mueller

This 2-phase study tested the Family Inventory of Needs-Pediatrics (FIN-PED), a 52-item instrument structured to include 2 subscales, the first measuring the importance of care needs and the second measuring the extent to which needs were met. In Phase I, an expert panel of 6 mothers of children with cancer rated the tool for clarity, apparent internal consistency, and content validity. All items met preset criteria for these assessments. In Phase II, 110 mothers rated the instrument for internal consistency reliability, stability over time, and internal construct validity. Both subscales achieved an estimated internal consistency of 0.94. Evidence of the instrument's stability over time was also achieved. Factor analysis resulted in 4 interpretable factors, suggesting that the tool is multidimensional.

Each year in Canada approximately 912 children are diagnosed with cancer (National Cancer Institute of Canada/Statistics Canada, 1998). Despite vast improvements in treatment outcomes, malignant diseases...
remain the second leading cause of pediatric deaths (Aitken & Hathaway, 1993). Approximately 67% of children diagnosed with cancer will survive beyond 5 years (Bleyer, 1993). However, these children will minimally require an annual assessment for recurrence of the original disease and may develop late side effects of treatment, which can include second malignancies and mental and cognitive changes. Parents are continuously challenged in coping with various levels of uncertainty and the demands imposed by different phases of the illness. Family members of a child with cancer face many stressful events over an extended period and experience many needs. A review of the pediatric literature from November 1983 through May 1996 suggests that health-care providers are sensitive to the needs of parents whose children are diagnosed with cancer (Foster, Hunsberger, & Anderson, 1989). The literature describes parental needs as honesty, support, and information about their child's condition; involvement in the care of their child; and participation in decision-making concerning treatment (Shields et al., 1995; Williams, 1992). There are few studies that document the use of a reliable and valid instrument for measuring these parental needs. This study was designed to address this gap.

Both mothers and fathers are affected by and involved in the care of their child. However, the literature indicates that most often mothers are the primary caregiver in cases of pediatric cancer, and that when both parents provide care they may be at different stages of adaptation and have different needs (Hayes & Knox, 1983). Given the lack of research in this area, it was judged useful to focus on one group of parents for the development and testing phase of the research program. Therefore, the purpose of this first study was to develop an instrument to measure the care needs of mothers whose children have been diagnosed with cancer. After further validation of this tool, studies to assess the reliability and validity of the instrument for use with fathers and siblings will be carried out.

Review of the Literature

A review of the empirical pediatric literature prior to the study (November 1983 through May 1996) revealed that few studies addressed the care needs of families of children diagnosed with cancer. Wittrock, Larson, and Sangren (1994) investigated coping strategies and self-reports of psychological adjustment in parents of children with cancer ($N = 17$) using an interview format. This information provided descriptions of the types of needs that might have relevance in the construction of a needs-assessment tool.
Measuring the Care Needs of Mothers of Children with Cancer

Shields et al. (1995) studied the psychosocial needs of pediatric cancer families from the perspective of social workers. The Family Needs Survey (Bailey & Simeonsson, 1988) used in that study had been developed to assess the functional needs of parents of young children with a handicap, a distinctly different group from those with cancer. Therefore, although their results provided information about the types of concerns parents might have, use of the tool for parents of children with cancer was judged to be limiting and unlikely to elicit the range of concerns specific to this population.

Sloper (1996) investigated parents' satisfaction with services and support and the effect on family life at one specific time, 6 months post-diagnosis. Parents' responses to the diagnosis and treatment of cancer in the early months were evaluated using a non-specified semi-structured interview method. Results confirmed that this early period is extremely stressful, but Sloper did not provide an instrument for subsequent testing.

The literature review uncovered no evidence of a psychometrically sound instrument to measure mothers' needs in a pediatric-care situation. Therefore, the search was widened to include studies describing family needs of adult cancer patients, in the hope of identifying a reasonable tool. Four studies were found.

Tringali (1986) asked 25 family members of adult cancer patients to rate the order of importance of 53 needs statements using a four-point Likert scale. Information needs were found to be most important; however, no psychometric estimates of the tool were reported.

Longman, Atwood, Sherman, Benedict, and Shang (1992) used a descriptive design to measure the needs of home-based adult patients as assessed by both the patients (N = 30) and family caregivers (N = 29). Needs were measured using the 114-item Patients' Needs Scale and the 90-item Caregivers' Needs Scale. This instrument gave promising psychometric results; however, it was considered too long for use with the present study population and was not specific to pediatric care.

Wingate and Lackey (1989) used an open-ended instrument, the Objects Content Test, to assess the care needs of adult cancer patients and their families. Content analysis of needs statements revealed that psychosocial needs were the most important to both patients and family caregivers. Participants were not asked to report the extent to which their needs had been met. This method required time-consuming qualitative analysis and was not specific to pediatric care.
The 20-item Family Inventory of Needs (FIN) developed by Kristjanson, Atwood, and Degner (1995) measures both the importance of care needs to a family member and the extent to which these needs have been met. This tool has been found to be simple and practical for use with stressed populations. Reasonable internal consistency estimates (0.83, 0.85) and content and construct validity estimates have been reported (Kristjanson et al.). Therefore, a decision was made to use the FIN as the basis for developing a tool to measure the care needs of mothers of children with cancer.

**Conceptual Framework of the Instrument**

The original Family Inventory of Needs (FIN) was developed based on *Fulfilment Theory* (Schaffer, 1953; Vroom, 1964). According to this theory, satisfaction is a function of the extent to which a person’s needs are met (Schaffer). The existence and perception of needs and needs fulfilment are hypothesized to be antecedents to the judgement regarding satisfaction with care.

The FIN was designed to measure two constructs: Importance of Family Care Needs and Fulfilment of Care Needs. Importance of Family Care Needs is defined as the family member’s perceived importance of needs for professional care. This is conceptualized as a continuum ranging from “extremely important” to “unimportant.” Fulfilment of Care Needs is defined as the judgement by a family member of whether his or her perceived needs have been met by health professionals. This is conceptualized as three items: “met,” “partly met,” and “unmet.”

These definitions were refined for the purposes of this study. Mothers’ Care Needs was defined as the needs that mothers identify related to their child’s cancer. Fulfilment of Care Needs was defined as the extent to which mothers reported that their needs had been addressed by health professionals.

Content in the original FIN was based on Molter and Leske’s (1983) Critical Care Family Needs Inventory (CCFNI) and Tringali’s (1986) use of the CCFNI with families of advanced cancer patients. Kristjanson et al. (1995) refined the CCFNI based on qualitative research results to index more precisely the needs of family members of advanced cancer patients. This 20-item tool was augmented and refined based on a review of pediatric literature specific to the care needs of family members of children with cancer. Fifteen of the 20 FIN items were minimally changed and the wording of five items was modified to better reflect the needs of one particular mother of a pediatric cancer patient.
Following a careful literature review, another 20 items were added. This augmented and modified tool was named the FIN-PED, to reflect both the core items in the original FIN and the added items in the adapted FIN. The researchers reasoned that the addition of “PED” would make the tool easily identifiable for use with pediatric populations.

Method

Ethical approval was obtained from the Ethical Review Committee of the University of Manitoba Faculty of Nursing and access approval was obtained from the Manitoba provincial cancer centre. Participants were assured that their names and responses would be kept confidential. Demographic data and instrument responses were identified only by numerical code. Data and codes were stored separately in a locked file accessible only to the researchers and research staff.

Phase I

The testing process used for Phase I was based on Imle and Atwood’s (1988) method for assessing the validity and internal consistency of inductively generated instruments. This method involves a three-part psychometric assessment. Each item is rated for clarity, apparent internal consistency, and content validity. This rating sequence ensures appropriate and logical responses to questions. For example, clarity of items must be established before the rater can assess apparent internal consistency. Participants were asked to evaluate the extent to which items in the instrument were clearly worded, belonged together, and actually measured the needs of mothers of children with cancer.

Sample and selection criteria. Six mothers were recruited from a Canadian pediatric cancer centre to review the FIN-PED. Participants were 18 years of age or older and were able to read and write English. Excluded were mothers of children diagnosed within the preceding 2 months and mothers whose children had died.

Testing criteria. Criteria developed by Imle and Atwood (1988) were used to assess the responses. Agreement of 83% (i.e., 5 of 6 mothers rating the item acceptable) was preset as the minimum. This criterion is based on calculating the proportion of experts who might agree, out of the total number planned for use, and then setting the standard error of the proportion to identify the cut-off for chance versus real agreement. According to Lynn (1986), this computation allows the researcher to establish a necessary level of percentage agreement at a .05 level of significance.
Clarity of items. Clarity, the first rating procedure, consisted of two parts: rating the clarity of the scale instructions and rating the clarity of the scale items, as either “clear” or “unclear.” Raters were asked whether the instructions clearly explained how to complete the scale. They were then asked whether each item in the scale clearly described a need. Space was provided for comments, and time was allotted for discussion of comments. Raters’ decisions and comments regarding clarity, format, and reading level were incorporated into the instrument.

Clarity of the instructions and clarity of the items were rated separately. All participants rated the instructions as clear. Five participants rated all items as clear and one participant rated two items as unclear. This level of agreement met the preset criterion of 83% for the directions and all items on the questionnaire. The first item rated as unclear was “be allowed to discuss the terminal stage of my child’s illness.” The words “terminal stage” concerned one mother because, to her, they suggested that a terminal phase was inevitable and this did not apply to her child’s diagnosis. This concern was apparently related to the sensitive nature of the item rather than to its clarity. In the revised version of the FIN-PED, a statement was added to acknowledge the sensitive nature of this question. The second item rated as unclear was “have health care professionals guide me in setting limits for my child.” This item was edited by changing the ending to “limits for my child’s behaviour.” No other items were rated as unclear; however, the participants did suggest a few small wording changes — for example, the phrase “depending on child’s age” was added to those items that concerned information-sharing with children.

Apparent internal consistency. Imle and Atwood (1988) define “apparent internal consistency” as the degree to which all scale items group together — that is, homogeneity of content. Respondents were first asked to indicate whether the items in the questionnaire belonged together. All respondents answered affirmatively. Respondents then rated whether each question belonged in the questionnaire. All respondents verified inclusion of each item. This level of agreement met the preset criterion of 83% for the items of the instrument.

Content validity assessment. Content validity assesses how well and how adequately items express the meaning of the conceptual domain without redundancy. Three questions were posed: (1) “In general, does the label and definition of the scale fit the whole set of scale items?” (2) [with respect to each individual item] “Does the item belong to the label and definition?” (3) “Is each item on the question-
naire unique (i.e., not repetitious)?” There was 100% agreement that the label and definition fit all items and no items were judged repetitive.

The last part of the pilot-testing procedure offered participants an opportunity to suggest additional needs. This step resulted in the addition of 12 items (see Table 1). A content analysis of these additional items revealed three general categories of need: needs of the ill child and siblings, needs related to health professionals, and practical needs related to understanding the health-care system. Mothers were firm in their opinion that the additional items should be included. The refined FIN-PED tested in Phase II comprised a total of 52 items (see Appendix).

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Additional Needs Identified by Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs Category</td>
<td>Item</td>
</tr>
<tr>
<td>Needs of the Ill Child and Sibling(s)</td>
<td>- know how to handle my child’s feelings</td>
</tr>
<tr>
<td></td>
<td>- have my child participate in decisions about his/her care (appropriate to his/her age)</td>
</tr>
<tr>
<td></td>
<td>- know how to handle the feelings of my other children</td>
</tr>
<tr>
<td></td>
<td>- know that health-care professionals accept my child even when he/she is angry</td>
</tr>
<tr>
<td></td>
<td>- know that where appropriate health-care professionals will ask my child’s permission to do things to my child</td>
</tr>
<tr>
<td>Needs Related to Health Professionals</td>
<td>- know that the knowledge of health-care workers fits my child’s needs</td>
</tr>
<tr>
<td></td>
<td>- know to whom I should direct my questions</td>
</tr>
<tr>
<td></td>
<td>- know to whom to turn if conflict situations arise</td>
</tr>
<tr>
<td>Practical Needs Related to the Health-Care System</td>
<td>- know where things are in the hospital</td>
</tr>
<tr>
<td></td>
<td>- know where things are in the city</td>
</tr>
<tr>
<td></td>
<td>- know where to park at the hospital/clinic</td>
</tr>
<tr>
<td></td>
<td>- have financial assistance to help cope with the costs of my child’s illness (parking, food, transportation, medicine)</td>
</tr>
</tbody>
</table>
Phase II

Three research questions were addressed in this phase: (1) To what extent does the FIN-PED evidence internal consistency? (2) To what extent does the FIN-PED evidence stability over time? and (3) To what extent does the FIN-PED evidence internal construct validity?

Sample. Mothers were selected from the same pediatric cancer centre used for Phase I, using the same selection criteria. A list of children diagnosed with cancer during the previous 10 years was compiled by clerical staff at the centre. Two mail-outs were made 2 weeks apart: the protocol was mailed to 250 mothers; 44% (N = 110) returned the first questionnaire, and 50 mothers who had completed the first questionnaire returned the retest questionnaire.

Demographic information about the mothers was obtained from 106 of the 110 respondents (see Table 2). The typical mother was under

| Table 2  Demographic Profile of Mothers (N = 106) |
|-----------------|-----------------|-----------------|
| Characteristic  | Frequency       | Percentage      |
| Age             |                 |                 |
| < 40 years      | 69              | 65              |
| ≥ 40 years      | 37              | 35              |
| Marital Status  |                 |                 |
| Single          | 12              | 11              |
| Not single      | 94              | 89              |
| Education Level*|                 |                 |
| Less than high school | 26          | 25              |
| High school     | 27              | 26              |
| College/vocational training | 26         | 25              |
| Undergraduate degree | 12        | 11              |
| Graduate degree | 13              | 12              |
| Occupation³     |                 |                 |
| Teacher         | 10              | 9               |
| Nurse           | 8               | 8               |
| Other profession| 9               | 9               |
| Clerical        | 14              | 13              |
| Other job       | 31              | 29              |
| Not working     | 33              | 31              |
| Distance from Urban Centre |       |                 |
| > 240 km        | 24              | 23              |
| 100–240 km      | 15              | 14              |
| < 100 km        | 14              | 12              |
| Urban residence | 53              | 51              |

*Totals for education (n = 104) and occupation (n = 103) are less than 106 due to missing data.
40 years of age (65%), either married or living in a common-law relationship (89%) in an urban dwelling (51%). Approximately 51% had not been educated beyond high school; 69% were employed outside the home.

Demographic and medical information about the children was provided by 109 mothers (see Table 3). The two most frequent disease categories represented were malignant solid tumours (37.4%) and leukemias (36.4%). The mean age of the children at the time of the survey was 11 years. Gender distribution was almost even. Most children had a history of hospital admissions related to cancer treatment or complications (e.g., fever, neutropenia, infections).

Table 3  Frequency and Percentage Distribution of Children’s Illness Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malignant solid tumours*</td>
<td>40</td>
<td>37.4</td>
</tr>
<tr>
<td>Leukemia</td>
<td>39</td>
<td>36.4</td>
</tr>
<tr>
<td>Brain tumour</td>
<td>10</td>
<td>9.3</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>16.8</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>55</td>
<td>50.0</td>
</tr>
<tr>
<td>Male</td>
<td>54</td>
<td>50.0</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–5 years</td>
<td>25</td>
<td>22.9</td>
</tr>
<tr>
<td>6–10 years</td>
<td>29</td>
<td>26.6</td>
</tr>
<tr>
<td>11–15 years</td>
<td>32</td>
<td>29.6</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>23</td>
<td>21.1</td>
</tr>
<tr>
<td>Number of Hospital Admissions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–4</td>
<td>44</td>
<td>45.8</td>
</tr>
<tr>
<td>5–19</td>
<td>36</td>
<td>37.5</td>
</tr>
<tr>
<td>&gt; 20</td>
<td>16</td>
<td>16.7</td>
</tr>
<tr>
<td>Reason for Hospital Admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Original diagnosis</td>
<td>41</td>
<td>6.4</td>
</tr>
<tr>
<td>Treatment</td>
<td>300</td>
<td>56.0</td>
</tr>
<tr>
<td>Relapse</td>
<td>5</td>
<td>0.8</td>
</tr>
<tr>
<td>Other</td>
<td>237</td>
<td>36.9</td>
</tr>
</tbody>
</table>

*excludes brain tumours.
Testing criteria. Internal consistency reliability was assessed using Cronbach’s standardized alpha coefficient. A criterion of 0.70 was preset as the minimum for internal consistency, which is considered acceptable for a newly developed instrument (Nunnally & Bernstein, 1994). As well, Carmines and Zeller (1989) suggest that 50% of item-to-total correlations should be between 0.40 and 0.70. Scores above 0.70 indicate redundancy and scores below 0.40 indicate that the item may not contribute information about needs parallel with other scale items. Test-retest reliability was also assessed. A correlation of at least 0.70 was preset as the criterion for satisfactory test-retest reliability (Nunnally & Bernstein).

Determination of the number of scale factors obtained from the factor analysis involved examination of the scree plot (graph of eigenvalues) and an expectation that interpretable factors would have eigenvalues of at least 1.0 (Kim & Mueller, 1988; Wood, Tataryn, & Gororsuch, 1996). Criteria for deciding which items to include in each factor were item loadings of greater than 0.40 on the factor, with a difference of at least 0.15 between loadings on different factors (Kim & Mueller).

Results

The possible range for the needs items was 1 to 5 (1 = not at all important; 5 = very important). The range of means for the needs statements was 2.94 to 4.94 with standard deviations between 30 and 1.72. For most items, the scores were slightly negatively skewed. The possible range for the Needs-Met subscale was 1 to 3 (1 = met; 2 = partly met; 3 = unmet). The range of means for the Needs-Met subscale was 1.07 to 1.85 with standard deviations between 0.26 and 0.81. Needs-Met items had slightly positively skewed distributions, indicating that most needs had been met or partly met.

Internal Consistency

The Importance of Needs subscale achieved an internal consistency estimate of 0.94 (time 1), as measured by Cronbach’s standardized alpha coefficient — well above the criterion of 0.70. The total score on the Importance of Needs subscale was also correlated with each item score. Thirty-eight of the 52 items (73%) on the Importance of Needs subscale achieved item-to-total correlations between 0.40 and 0.70. This is well above the preset range of at least 50% of items within this range. No items had item-to-total correlations greater than 0.70.
The Needs-Met subscale of the FIN-PED instrument achieved an internal consistency estimate as measured by Cronbach's standardized alpha coefficient of 0.94 — well above the criterion of 0.70. Sixty-nine percent of the items on the Needs-Met subscale achieved item-to-total correlations between 0.40 and 0.70. This is also above the preset criterion of at least 50% of items between this range. No items had item-to-total correlations greater than 0.70.

**Stability over Time**

Fifty of the 110 respondents completed and returned the retest questionnaire. Because of this relatively small sample size, a nonparametric correlational statistic was used to assess stability over time. A Spearman's correlation coefficient of 0.78 (p = 0.008) was obtained, indicating that the scale was stable over this tested time period.

**Internal Construct Validity**

Internal construct validity refers to the internal structural validity of the instrument being tested. This type of assessment is used to determine the dimensionality of the instrument and the domains of a construct measured by a particular scale (Waltz & Strickland, 1988). Factor analysis is the usual method of analysis for this type of assessment.

Factor analysis of the Importance of Needs scale using principal axis factoring with varimax rotation was used to assess the internal construct validity of the instrument and identify possible sub-dimensions of the subscale. Varimax orthogonal rotation was deemed appropriate given the exploratory nature of the factor analysis (Kim & Mueller, 1988). Thirteen factors had eigenvalues greater than 1.0, explaining 82% of the variance. The scree plot also suggested that the first 13 factors should be examined as part of a preliminary interpretation of results.

Eigenvalues ranged from 1.13 to 13.94. Percentage of variance ranged from 27 for the first factor extracted to 2 for the 13th factor. Item factor loadings meeting the preset criterion ranged from values of 0.55 to 0.97. Five items loaded on more than one factor and were not interpretable. Nine factors contained only one or two items.

Examination of the items within Factors I to IV identified groups of needs concerning: Positive Involvement in Child's Care, Information Specific to Child's Plan of Care, Other Children's Needs, and Open and Clear Responses to Questions. These four factors accounted for 51% of the variance. Factors, items, and factor loadings are shown in Table 4.
Table 4  Factor Analysis of FIN-PED (Needs Subscale)

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor I: Positive Involvement in Child’s Care</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>feel there is hope</td>
<td>.92</td>
</tr>
<tr>
<td>17</td>
<td>know <em>when</em> to expect side effects to occur</td>
<td>.82</td>
</tr>
<tr>
<td>16</td>
<td>know <em>what</em> side effects the treatment can cause</td>
<td>.82</td>
</tr>
<tr>
<td>25</td>
<td>have thorough information about how to care for my child at home</td>
<td>.73</td>
</tr>
<tr>
<td>30</td>
<td>know that health-care professionals offer me the opportunity to participate equally in my child’s care</td>
<td>.61</td>
</tr>
<tr>
<td>40</td>
<td>have trust in the health-care system</td>
<td>.55</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor II: Information Specific to Child’s Plan of Care</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>be informed of changes in my child’s condition</td>
<td>.94</td>
</tr>
<tr>
<td>12</td>
<td>know what treatment my child is receiving</td>
<td>.92</td>
</tr>
<tr>
<td>26</td>
<td>feel that the health-care professionals are sincere in caring about my child</td>
<td>.81</td>
</tr>
<tr>
<td>6</td>
<td>have explanations given in terms that are understandable to me</td>
<td>.69</td>
</tr>
<tr>
<td>14</td>
<td>be told when and why changes are being made in my child’s treatment plan</td>
<td>.62</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor III: Needs of Other Children</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>51</td>
<td>know <em>how</em> to give information to my other children (appropriate to his/her age)</td>
<td>.92</td>
</tr>
<tr>
<td>50</td>
<td>know <em>what</em> information to give to my other children (appropriate to his/her age)</td>
<td>.91</td>
</tr>
<tr>
<td>52</td>
<td>know how to handle the feelings of my other children</td>
<td>.78</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor IV: Open and Clear Response to Questions</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>know I can ask questions any time</td>
<td>.86</td>
</tr>
<tr>
<td>5</td>
<td>know to whom I should direct my questions</td>
<td>.84</td>
</tr>
<tr>
<td>8</td>
<td>know the probable outcome of my child’s illness</td>
<td>.84</td>
</tr>
</tbody>
</table>

To confirm internal consistency reliability of these sub-dimensions, a correlation matrix was re-examined to assess inter-item correlations for items on each factor. The four-factor solution resulted in inter-item correlations that met the preset criterion of 50% inter-item correlations between 0.30 and 0.70. All inter-item correlations for the first factor
Positive Involvement in Child's Care) were between 0.38 and 0.77. Eight of the 10 inter-item correlations for Factor II (Information Specific to Child's Plan of Care) were between 0.39 and 0.73. Items 19 and 12 and items 19 and 26 achieved inter-item correlations of 0.90 and 0.81, respectively, suggesting slight redundancy. Factor III (Other Children's Needs) inter-item correlations fell between 0.72 and 0.91. Factor IV (Open and Clear Response to Questions) inter-item correlations were between 0.49 and 0.75. A Cronbach's alpha coefficient of 0.88 was obtained for the 17-item abbreviated scale based on the four-factor solution. Item-to-total correlations for this abbreviated scale ranged from 0.28 to 0.72, with 12 of the 17 correlations between the preset criterion of 0.40 and 0.70. The Kaiser-Meyer-Olkin measure of sampling adequacy (MSA) was acceptable (0.81), and no item had an individual MSA value below 0.66. Therefore, despite the relatively low observations-to-variables ratio, the results of the factor analysis may be considered relatively stable by this criterion.

According to Carmines and Zeller (1989), if a scale is unidimensional, the first extracted component (factor) should account for at least 40% of the variance in the items. Factor I in this scale accounted for 27% of the variance in the items, suggesting that the FIN-PED is multidimensional. To further assess whether the Importance of Needs scale was multidimensional, a theta coefficient was calculated. According to Carmines and Zeller, if a scale is multidimensional, the theta coefficient should be higher than the Cronbach's alpha coefficient. In this instance the Cronbach's alpha coefficient was 0.94 and the theta coefficient 0.95, providing further evidence that the FIN-PED may be multidimensional.

Posthoc Analysis

Posthoc analysis was used to compare the core items from the original FIN with the modified version of these items included in the FIN-PED. Internal consistency reliability for the revised 20 items from the original FIN was 0.61. Item-to-total correlations ranged from 0.12 to 0.62 with a mean item-to-total correlation of 0.38. Prior testing of the reliability of the original FIN with adult relatives of adult cancer patients resulted in an internal consistency estimate of 0.83, suggesting that the items that form this scale perform less reliably when tested with mothers of children with cancer. This comparison confirmed that the altered FIN-PED instrument is likely more appropriate for use with this population.
Discussion

Both subscales of the FIN-PED demonstrated high internal consistency, as measured by Cronbach’s standardized alpha coefficients and item-to-total correlations. Examination of inter-item correlations among items within sub-dimensions (as determined by factor analysis results) revealed acceptable inter-item correlations. Reliability estimates obtained by calculating the theta coefficient, together with these results, suggest that mothers’ care needs may be multidimensional.

Although an assessment of internal consistency of the tool is helpful, clinical reasoning suggests that care needs may not be as meaningfully measured using a parallel item reliability model (e.g., Cronbach’s alpha). For example, individuals who rate one need as important (e.g., need for information) may not necessarily rate another as important (e.g., need for support from other parents). Therefore, the more appropriate reliability model for further testing of the FIN-PED may be additional assessments of stability of the tool over time.

Further research is needed to confirm the test-retest reliability of the FIN-PED, considering the relatively small number of scores available for testing this type of reliability in the present study. Subsequent testing of the abbreviated four-factor scale is also warranted, to determine whether reliability estimates obtained using the data of this study hold. If reliability estimates remain high, the brevity of this 17-item tool would make it clinically practical. Separate assessment tools for measuring the needs of siblings and fathers could be developed and tested to supplement the FIN-PED. During the pilot study, mothers reported that they believed their needs were different to those of their spouse, providing further support for the need to develop and test a specific tool for fathers.

Although results from this three-phase instrument refinement and testing project appear promising, it would be premature to recommend use of the 17-item abbreviated tool in clinical practice. These results are based on a sample of 110 mothers of children with cancer recruited from one care setting. No claim is made regarding the representativeness of the sample. As well, the tool is still considered immature and warrants further testing. Publication of these results is intended to expedite this process.

The construct validity of the tool might be further assessed by comparing the responses of known groups (e.g., mothers who belong to a parent support group compared to those who do not; mothers of chil-
dren with longstanding diagnosis compared to mothers of children recently diagnosed).

Enskär, Carlsson, von Essen, Kreuger, and Hamrin (1997) have developed and tested a tool in Sweden to measure the life experience of parents of children with cancer. Their report had not yet been published at the time of our study (1994–96). The parallel development of these instruments confirms the international necessity for a needs assessment tool available in different languages. Future concurrent validity assessments of the FIN-PED using Enskar et al.’s tool are recommended.

Summary

The FIN-PED has been developed to identify the needs of mothers of children diagnosed with cancer. This instrument may eventually be used to assist in planning care for children with cancer. Further reliability and validity testing is required to confirm the initial results obtained in this study. Multi-site testing is also recommended, to determine the needs of mothers of children with cancer irrespective of treatment location.

References


### Appendix  Family Inventory of Needs — Paediatrics

Below is a list of needs identified by some family members who have a child with cancer. Please rate how important each item is from 1 to 5 as it relates to your present situation. If an item is not at all important to you, give it a 1. If it is very important to you, give it a 5. If it is somewhere in between, give it a score between 1 and 5 which reflects how important it is for you. If you rated a need greater than (1) then check whether each need is currently met, partially met, or unmet.

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Ratings from 1-5</th>
<th>If you rated an item higher than 1, check if need was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. have my questions answered honestly.</td>
<td></td>
<td>MET        PARTLY MET UNMET</td>
</tr>
<tr>
<td>2. believe that the health-care professionals caring for my child are competent.</td>
<td></td>
<td>MET        PARTLY MET UNMET</td>
</tr>
<tr>
<td>3. know that the knowledge of health-care workers fits my child’s needs.</td>
<td></td>
<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>4. know I can ask questions any time.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>5. know to whom I should direct my questions.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>6. have explanations given in terms that are understandable to me.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>7. where appropriate, have explanations given to my child in terms that are understandable to him/her.</td>
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<tr>
<td>8. know the probable outcome of my child’s illness.</td>
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<tr>
<td>9. know what my child’s stay in the hospital will be like.</td>
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<tr>
<td>10. know how to handle my child’s feelings.</td>
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<tr>
<td>11. know why things are done to my child.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>12. know what treatment my child is receiving.</td>
<td></td>
<td>MET        PARTLY MET UNMET</td>
</tr>
<tr>
<td>13. know what situations I can and cannot control while my child is in hospital.</td>
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<td>MET        PARTLY MET UNMET</td>
</tr>
<tr>
<td>14. be told when and why changes are being made in my child’s treatment plans.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>15. be assured that the best possible care is being given to my child.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>16. know what side effects the treatment can cause.</td>
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<td>MET        PARTLY MET UNMET</td>
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<tr>
<td>17. know <em>when</em> to expect side effects to occur.</td>
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<tr>
<td>18. feel there is hope.</td>
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<tr>
<td>19. be informed of changes in my child's condition.</td>
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<td></td>
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<tr>
<td>20. be involved in decisions about my child's care.</td>
<td></td>
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<tr>
<td>21. where possible, know how much time I can take in making my decisions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. know how I can help care for my child in the hospital.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. know <em>what</em> information to give to my child with cancer (appropriate to his/her age).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. know <em>how</em> to give information to my child with cancer (appropriate to his/her age).</td>
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</tr>
<tr>
<td>25. have thorough information about how to care for my child at home.</td>
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<tr>
<td>26. feel that the health-care professionals are sincere in caring about my child.</td>
<td></td>
<td></td>
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<tr>
<td>27. know that health-care professionals accept my child even when he/she is angry or upset.</td>
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<td></td>
</tr>
<tr>
<td>28. know the names of the health-care professionals involved in my child's care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. know how to contact the health-care professionals involved in my child's care.</td>
<td></td>
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<tr>
<td>30. know that health-care professionals offer me the opportunity to participate equally in my child's care.</td>
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<tr>
<td>31. have a respectful relationship with the health-care professionals caring for my child.</td>
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<td></td>
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<tr>
<td>32. know to whom to turn if conflict situations arise.</td>
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<tr>
<td>Item</td>
<td>Ratings from 1-5</td>
<td>MET</td>
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<td>----------------------------------------------------------------------</td>
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<td>-----</td>
</tr>
<tr>
<td>33. have my child feel trust in the health-care professionals caring for him/her.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. have my child participate in decisions about his/her care (appropriate to his/her age).</td>
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<tr>
<td>35. know that where appropriate health-care professionals will ask my child’s permission to do things to my child.</td>
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<tr>
<td>36. have health-care professionals guide me in setting limits for my child’s behaviour.</td>
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</tr>
<tr>
<td>37. know health-care professionals will respect my family values regarding my child’s behaviour.</td>
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<tr>
<td>38. feel that health-care professionals accept me even if I am angry or upset.</td>
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<tr>
<td>39. feel encouraged by health-care professionals to maintain a normal lifestyle.</td>
<td></td>
<td></td>
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<tr>
<td>40. have trust in the health-care system.</td>
<td></td>
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</tr>
<tr>
<td>41. meet with other mothers/parents dealing with similar issues.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. be involved with a support group.</td>
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<td></td>
</tr>
<tr>
<td>43. have someone be concerned with my health.</td>
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<td></td>
</tr>
<tr>
<td>44. be told about people who could help with my concerns.</td>
<td></td>
<td></td>
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<tr>
<td>45. know where to park when at the hospital/clinic.</td>
<td></td>
<td></td>
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<tr>
<td>46. know where things are in the hospital.</td>
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<td></td>
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<tr>
<td>47. know where things are in the city.</td>
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</tr>
<tr>
<td>48. have financial assistance to help cope with the costs of my child’s illness (e.g., parking, food, transportation, medicine).</td>
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</tbody>
</table>
The following question is sensitive in nature, but your response would be helpful to us.

If you rated an item higher than 1, check if need was:

<table>
<thead>
<tr>
<th>Need to:</th>
<th>Ratings from 1–5</th>
<th>MET</th>
<th>PARTLY MET</th>
<th>UNMET</th>
</tr>
</thead>
<tbody>
<tr>
<td>49. be allowed to discuss the terminal stage of my child’s illness,</td>
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<tr>
<td>if necessary.</td>
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</tbody>
</table>

If you have children in addition to your child with cancer please answer the following three questions (50, 51 and 52). If you do not have other children, please put an X in this space.

If you rated an item higher than 1, check if need was:

<table>
<thead>
<tr>
<th>Need to:</th>
<th>Ratings from 1–5</th>
<th>MET</th>
<th>PARTLY MET</th>
<th>UNMET</th>
</tr>
</thead>
<tbody>
<tr>
<td>50. know what information to give to my other children</td>
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<td></td>
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<tr>
<td>(appropriate to his/her age).</td>
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<tr>
<td>51. know how to give information to my other children</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(appropriate to his/her age).</td>
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</tr>
<tr>
<td>52. know how to handle the feelings of my other children.</td>
<td></td>
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</tr>
</tbody>
</table>

Please tell me anything else health-care providers could do to improve the care for you and your child:

Please tell me anything you would like to about the questions I have asked you. If you need more pages for your responses, please feel free to add them.

Thank you for your participation.
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Acknowledgements

This study was supported by operating funds from the Health Sciences Centre Research Foundation and the Manitoba Association of Registered Nurses Foundation; fellowship support to the first author from the Canadian Nurses Foundation; and investigator awards to the second author from the Manitoba Health Research Council and to the third author from the National Health Research and Development Program and the Medical Research Council of Canada.

Correspondence should be addressed to E. Marilyn Goodyear Whiteley, Health Care Consultant, 537 Cordova Street, Winnipeg, MB R3N 1A8.
Happenings

A New Global Resource on the Internet: Canadian-International Nurse Researcher Database (CNRD)

Howard Brunt and Colleen Varcoe

Meeting the Challenge of the Explosion in Nursing Knowledge

A problematic aspect of the knowledge explosion in nursing and the health sciences has been the lack of user-friendly, intuitive, up-to-date databases for researchers, clinicians, policy-makers, and others to link up with experts in both methodologic and substantive areas. Examples of challenging situations include:

- the researcher seeking someone to assist with data analysis
- the editor or grant administrator requiring an expert reviewer
- the health-care provider seeking treatment advice
- the investigator attempting to establish a national or international research network
- the policy-maker having to make evidence-based decisions
- the individual seeking advice and support for optimizing health

The Canadian-International Nurse Researcher Database has been developed to address such challenges as these. Launched in the spring of 1999, the CNRD is rapidly becoming a valuable addition to nurses’ research infrastructure.

J. Howard Brunt, R.N., Ph.D., is Professor, School of Nursing, and Associate Vice-President, Research, University of Victoria, British Columbia. Colleen Varcoe, R.N., Ph.D., is Assistant Professor, School of Nursing, University of Victoria.
Canadian-International Nurse Researcher Database: What Is It?

The CNRD is a free service supported through sponsorships from a variety of sources: government agencies, professional associations, consumer groups, non-governmental agencies, academic institutions, the private sector. Its initial development was funded by the Canadian Association for Nursing Research, the University of Victoria School of Nursing, the British Columbia Health Research Foundation, and the Canadian Association of University Schools of Nursing.

The CNRD utilizes a unique array of computing technologies that permit interactive Boolean searching, self-editing of personal data records in a secure web-based environment, instantaneous updating of information with a minimum of administrative upkeep, and generation of evaluative data. The objectives of the CNRD are to:

- promote excellence in nursing practice through research and evaluation
- strengthen links among researchers, practitioners, administrators, educators, and policy-makers for evidence-based health-care delivery
- promote and support research networks
- educate nurses, other health professionals, and the public in nursing research

The CNRD is easily accessed on the worldwide web. An individual seeking expert opinion in either a particular research method (e.g., grounded theory analysis; randomized control design) or a substantive area (e.g., care of the elderly; wound care) can search the database using the appropriate terms. Searches can be conducted by either entering terms freeform or using menu selection. The full index of database terms can be either printed or viewed onscreen. Boolean searching (e.g., phenomenology and suffering and children) helps users locate individuals who more precisely match their requirements. Upon completion of the search, the user can examine the full profile of the persons found in the database and e-mail them directly from within the CNRD. To protect anonymity, e-mail is forwarded by the CNRD, so members' e-mail addresses are not divulged. Once correspondence has been established, the CNRD member can decide whether to respond to an inquiry.

Nurses wishing to enter themselves in the database can do so easily in a password-secure environment designed with a flexible data-input structure. Database members can modify their profile at any time.
Nurses who cannot find a particular term in the database to describe their expertise can easily add a new term, which then instantly updates the database. The administrator regularly reviews new terms for their appropriateness. The structure of the CNRD will be modified over time as usage patterns evolve.

**Future Plans for the CNRD**

An international advisory committee has been formed to help steer the evaluation and development of the CNRD. Nurses with an interest in research infrastructure development or evaluation design, particularly based on information technology, are encouraged to consider serving on the advisory committee (contact Howard Brunt, below). The intention is to maintain the service through sponsorships and grants from major international nursing organizations; the advisory committee is currently attempting to increase the CNRD's base of support. While the database was originally developed in English, versions in both Spanish and French are envisioned as international support continues to grow.

Ultimately, the key to the CNRD's success is the registration of as many nurse researchers as possible. The capacity of the database is virtually limitless. By entering your expertise, you are indicating your willingness to share your knowledge and experience with others around the world. You are cordially invited to become a member of the CNRD. For more information, contact Howard Brunt, R.N., Ph.D., Office of the Vice President – Research, University of Victoria, Victoria, BC V8W 2Y2. E-mail: hbrunt@hsd.uvic.ca

Visit the Canadian-International Nurse Researcher Database at www.nurseresearcher.com
Book Review

Nurse-Social Worker Collaboration in Managed Care: A Model of Community Case Management
Joellen W. Hawkins, Nancy W. Veeder, and Carole W. Pearce

Reviewed by Jean-Pierre Bonin

The changes afoot in the American health-care system, particularly as regards managed care, have created a problem for the professions of nursing and social work. These two professional groups have to cope with privatization, staff cuts, rationing of services to the underprivileged, and a lack of respect for professional training that was once held in high regard. Besides causing a sense of insecurity, managed care has fuelled rivalry and animosity between two professions that originally worked hand in hand.

The authors of Nurse-Social Worker Collaboration in Managed Care (two nurses and a social worker), recognizing that neither of these two professional groups is about to stop practising in the community, propose a model for their collaboration. The Biopsychosocial Individual and Systems Intervention Model (BISIM) would return nurses and social workers to their early arena, the community; it identifies interventions that would fulfil the two chief mandates of managed care, efficacy and efficiency.

The first two chapters describe the present care situation, typified by changes in the health-care system in the United States and managed care. The authors' treatment of managed care — a concept that refers to a host of services that differ from one state to another and one service provider to another — is meticulous, well documented, and uncommonly clear. They provide an historical review of this type of care, which apparently dates back to the 13th century, and then define the various managed-care schemes: indemnity insurance plans, health maintenance organizations (with a brief description of each HMO model), preferred provider organizations (with a description of several PPO models), exclusive provider organizations, employer-negotiated arrangements, government-sponsored organizations, health-care systems, case management, hospital case management, and community case management. Next, the authors
describe the roles of physicians, nurses, and social workers as case managers. The roles of nurses and social workers appear quite similar, and the authors stress their advocacy function in a system that appears often to forget care in favour of management driven by cost-saving and efficiency.

Chapter 3 presents a history of nurse-social worker collaboration, beginning with the turn-of-the-century settlement-house movement in the United States. Founded to help both professions serve the poor, immigrants, workers, schoolchildren, and boarding-house tenants, this movement should serve as a lesson in nurse-social worker collaboration. However, the paths of the two professions later diverged, owing in part to their different evolution, growth, and training. In the wake of the Flexner Report, which concluded that neither group merited professional status, nurses and social workers had to sharply circumscribe their functions in order to assert their status and unique contribution. Furthermore, as settlement houses dwindled in number, hospitals introduced mechanisms that restricted their opportunities for collaboration.

In Chapter 4, Hawkins, Veeder, and Pearce describe the 1995–96 study supporting the BISIM. Thirty-three nurses and social workers were interviewed at length for their views on their profession past, present, and future, the current state of chaos in delivery of services, and the opportunities open to them. The subjects affirmed the benefits of collaboration, pointing out that in fact it has always existed and has served patients and their families well. They expressed the opinion that nurses and social workers could blend their different approaches to training and their different skills to better meet the needs of patients. They also pointed out that both professions are now opting for a holistic approach. However, there were grey areas, and some drawbacks to collaboration also emerged, such as differences in wages and schedules as well as philosophical differences.

The succeeding chapters offer theoretical and practical descriptions of the BISIM, taking into account the findings of the 1995–96 study, the historical background, and the current literature. The BISIM can be characterized as follows: (1) It has a dual focus: the patient and the system. (2) It provides advanced case management by experienced workers. (3) It employs clinical case management. (4) It takes a holistic view of the biopsychosocial individual in situ (for nurses, holistic embraces body and mind; for social workers, the whole environment). (5) Its conceptual framework includes a life-based model for improving the patient’s strengths and skills. (6) It uses an interdisciplinary model
of case management. (7) It distinguishes between nurses and social workers as team members by considering their unique training and skills, recognizing that some functions might be fulfilled by either profession. (8) It is flexible in its assessment of community needs and the community’s response to changes in individuals, groups, communities, and organizations. (9) It values education in the promotion of community health and the prevention of physical and mental disease. (10) It features a strong advocacy component. (11) It is available for as long as required by the community. (12) It includes qualitative and quantitative monitoring of outcomes.

The authors anchor these concepts in reality, identifying the community interventions that are needed and offering practical examples culled from case studies. Despite the lofty principles of the model, the authors acknowledge that it affords nurses a somewhat narrow scope. It regards nursing as “biosocial,” social work as “psychosocial” (nurses look to the biological first, then to the psychosocial, whereas social workers look to the psychosocial first). Nurses are assumed to have a micro focus (the individual), social workers’ a macro focus (the individual in the environment, and group dynamics). Lastly, nurses focus on the delivery of care, especially as regards drug compliance, whereas social workers focus on the client. All this leaves a somewhat archaic impression of nursing, an impression that, in this reviewer’s opinion, disregards the evolution of the profession in recent decades and conceptual models of nursing recently proposed. Case-management nurses, especially in psychiatry, generally take a patient-centred, “whole person” approach, including facets of the individual that the authors assign to social workers.

Nurse-Social Worker Collaboration in Managed Care provides an interesting basis for discussion around the notion of bringing the two professions of nursing and social work into harmony. The model proposed by Hawkins, Veeder, and Pearce is well documented as to the history of collaboration, but it offers a limited role for members of each profession on case-management teams. Certain premises of this model should be revisited so that nurses can further define the role they are prepared to play within the system.

Jean-Pierre Bonin, N., M.Sc., Ph.D.(cand), is a lecturer in the faculty of nursing at the Université de Montréal. He is also a researcher at the Centre de Recherche Fernand-Séguin, which is affiliated with the Louis-H. Lafontaine Hospital, Montreal.
Video Review

Psychiatric Aspects of Home Health Care
(Overview and Assessment; Interventions and Safety Concerns; Families, Care Givers and Community Resources)
3 videos ranging from 22 to 26 min.

Reviewed by Madeleine Buck

The video series Psychiatric Aspects of Home Health Care is timely and relevant considering the changes that are now taking place in health-care delivery — one could even say that, in light of shifts in the care of people with mental illness in the 1970s and 1980s, it is long overdue!

Overview

This three-part series addresses important issues related to providing follow-up for people with mental illness in their own environment. The merits of following such clients in their homes is made clear throughout, with nurses offering testimonials on how this approach has enabled them to assess and intervene more accurately and more creatively. There are sequences illustrating the fact that nurses are able to collect more relevant and meaningful data on their clients by seeing them in the home setting, in the context of their family life (or lack thereof) and the demands of their day-to-day existence. Other sequences demonstrate nurses’ ability to problem-solve with clients in ways that would not be possible in a hospital setting.

Though not intended as a formal primer on mental illness, the series does outline the types of mental illness that are likely to be encountered in the home environment. Basic theory is used to highlight symptomatology and manifestations of five forms of mental illness: schizophrenia, bipolar disorder, depression, panic disorder, and dementia. The theory is complemented nicely by interactions with clients to illustrate some of the symptoms. Also covered are means of identifying and addressing more subtle mental-health problems and potentially suicidal situations.
The series also deals with — and this is perhaps its most interesting feature — situations that are likely to arise only in a home or community environment, or, at any rate, to be considerably altered outside the hospital setting. These include: developing sufficient trust for a client to readily and openly accept the nurse into their home; dealing with "dual diagnoses"; detecting symptoms of mental illness that have gone unnoticed during inpatient or outpatient follow-up; conducting oneself in the client's "territory"; locating and dealing with other family members, who may also have mental or physical problems; negotiating a client's attempts to become a "friend"; and addressing a home environment that is not healthful. A segment on identifying and coping with threats to personal safety provides specific cues and concrete solutions in managing these difficult situations.

Process issues, from developing initial rapport to terminating a relationship with a vulnerable client, are well addressed. Various communications strategies are discussed and excellent examples of collaborative nurse/patient relationships provided. Nurses are shown dealing with situations of anger, severe depression, paranoia, and belligerence. We see them picking up on subtle behavioural cues, pointing out client strengths, engaging the client in setting priorities and problem-solving, openly negotiating goals with the client, and providing feedback to the client on meeting or failing to meet goals. The videos also address what a nurse can realistically hope to achieve in a particular situation, and the importance of consulting a multidisciplinary team — not only for personal support but in order to address client-related challenges as accurately and as comprehensively as possible.

Presentation

The mix of a formal theory component, nurse testimonials, nurse-client interactions, and interviews with family members ensures a comfortable balance of information and entertainment. Nurse-client relationships are followed as they evolve over time, enabling the viewer to see how the relationships develop — after watching the first video, the viewer is eager to follow through with the rest of the "story." Though the three videos in the series can be viewed separately, seeing them in sequence will allow the viewer to track the various issues in the nurse-client relationship.
Audience

This series would be a good primer for any nursing student as well as any nurse embarking on a career in the community — it will help allay anxieties by providing realistic strategies for negotiating several situations (including those involving a clientele designated "non-psychiatric"). Nurses already working in a home environment will stand to learn new or different ways of meeting particular challenges. The videos highlight the importance of addressing mental-health issues that might be overlooked because of a focus on physical recovery, such as during the postoperative period. Some excerpts could also be used to justify home care in general, or to illustrate specific components of the nurse/client relationship — particularly to those nursing students who require vivid representation of communications theory and process.

The series was made in the United States and therefore includes references to insurance agencies and Medicaid that are not applicable to Canadian audiences. However, these instances do not detract from the goal of addressing important challenges in home care.

Summary Assessment

The richness of Psychiatric Aspects of Home Health Care lies in its presentation of nurse-client situations as they unfold. This video series provides an uplifting view of the merits of home care for clients who face many challenges, and is realistic in its portrayal of what the disappointments as well as the rewards can be for the nurse. It offers a nice complement of theory and lively illustration, the graphic depictions successfully consolidating the ideas presented. Any nurse viewing this series will leave with something new to test out.

Madeleine Buck, N., M.Sc.(A), is a faculty lecturer in the School of Nursing, McGill University, Montreal.
VOLUME 32

Primary Health Care
Submission deadline: October 15, 1999
Publication date: June 2000

Philosophy / Theory
Submission deadline: January 15, 2000
Publication date: September 2000

Chronicity
Submission deadline: April 15, 2000
Publication date: December 2000

Abuse and Violence
Submission deadline: July 15, 2000
Publication date: March 2001

VOLUME 33

Economics of Nursing Care
Submission deadline: October 15, 2000
Publication date: June 2001

Home Care
Submission deadline: January 15, 2001
Publication date: September 2001

Women’s Health
Submission deadline: April 15, 2001
Publication date: December 2001

Health Resource Planning
Submission deadline: July 15, 2001
Publication date: March 2002
VOLUME 34

Coping / Adaptation
Submission deadline: October 15, 2001
Publication date: June 2002

Ethics, Values, & Decision-Making
Submission deadline: January 15, 2002
Publication date: September 2002

Addiction
Submission deadline: April 15, 2002
Publication date: December 2002

Culture & Gender
Submission deadline: July 15, 2002
Publication date: March 2003

VOLUME 35

Nursing-Care Effectiveness
Submission deadline: October 15, 2002
Publication date: June 2003

Gerontology
Submission deadline: January 15, 2003
Publication date: September 2003

Health Promotion
Submission deadline: April 15, 2003
Publication date: December 2003

Continuity & Transitional Care
Submission deadline: July 15, 2003
Publication date: March 2004
Primary Health Care  
June 2000 (vol. 32, no. 1)

Primary health care is considered to be essential health care that is based on practical, scientifically sound, and socially acceptable methods and technologies that are universally accessible to people in their local communities. This issue of the CJN/R will focus on the spectrum of papers related to primary health care, including theoretical development, empirical studies of primary health-care interventions and outcomes, and policy directives supporting primary health care. The foci of empirical work may include specific populations (e.g., vulnerable groups), health systems, or a level of community. A range of methods and research approaches are sought, including evaluation studies, instrument development, validation studies, surveys, and qualitative studies. Priority will be given to papers that advance our knowledge of nursing's role in primary health care.

Guest Editor: Dr. Karen Chalmers  
Submission Deadline: October 15, 1999

Philosophy/Theory  
September 2000 (vol. 32, no. 2)

The rapid changes in the health-care system, the development of new technologies, and, consequently, the changes in nursing roles and responsibilities are all challenging nurses to critically examine and defend what constitutes nursing practice. This examination prompts us to consider the nature, scope, and goal of nursing practice. In addition to these issues, nursing scholars are grappling with questions related to what it means to know, the nature of truth, and the basis on which we claim that our research methods lead to knowledge. To address these concerns, philosophic and theoretical papers are invited on topics that speak to the nature of nursing and the nature of nursing knowledge. Priority will be given to manuscripts that have the potential to stimulate discussion of critical issues facing the discipline of nursing.

Guest Editor: Dr. Joy Johnson  
Submission Deadline: January 15, 2000

Please send manuscripts to:
The Editor, Canadian Journal of Nursing Research,  
McGill University School of Nursing, 3506 University Street,  
Montreal, QC H3A 2A7 Canada
Bulletin Board

Conference
Joan Gilchrist Nursing Exploration Series: Private or Public Health Care? Nurses Confront the Dilemma, September 24, 1999, Montreal, Quebec. A day to debate choices for nurses. Speakers: Pat Armstrong, co-author of Universal Health Care: What the United States Can Learn from Canada and Wasting Away: The Undermining of Canadian Health Care; and Betty Gourlay, President of the Canadian Association of Nurses in Independent Practice. Information: mgabriel@wilson.lan.mcgill.ca or 514-398-4144

Call for Abstracts

New Website
The Canadian-International Nurse Researcher Database (CNRD) is a nursing research infrastructure project developed by Drs. Howard Burnt and Colleen Varcoe of the University of Victoria, British Columbia, in consultation with nurses around the world. CNRD is an invaluable, free internet resource for nurse researchers, administrators, policy-makers, and clinicians: www.nurseresearcher.com

Information for the Bulletin Board must be submitted in writing.
McGill University Health Centre
Associate Director for Nursing Research

The McGill University Health Centre is a recently merged quaternary care, academic health-science centre in the heart of the cosmopolitan city of Montreal. It has 1,300 beds, approximately 700,000 ambulatory care visits per year, and a staff of 10,000, of which 4,000 are nurses.

The Department of Nursing is seeking an **Associate Director for Nursing Research**, who will provide leadership to promote excellence in nursing research, building on the McGill University Health Centre's existing nursing research program (approximately $4.5 million in peer-reviewed funding over the last three years). The Associate Director for Nursing Research is responsible for the overall McGill University Health Centre Nursing Research program, including staff, activities, and resources, and for recruiting additional nurse researchers, obtaining new resources, and effectively using existing resources to strengthen nursing research and its ties to practice and education. This nursing leader will actively contribute to the development of the discipline and the preparation of new nurse researchers and will participate with other senior leaders in strategic planning for nursing. The Associate Director for Nursing Research will have a leadership role in the McGill University Health Centre Research Institute and will hold a faculty appointment in the McGill University School of Nursing. The successful candidate will work in collaboration with colleagues in nursing and other disciplines. The Associate Director for Nursing Research will enhance the McGill University Health Centre's profile by developing effective relationships with funding agencies, professional organizations, other health-care and academic institutions, and community groups.

**Requirements:**
- OIIQ Registration
- Ph.D. in nursing or related discipline
- More than 5 years' experience as an investigator
  (administrative experience is an asset)
- Demonstrated record of research productivity
- Excellent leadership and communication skills
- Demonstrated ability to work in a decentralized management setting
- Fluency in both English and French

Interested candidates should send their curriculum vitae to Valerie Shannon, Director of Nursing, McGill University Health Centre, 1650 Cedar Avenue, Montreal, Quebec H3G 1A4, no later than November 30, 1999.
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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, positions and affiliations, information on financial assistance, acknowledgements, and address for reprint requests.

Abstract: Research articles must include a summary of 100–150 words on the purpose, design, sample, findings, and implications of the research. 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 including references, tables, and figures (which are placed at the end of 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.
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La Revue canadienne de recherche en sciences infirmières est publiée quatre fois par année. Son mandat est de diffuser 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 liés à l’éducation, à l’histoire de même que des articles liés à la méthodologie, la théorie et l’analyse critique qui favorisent le développement des sciences infirmières. Nous vous invitons à nous faire parvenir également vos commentaires sur les articles publiés.

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SUBSCRIPTION RATES: Institutions (including hospitals, schools, libraries, and agencies): $160/one year. Individual subscriptions: $75/one year. Students: $45/one year. Cheques payable to Canadian Journal of Nursing Research. Visa and MasterCard accepted. Canadian subscribers please add 7% GST. There is a $16 surcharge per year for foreign subscriptions.

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This issue has been supported by an SSHRC (647-95-0048) grant.

Nous avons reçu les subventions du CRSHC (647-95-0048) pour ce numéro.

ISSN 0844-5621

The Canadian Journal of Nursing Research is indexed in /La Revue canadienne de recherche en sciences infirmières se retrouve dans les indexes suivants:

BNI, CINAHL; Health Care Management Studies; Hospital Abstracts; Index de la santé et des services sociaux; MEDLINE; Micromedia’s Canadian Business & Current Affairs (CBCA) database; Nursing Abstracts; Sociological Abstracts (SA); Social Planning/Policy and Development Abstracts (SOPODA).

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Cover, design & layout/Couverture, conception et mise en page : Résolutique Globale, Montréal
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