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McGill University School of Nursing

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GUEST EDITORIAL

Poverty and Human Development

Cheryl Forchuk

It is hard for us as nurses to escape the important role played by poverty and human development. While this issue encompasses so much of our work, paradoxically we often render it invisible in our practice and our research. A defining moment for me occurred when I was working in a psychiatric setting and the government introduced a policy of co-payment for medications taken by recipients of public assistance. I recall the rhetoric of the time: "It's only $2 per prescription. It will barely make a difference." One consumer of mental health services came to me with his bank book and detailed budgeting sheets. He had managed to balance his budget by cutting back to two meals a day. He was taking several medications, so the new policy was going to stretch his $800-a-month disability income to the limit. He already had no discretionary income and had given up his phone. He had identified two alternatives and wanted input on which was the healthier choice: to cut down to one meal a day, or to start taking his medications every other day.

Inadequate social assistance, disability payments, and minimum wages across Canada still keep many of our vulnerable citizens in poverty and force them to make difficult choices. In Ontario currently, a single person receiving provincial disability support gets $1,020 per month and a single person receiving welfare benefits gets $572. It is difficult to pay for rent, utilities, transportation, clothing, and food with these levels of support. I have researched issues related to income support, adequate housing, and homelessness, since the people I work for are struggling with these issues (Forchuk et al., 2007; Forchuk, Ward-Griffin, Csiernik, & Turner, 2006).

This issue of *CJNR* addresses the complex subject of poverty and human development. This topic has been addressed previously by the Journal, in response to a call by the Council of Science Editors for all journal editors to publish a special issue on poverty and human development last autumn. This focus was in support of the Millennium Development Goals set by the United Nations to reduce extreme poverty by the year 2015. The October 2008 issue of *CJNR* included several short reports exemplifying the contributions of Canadian nurses to this worldwide endeavour. The current issue goes into more detail, with lengthy reports on those contributions.

Our present focus topic is certainly timely considering the global economic challenges that we face today. These challenges will make the 2015 goal more difficult to achieve. For nurses, however, poverty is a constant concern as a social determinant of health and as a barrier to access to needed services and human development. Poverty underpins many of the social determinants of health. For example, access to education, housing, transportation, and social support is more difficult in the absence of adequate income. When we see a client struggle with poverty, it important for us to consider the impact of poverty on health, the systemic issues at play, and the worldwide effort to address poverty and human development.

In the pages that follow, Dennis Raphael provides an excellent overview of the concept of poverty, including current research aimed at understanding and addressing this problem, such as through appropriate public policies. He highlights the need for wider dissemination of findings and for advocacy to ensure their implementation.

Two of the contributions in this issue of the Journal address homelessness. Manal Guirguis-Younger and colleagues examine knowledge-integration strategies employed by nurses and other care providers in assisting people who are homeless. Miriam Stewart and colleagues evaluate a strategy for promoting health and coping among homeless youths. Jodi Hall and Lorie Donelle look at methodological issues with respect to another vulnerable group, women serving court-mandated probation or parole orders. However, all of the articles identify, to some extent, the difficult methodological issues that can arise with research in this area.

The Happenings column gives us reason to hope for changes in both policy and practice. Myra Piat and colleagues present an overview of initiatives launched by the newly formed Mental Health Commission of Canada to specifically address issues related to homelessness and mental health.

Nurses can play a key role in advocating not only for our individual clients but for change within the systems in which we operate. To achieve visibility on this front, we need to proclaim loudly that poverty is a health issue and therefore a nursing issue. We hope that this focus issue of *CJNR* will raise the profile of poverty and human development and will prove to be an opportunity for thoughtful reflection on how we can best participate in the necessary processes of change. How can nursing research contribute to the goal set by the United Nations for 2015? As we continue to identify the specific issues, we must work across sectors (health, social welfare, housing, and corrections, to name but a few) to develop and test programs and policies that support human development by reducing poverty. We need to cast our eyes higher and resolve to address the problems not just one person at a time, or even one system at a time, but through the entire web of systems that together serve to perpetuate poverty.

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Discourse

Poverty, Human Development, and Health in Canada: Research, Practice, and Advocacy Dilemmas

Dennis Raphael

Introduction

Canada's poverty rates are among the highest in the wealthy industrialized nations (Organisation for Economic Co-operation and Development [OECD], 2008). Despite the accumulating evidence that impoverishment is one of the greatest threats to human development, health, and quality of life, little progress has been made in addressing the incidence and effects of poverty (Raphael, 2007i). Much of this inaction has to do with the reluctance of government authorities to implement policies that will (a) reduce the extent of material deprivation experienced by Canadians, and (b) provide health supports and services to impoverished Canadians (Raphael & Bryant, 2006). Governments are assisted in their avoidance of these issues by the existence of conflicting models of poverty and its effects, the limiting of health-related research to traditional approaches associated with epidemiological and behavioural models of health and its determinants, and the difficulties associated with engaging in forceful health advocacy in increasingly conservative political environments (Raphael, Curry-Stevens, & Bryant, 2008).

These issues are especially important to health-care workers, as the presence of poverty (a) influences human development in all its spheres, (b) is a determinant of morbidity and mortality associated with a variety of disorders, and (c) shapes the ability of Canadians to access and benefit from health services (Raphael, 2007c, 2007g). Examination of these issues and how they could be addressed by health authorities, agencies, and advocacy groups suggests ways forward for researchers, health-care workers, and citizens concerned with maximizing human development and enhancing health.

Defining Poverty

There are two main conceptual issues related to poverty. The most widely discussed is definitional and concerns the distinction between absolute and relative poverty (Gordon, 2006). *Absolute poverty* can be defined as an inability to have one's basic human needs met. Starving people in the developing world and Canadians sleeping on the street or queuing up at food banks are the most common images of poverty in Canada (at least as evidenced by the comments of the hundreds of undergraduate students I encounter each year). *Relative poverty* can be defined as an inability to obtain the economic and social resources necessary to engage in the kinds of behaviour expected of members of a particular society (e.g., attending educational, social, or recreational events; maintaining a healthy diet; securing adequate housing; dressing appropriately for the seasons; buying gifts for special occasions) (Townsend, 1993). With both definitions, poverty entails material and social deprivation and an inability to participate in various societal activities (Pantazis, Gordon, & Levitas, 2006).

It is accepted among Canadian poverty researchers and international organizations such as the United Nations Development Program (UNDP), the United Nations Children's Fund (UNICEF), and the OECD that relative poverty — usually based on an individual or family income less than 50% of the median national income — is the most useful measure for ascertaining poverty rates in wealthy developed nations such as Canada (Innocenti Research Centre, 2005; OECD, 2008; UNDP, 2008). The use of such indicators finds Canada performing very poorly in terms of poverty ranking: 19th of 30 industrialized nations for adults, 21st for families with children, and 20th for children (OECD, 2008). Most poverty researchers in Canada apply relative poverty metrics (see below) for determining the presence of poverty (Williamson & Reutter, 1999).

The second conceptual issue is explanatory, and though less discussed it profoundly shapes the manner in which poverty is conceived and researched. The distinction here is between individual (liberal) and structural (critical) explanations for the existence of poverty (Wright, 1994). Individual explanations focus on the attributes of individuals and how these lead to poverty. According to these explanations, poverty results from a lack of education (on the part of individuals and groups), lack of motivation, the presence of physical or mental illness, or intentional dependence on the welfare or social assistance system (Raphael, 2007e).

Most enlightened researchers and health-care workers avoid motivational or dependence-type analyses. However, poverty is frequently attributed to illness or lack of education. Such analyses assume that if adequate health promotion and care or adequate educational programs were available poverty rates would be reduced. They ignore the fact that society is organized such that vulnerable people (i.e., those with little education or with a physical or emotional affliction) end up living in poverty.

These individual analyses fail to acknowledge the fact that the structural organization of society shapes the extent and depth of poverty. Is it reasonable to assume that the parents of Scandinavian children — among whom the poverty rate is less than 5%, as compared to 15% among Canadian children — are profoundly more educated, motivated, and lacking in physical or mental illness than their Canadian counterparts (OECD, 2008)? Clearly, there has to be more to cross-national jurisdictional differences in poverty rates than the presence or absence of various individual characteristics. Nevertheless among health researchers in Canada there has been little conceptual analysis and research examining societal structures (e.g., wage structure; income and wealth distribution; provision of necessities such as child care, housing, and food as a basic right) as determinants of poverty rates and their subsequent effects upon health (Raphael et al., 2006).

Measuring Poverty

Internationally, poverty is usually indicated if individual or family income is less than 50% of the median national income. Statistics Canada's Low Income Measure (LIM) is the Canadian manifestation of this poverty measure (Raphael, 2007a). The more commonly applied Low Income Cut-Off (LICO) identifies whether an individual or family is experiencing the "straitened circumstances" associated with spending significantly more than the average individual or family on basics such as food, housing, and clothing. The LICO can be calculated using either before-tax or after-tax income. Another commonly used measure is the Market Basket Measure (MBM) devised by Human Resources Development Canada (2003). All of these measures provide roughly comparable estimates of the incidence of poverty in Canada (Raphael, 2007a).

Poverty in Canada

The poverty rate in 2004, based on pre-tax LICOs, was 15.5% for all Canadians and 17.1% for children (Raphael, 2007k). The depth of poverty varied across the country, from 19.2% for adults and a whopping 23.5% for children in British Columbia, to 11.7% for adults and 10.8% for children in Prince Edward Island (Raphael, 2007k). Poverty rates for female-led families are exceptionally high in Canada (52.1%). As noted above, international comparisons place Canada 19th of 30 nations for adult poverty and 21st of 30 nations for child poverty. Poverty rates are exceptionally high among recent immigrants of colour, Aboriginal Canadians, single adults, and people with disabilities (Raphael, 2007k). Women show higher rates than men and children show higher rates than adults.

Poverty and Its Effects on Human Development

A remarkably consistent body of evidence has accumulated concerning the detrimental effects of poverty on human development (however defined), health status, and quality of life (Raphael, 2007g). These effects are not limited to individuals but carry over into community well-being, as evidenced by issues of safety, crime, and community cohesion and solidarity (Raphael, 2007j). The various models of this process range from physiological models of stress and its impact on the immune, metabolic, and endocrine systems, to political economy models focused on the distribution of societal resources (Raphael, 2007h). Poverty is not only the primary determinant of children's intellectual, emotional, and social development but also an excellent predictor of virtually every adult disease known to medicine, including type II diabetes, heart disease and stroke, arthritis, a variety of respiratory diseases, and some cancers (Davey Smith, 2003). An emerging theme is powerlessness, both political and personal, as an important contributor to poor health due largely to the inability of individuals — especially those in the lowest socio-economic stratum — to influence the material conditions of their lives (World Health Organization, 2008).

In addition to the statistical evidence on the effects of poverty, an emerging body of research has put a human face to the material and social deprivation experienced by impoverished Canadians (Raphael, 2007d). Of particular value has been work documenting the social exclusion experienced by low-income Canadians (Reutter et al., 2009; Stewart et al., 2008) and children's experience of poverty (McIntyre, Officer, & Robinson, 2003; Robinson, McIntyre, & Officer, 2005). Such narratives illustrate the clear links between material and social deprivation and adverse outcomes.

Of particular relevance is the experience of impoverished Canadians with the health and social service systems (Raphael, 2007c). Interactions with government social service systems are especially problematic, characterized by stigma, shame, and sometimes even outright degradation. Interactions with community agencies and organizations are much more positive (Williamson et al., 2006). Interactions with the health-care system are generally positive, but there are significant issues related to access to care and the affordability of medical and ancillary services (Schoen & Doty, 2004).

While there has been research into the effects of poverty on human development, health status, and quality of life in Canada, this work has been carried out by only a handful of researchers (Raphael et al., 2006). Contrast this situation with the research (and media) emphasis on medical treatment and epidemiological studies of behavioural risks, with their focus on the "holy trinity of risk" — tobacco use, poor diet, and lack of exercise (Canadian Population Health Initiative, 2004; Gasher et al., 2007; Hayes, 2007; Nettleton, 1997). More attention, both research and practical, on reducing poverty and its effects and on documenting the lived experience of poverty is sorely needed.

Research and Interventions to Ameliorate the Effects of Poverty

Significant effort goes into ameliorating the effects of poverty on human development, health status, and quality of life. This work is carried out by those working in the health-care and public health systems; community agencies; and the education, social work, police and justice, housing, and nutrition sectors. Diderichsen, Evans, and Whitehead (2001) outline a model comprising various levels of intervention aimed at addressing the effects of social stratification whereby the layer at the bottom experiences poverty and its effects. In this model, societal characteristics structure human development and health. Public policies shape the extent of social stratification within a society. Stratification results in many individuals at the bottom being exposed to the most adverse living circumstances — those associated with problematic human development, poor health status, and inferior quality of life.

Interventions can take place on many levels. One can respond to the problems by directing attention to the end of the sequence and setting up new and improved health, social service, justice, and police systems. Currently, many of Canada's policy responses to poverty are focused on such efforts. Further upstream, one can attempt to decrease the vulnerability of impoverished people by enhancing their coping skills: *We will not improve your living conditions but we will attempt to provide you with the skills needed to cope with the deprivation associated with adverse living conditions.* While there is some evidence showing their effectiveness, these interventions do little to address the source of the afflictions: poverty. The emphasis is on making exposure to adverse living conditions more palatable through the targeting of services. The extent to which these services can achieve success, considering the unfavourable living circumstances of impoverished people, is open to debate.

Interveners can also move still further upstream and attempt to reduce the negative conditions to which impoverished people are exposed. This could include the provision of universal affordable child care, health and social services, and educational and recreational opportunities that are viewed as entitlements rather than as user-paid options. This decommodification of resources, services, and benefits has been the direction taken in many nations to reduce the detrimental effects of social stratification in general and the effects of material and social deprivation associated with poverty in particular. Canada scores very low on these indices of decommodification (Coburn, 2006).

Perhaps the most efficacious means of reducing the effects of poverty would be to provide monetary resources to people so they will not experience poverty in the first place. This would take the form of employment that pays a living wage, social assistance and disability benefits raised to health-sustaining levels, and transfers to citizens on the basis of both universal entitlement and identified needs (Raphael, 2007f). In many European countries this is the approach that has proved the most successful. The structural analysis of poverty that is implied in this approach — and in related research — is rarely employed in the Canadian health sector.

Research and Interventions to Eliminate Poverty

There is increasing recognition that the determinants of the incidence of poverty have more to do with the making of public policy than with the altering of human characteristics (Alesina & Glaeser, 2004; Rainwater & Smeeding, 2003). How it is that poverty has been virtually eliminated in the Nordic nations while remaining at consistently high levels in Canada and the United States? Indeed the OECD reports that, over the past decade, income inequality and poverty have increased more in Canada than in most other developed countries (OECD, 2008). In addressing the above question, analysts have been focusing on economic and political systems as the primary determinants of poverty.

The workings of our economic and political systems and the societal discourses that are used to justify their approach have been nicely organized by two Canadian sociologists, Saint-Arnaud and Bernard (2003). Building upon Esping-Andersen's (1990, 1999) insights regarding various forms of the welfare state, these authors provide a narrative that succinctly sums up the relationship between systemic differences in poverty rates and the development of different ways of addressing citizen security in terms of public policy. Saint-Arnaud and Bernard identify four types of welfare state: *liberal, social democratic, conservative,* and *Latin.*

The United States, Canada, and the United Kingdom are *liberal* welfare states. Of the four types, the liberal welfare state provides the least support and security to its citizens. Despite the persistence of the United States as a welfare state outlier, characterized by striking shortcomings in the provision of security to its citizens, the public policy profiles — and poverty rates — of both Canada and the United Kingdom have consistently been found to be closer to those of the United States than to those of European welfare states, where citizens are assured of more security and support (Bernard & Saint-Arnaud, 2004). In liberal welfare states the dominant ideological inspiration is liberty and the dominant institution is the marketplace. The result is minimal government intervention in the workings of the marketplace; indeed such intervention is seen as providing a disincentive to work and as breeding "welfare dependence."

The outcomes of this ideological persuasion in the United States, Canada, and the United Kingdom are meagre benefits provided to social assistance recipients, weak legislative support for the labour movement, underdeveloped policies for assisting those with disabilities, and a reluctance to provide universal services and programs. The services and programs that do exist are residual — intended to provide the most basic needs of the most deprived. Of the developed nations, Canada ranks among the lowest in terms of public spending on infrastructure in general and on families, pensions, early childhood education and care, and supports for persons with disabilities. Also, Canada's social assistance rates are among the lowest in the world (Raphael, 2007b). The end result is very high poverty rates (Innocenti Research Centre, 2005, 2008).

The opposite situation prevails in *social democratic* welfare states. The ideological inspiration for the central institution of these nations — the state — is equality, the reduction of poverty, and full employment (Saint-Arnaud & Bernard, 2003). The government's responsibility is not seen as limited to meeting the most basic needs of the most deprived. Rather, the organizing principle is universalism in terms of social rights. Denmark, Finland, Norway, and Sweden best exemplify this form of the welfare state. Governments with social democratic political economies are proactive in identifying social problems and issues and in promoting the economic and social security of their citizens.

The social democratic welfare state is associated with the virtual elimination of poverty, gender and class equality, and regulation of the market in the service of the people (Esping-Andersen, 1999). Public policy is directed at supporting programs that serve to reduce social inequality, such as child care, services for those with disabilities, programs that address racism and homophobia, job training, and support for education (Swedish Ministry of Health and Social Affairs, 2002; Swedish Ministry of Industry Employment and Communications, 2004a, 2004b; Swedish National Institute for Public Health, 2003).

Even welfare states that are considered *conservative* (e.g., France, Germany, Netherlands) or *Latin* (e.g., Greece, Italy, Portugal) generally ensure a level of social security that is superior to that provided by liberal welfare states (Bambra, 2004; Esping-Andersen, 1999; Navarro & Shi, 2001). In conservative and Latin welfare states, the ideological favouring of social stability, wage stability, and social integration is expressed through the provision of benefits based on insurance schemes covering a variety of family and occupational categories. These well-organized benefit schemes are directed towards the primary wage earner, with less concern for the promotion of gender equality than is found in social democratic welfare states.

Faced with evidence of these distinctions and their importance for measuring social and health inequalities, what can researchers and workers in liberal political economies do to increase their understanding of poverty and its effects and develop means of addressing these issues? There is clear evidence — supported by the Canadian experience — that poverty-reducing policies are more likely to develop when social democratic parties are in power or are part of minority governments along with other political parties (Raphael, 2007e). Critical analyses of ideological and political barriers to poverty reduction, though rarely conducted in Canada, appear to be a fruitful area of research activity.

More importantly, advocacy for poverty-reducing policies not only must continue but should be clearly related to human development, health, and quality of life. Evidence shows that such advocacy is favourably received by the Canadian public, if not always by our elected representatives (Reutter, Harrison, & Neufeld, 2002; Reutter, Neufeld, & Harrison, 1999). Many health researchers and workers have told me personally that raising such issues can be a "career-threatening move." Whether or not that perception is accurate, it must be addressed and, if appropriate, responded to strongly by the health-care community. Recommended actions are those that focus on addressing the social determinants of health (e.g., income, housing and food security, social inclusion/exclusion, early childhood development, and access to health care) (Campaign 2000, 2008; Canadian Association of Food Banks, 2004; Raphael, 2008). Research is needed to look into why such efforts have so far proved to be relatively ineffectual.

Conclusion

There are many fruitful areas for research into poverty and its effects on human development, health, and quality of life. These include careful, theoretically driven analyses of statistical databases to identify the determinants of human development, health status, and quality of life (Raphael et al., 2006). Inquiry into the lived experience of poverty and barriers to/access to health care is also needed (McGibbon, 2008). We need more critical analyses of the economic, political, and social barriers to the implementation of public policies that address poverty. There is resistance within much of the health sector to the idea of such analyses, yet the carrying out of these kinds of research and the dissemination of the findings are essential, as is the implementation of recommendations resulting from these analyses. To date there has been some excellent work done to research the structural determinants of poverty and the means by which both poverty and its adverse effects might be ameliorated. Further efforts are needed.

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Résumé

Stratégies d'apprentissage et d'intégration des connaissances chez les infirmières et les intervenants au service des sans-abri

Manal Guirguis-Younger, Ryan McNeil et Vivien Runnels

Répondre aux besoins des sans-abri est souvent une tâche difficile pour le personnel de la santé, vu les problèmes complexes qui touchent cette population et les lacunes en matière de connaissances. Comment améliorer la capacité des intervenants à dispenser des soins aux sans-abri? Les auteurs ont analysé les stratégies d'apprentissage et d'intégration des connaissances mises en œuvre par des infirmières et des travailleurs de la santé employés par des organismes de services aux sans-abri dans une ville canadienne. Huit intervenants ont participé à des entrevues semi-structurées; les données ont été soumises à une analyse narrative ainsi qu'à une analyse comparative constante. On a cerné trois stratégies : intégration des expériences passées dans l'exercice clinique; interaction avec les clients pour cerner leurs besoins et leurs limites; échange de connaissances entre professionnels. Une meilleure appréciation de ces méthodes pourrait inciter les programmes de sciences infirmières et les organismes de santé à mieux transmettre aux intervenants les compétences nécessaires pour dispenser des soins aux sans-abri.

Mots clés : sans-abri, sciences infirmières

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Learning and Knowledge-Integration Strategies of Nurses and Client Care Workers Serving Homeless Persons

Manal Guirguis-Younger, Ryan McNeil, and Vivien Runnels

Health-care workers serving homeless persons often face difficulties in addressing the needs of this population due to the complexity of the health challenges and gaps in clinical knowledge. How can health-care workers enhance their ability to care for this population? The authors explore the learning and knowledge-integration strategies of nurses and client care workers employed by organizations targeting homeless persons in a Canadian city. Semi-structured qualitative interviews were conducted with 8 health-care workers. The data were examined using narrative analysis and constant comparative analysis. Three strategies were identified: integrating past experiences into clinical practice, interacting with clients to identify care needs and boundaries, and engaging in interprofessional knowledge exchange. A better understanding of these strategies may help nursing programs and health-services organizations to equip health-care workers with the skills they need to serve homeless persons.

Keywords: homeless persons, education, nursing, evidence-based medicine

Introduction

Thousands of Canadians experience homelessness each year, although the extent of homelessness is unknown. Statistics Canada (2001) has estimated that, over a 1-year period in Canada, more than 14,000 persons stay at least one night in an emergency or temporary shelter intended for persons with no place of residence. Critics, however, point out that this estimate underreports the number of persons who are homeless because it does not include rough sleepers and the hidden homeless (Frankish, Hwang, & Quantz, 2005). Elsewhere it has been estimated that as many as 150,000 persons experience homelessness each year in Canada (Laird, 2007).

Persons who are homeless often have diverse and complex health challenges that are unmet by mainstream health services, resulting in mortality rates several times higher than those for the general population (Guirguis-Younger, Runnels, Aubry, & Turnbull, 2006; Hwang, 2000; Hwang et al., 1998). Previous studies have reported that the health status of this population is impacted by high incidences of substance use, mental health challenges, traumatic brain injuries, mobility impairments, and chronic and infectious diseases (Hwang, 2001; Hwang et al., 2008; Klee & Reid, 1998; Kral, Molnar, Booth, & Watters, 1997; Nyamathi, Leake, & Gelberg, 2000). Both the severity and the complexity of these health challenges are exacerbated by a life of homelessness. Persons who are homeless face barriers to accessing primary, secondary, and tertiary care due to poverty, discrimination, and social and geographic isolation (Hwang, 2001; Kushel, Vittinghoff, & Haas, 2001; Wen, Hudak, & Hwang, 2007). The demands of meeting basic needs, such as food, shelter, and addiction management, make it difficult for clients to access medication and adhere to treatment and its follow-up with nurses, physicians, and care specialists (Gelberg, Gallagher, Anderson, & Koegel, 1997; Kim, Kertesz, Horton, Tibbetts, & Samet, 2006).

Over the past decade, community and health-care leaders across Canada have sought to develop specialized services that are responsive to the health needs and challenges of homeless persons. These include integrated health and social service networks, shelter-based health services, mobile health units, and specialized health facilities offering harm-reduction, mental health, primary care, hospice, and palliative services (Daiski, 2006; Hwang, Tolomiczenko, Kouyoumdjian, & Garner, 2005; Podymow, Turnbull, & Coyle, 2006; Podymow, Turnbull, Coyle, Yetsir, & Wells, 2006). Persons who are homeless pose significant and unique challenges for nurses and client care workers. In addition to providing physical care, nurses and client care workers may have to address clients' emotional needs in order to maximize positive health outcomes (Nyamathi et al., 2008). The requisite skills to address these needs are not always included in formal education. Consequently nurses and client care workers have to identify and develop strategies for obtaining knowledge and integrating it into their practice. This article explores the learning and knowledge-integration strategies used by nurses and client care workers employed by health-care organizations that target homeless persons.

Methods

Design and Procedure

Semi-structured in-depth qualitative interviews were conducted with eight nurses and client care workers as part of a Social Sciences and Humanities Research Council–funded study investigating the health and end-of-life care needs of homeless persons. A case-study design was used to explore multiple factors entailed in delivering health care, including nursing care, to persons who are homeless (Yin, 2003). The interview guide was designed to allow the participants to describe in detail their role as providers of health care to homeless persons. Participants were asked to share their impressions of the barriers to and facilitators of health-service delivery, training and education needs, and strategies used to facilitate their work with homeless persons. The study was approved by the Research Ethics Board at Saint Paul University in Ottawa, Ontario.

Participants and Setting

Data were collected through individual interviews conducted on the premises of organizations providing health care to homeless persons. Services provided by these organizations included primary care, mental health care, rehabilitative care, and end-of-life care. The sample comprised four registered nurses, one registered practical nurse, and three client care workers. Client care workers provide personal support such as assistance with basic hygiene and medications and monitoring of needs. They receive formal training at the college level.

Institutional permission was obtained to access the premises of the participating health-care organizations. Potential participants were then given a letter outlining the study and requesting them to indicate their willingness to take part by contacting the research team to schedule an interview. Interviews ranged in duration from 1 to 3 hours. One interview was conducted over two separate sessions. Detailed information about the participants and the setting is withheld in order to avoid compromising participant confidentiality.

Data Analysis

The interviews were audiotaped and transcribed verbatim by research assistants. The transcriptions were kept in separate files and line numbers were assigned to facilitate coding. The transcriptions were then examined using narrative analysis and constant comparative analysis (Reissman, 1993; Strauss & Corbin, 1990). The purpose of the analysis was to identify themes related to the special knowledge and competencies of nurses and client care workers providing services to homeless persons. The transcripts were independently reviewed by two members of the research team. Significant themes and sub-themes were identified through multiple discussions and explication of each theme.

Findings

Analysis of participants' experiences identified three primary strategies used to acquire knowledge and facilitate its integration: informing one's practice by integrating past professional experiences with marginalized populations or experiencing marginalization oneself, establishing and implementing a client-centred approach, and increasing one's ability to address client care needs by engaging in interprofessional knowledge exchange.

Integrating Past Experiences

One of the main themes that emerged was integrating one's personal and employment experiences into frontline health-care work. By integrating past experiences into their work with homeless persons, participants were able to (a) contextualize client care needs, (b) integrate effective and efficient communication strategies, and (c) address situations requiring immediate attention and prioritize clients' needs.

Contextualizing clients' needs. While participants reported diverse professional and personal experiences, from serving with the armed forces to acting as caregiver to an elderly parent, these experiences shared many characteristics insofar as they helped the participant to prioritize and attend to the care needs of clients. One nurse recounted a personal experience:

> *I lost my mother when I was 40, and she was only 62 and she died of breast cancer. I went through the whole journey with her over 2½ years. I knew what I wanted for my mother — I knew what comfort I wanted for her and I knew what services I wanted available to her.*

The participant drew upon this experience to better understand end-of-life needs and to address the emotional needs of clients.

Participants believed that it was inappropriate to deny services to clients who are disruptive or even abusive. They explained that when working with this population they viewed such behaviours in the context of mental illness, addictions, and the broad set of difficulties facing persons who are homeless. When using this approach, participants drew strength and confidence from their previous experience working with difficult persons, such as angry customers. A client care worker explained:

> *I had to deal with people at the office where I used to work, and they had problems too…they would get upset also. That prepared me in a way… some of the cases were very hard but I always managed to work through it.*

Integrating communication strategies. Communication strategies used in prior work settings were often adapted and integrated into clinical practice. These included strategies to communicate with clients and to ensure privacy of health information. One nurse described a particularly helpful strategy that he used to ensure patient confidentiality:

> *We've had issues where family members want to know more about the client and the client doesn't want that… We've actually developed systems*

> *where we would relay information on the phone. We would use a code I came up [with]. I used to be in the military, so I came up with this. I would say, "How old are you?" The response was "Happy Easter." Then I knew I was talking to his sister. I could relay everything to his sister, because we had issues with his ex-wife calling and people telling her information.*

This strategy was helpful in respecting the client's choice of whether to disclose health information to family and friends. Another participant drew upon previous experience working as a dispatcher for a trucking company:

> *I had to deal with truck drivers. I was a dispatcher…talking on the phone…receiving calls from companies. That helped, because here we answer the phone quite a bit, we're talking with the public, and there's appointments to be written down or…just talking with people. People at the office where I used to work…they had problems too, like "Where's my van"… "I have a pickup to do"… They would get upset also. So that prepared me in a way.*

Addressing immediate situations and balancing the care needs of clients. Participants identified professional skills they had developed that helped them to address situations requiring immediate attention and to prioritize clients' needs. Experience with demanding situations in a variety of settings helped them to engage confidently in clinical decision-making, devise strategies for identifying urgent needs, and prioritize care tasks in an unpredictable environment. One nurse described the decision-making process:

> *You figure out who is the most important…you're most worried about the person with the oxygen, and once that's taken care of you can worry about the person that's in pain. And then you deal with…on the phone you just ask the client care worker to take a message, and then what you do with the person that's intoxicated — you would deal with them probably last, because it's not going to change if I deal with it 5 minutes from now or 5 minutes after [that].*

Establishing and Implementing a Client-Centred Approach

Participants identified the important role played by client-focused strategies in the deliverability of health services to clients. They established the necessary conditions for a client-focused approach by (a) engaging in transparent discussions with clients about all aspects of their care, (b) communicating to clients the consequences of their decisions, and (c) developing and following a treatment plan in keeping with the client's preferences. This allowed them to implement care strategies that were respectful of clients' individual needs and experiences.

Establishing conditions for a client-centred approach. Service refusal and non-compliance with treatment among homeless persons can often be linked with mistrust of mainstream health services and difficulty adjusting to institutions providing services (Hwang, 2001). Nurses and client care workers stated that building trust is a necessary step in facilitating effective service delivery to marginalized individuals. One nurse observed:

> *First, they have to trust me, and the trust sometimes takes a while… After a while of seeing you, they warm to you and then start telling you the whole story, and then you can really help them and assess what they really need.*

Participants also built trust by engaging in informal activities with clients. A client care worker reported:

> *Talking with them. Spending time with them. Playing cards with them. Bringing them down to the big TV room. Taking them out for a walk or taking them with their wheelchair. Just trying to find a way to get close to them.*

Trust-building had three further components: maintaining transparency concerning health status and treatment, implementing client-paced treatment, and establishing boundaries and consequences with respect to behaviour.

Transparency. Participants identified honesty as a necessary condition for a trusting relationship between health-care workers and clients. One nurse observed:

> *You don't lie to them. You tell them. Honesty is your best bet with this clientele… And you stick to your word too. That way they know if you say something you mean it. And then, eventually, they trust you after a little while.*

The participants also said that honesty helps to establish a context whereby services can be provided by health-care workers and accepted by clients. Both nurses and client care workers expressed a belief that the strategies of gentle persuasion and respectful confrontation can help clients come to terms with their condition and consider treatment options. A nurse clinical manager explained:

> *We just give them time, ask questions subtly, just like, "Who are you connected to?" And then we get more information from that person, and it just opens doors… A lot of guys will come and say, "I have no addiction,"*

> *and then you'll look at them in a while and [ask], "Okay, why are there track marks on your arm?"*

Client-paced treatment. Because mental illness can complicate treatment, participants made sure that treatment was paced to accommodate the client's needs and preferences. One nurse reported:

> *We have a guy right now here — he has terminal cancer. He wasn't getting treatment for ages because he believed that was just an excuse for some surgeon to go in and steal his kidney. Fortunately he keeps coming back here and we've been able to start treatment. However, it's taken us a year to get to that point.*

By disclosing details of the treatment plan and assuaging fears, nurses and client care workers were able to ensure that crucial health interventions were accepted by their clients. Participants viewed the time taken to develop relationships and accommodate clients' needs and preferences as a necessary part of health-service delivery.

Boundaries and consequences. Participants stated that the majority of their clients received health services primarily in shelters or through affiliated organizations. In an effort to keep clients in contact with services, participants encouraged them to follow established shelter rules. Participants conveyed the idea that setting clear limits facilitated the delivery of health care by clarifying expectations and allowing clients to assume part of the responsibility for their own care. One nurse stated:

> *You're just straight up: you can't do this, you can't do that, I will do this for you, I won't do that for you, if you do this we'll have to send you to… if you come back drunk we'll have to send you to outreach, if you come sober I won't… And it just happens over time. Because they see we actually do care about them and we want what's best for them. So they begin to trust us. And that's how it kind of works.*

Implementing a client-centred focus. Both nurses and client care workers used the term "client" rather than the customary "patient" to describe persons accessing health services. This use of language reflects the multiple dimensions of care delivery in particular settings. The care provided by the participants was focused on the physical, social, and emotional needs of clients.

Basic needs. Persons who are homeless face many challenges that may cause them to focus primarily on meeting basic needs such as food, clothing, and shelter. Nurses and client care workers were keenly aware that their clients frequently lacked the basic necessities and that it was critical this issue be addressed as part of service delivery. One client care worker said:

> *First, well, I give them what they need. I give them soap, towels, toothbrush, toothpaste, deodorant. And if they need clothes I'll get them clothes. Make sure the TV is going for them and just talk with them.*

Participants indicated that this approach helped to make clients "feel at home." They further engaged with clients to see how they could help them meet basic needs and any additional needs that were revealed once a relationship had developed. A client care worker put it this way:

> *If I see something is not right or missing, I contact the head nurse, and she always is able to give me an answer, or she will give me a contact [so] I can find out what we need for this person.*

Respecting clients' physical space and being attuned to their personal vulnerabilities. Nurses and client care workers were aware that homelessness creates the conditions for vulnerability to violence and trauma. They therefore sought to create a safe atmosphere for their clients. A nurse reported:

> *You ask them if there's anything they need. You explain that, you know, "This room is your room and you've got a TV — you can watch whatever you want." And you tell them basically what time the meals are, you know, "You can ring the bell, you can come to…or only ring the bell if it's an emergency."*

Participants were accepting of the needs and experiences of clients and were prepared to assuage their sense of being stigmatized because of their homelessness. A client care worker stated:

> *I can talk with them. I don't care what these people have done. Doesn't matter to me. My job here is to help them, and that is what I will do.*

Honouring clients' lives. Nurses and client care workers indicated that an important part of creating a client-focused model of care was honouring clients' lives and narratives. To them, a component of holistic care was the setting aside of time and physical space to sit with clients and listen to their stories. A nurse observed:

> *No one grows up saying, "Gee, when I grow up I want to be a homeless person who has nowhere to live." Everyone has a story of how they got there and why they got there. And some of it is tragic, some of it is funny, and some of it is painful. But it's a story that they want to tell.*

Participants believed that if clients want to share their personal stories, then they should listen.

Engaging in Interprofessional Knowledge Exchange

Participants described interprofessional knowledge exchange and integration strategies that enhanced their ability to provide care. These strategies were multifaceted and reflected the important role of knowledge about client needs and specific clinical approaches. The strategies included: seeking formal and informal opportunities to acquire knowledge from other health-care workers and from experts, identifying complementary clinical roles, and offering emotional support to co-workers.

Continuing education, both formal and informal. Participants sought out formal and informal opportunities to engage with other health professionals and local and regional experts to better understand the health-care needs of homeless persons and to devise strategies for improving care. Through opportunities such as orientation and refresher courses and workshops, peer observation of practice, and discussions with members of the care team, participants learned how to address clinical challenges and gaps and emerging health trends such as increased drug use and co-occurring HIV/AIDS and hepatitis C. One client care worker said:

> *I'm always willing to learn. I take courses at least once or twice or three times a month. I get into every course that's going by. Tonight I'm going on a 3-hour course…on diabetes. Friday I'm going to the one on palliative care.*

The diverse and complex care needs of homeless persons required participants to develop strategies for integrating knowledge into their work setting. Participants engaged with other health professionals to identify possible ways of doing so. This helped them to contextualize knowledge and then use it. One participant reported:

> *My first couple [of] shifts, I had a buddy shift with another RPN. She showed me what you do and things like that. Honestly, you really start relying upon the client care workers. When I first started here, I relied upon the regular client care worker, or a client care worker that knew the clients.*

Identifying complementary roles. Participants expressed the view that the complementary roles of nurses and client care workers served to enhance overall care. Under the close supervision of nurses, who provided feedback and constructive criticism, client care workers learned skills that could be applied in other health-care settings. "I worked in the community for almost 13 years and we didn't do dressings," said one client care worker. "Here we have the chance." A nurse clinical manager elaborated:

> *Because we have close to 60 people that we technically see every day, the client care workers really have to do the hands-on. I teach them how to do*

> *the dressings. I teach them how to do insulin, how to monitor blood pressure, how to check blood sugars. And then they can do it on their own.*

According to client care workers, this system had a positive effect on their confidence and their job satisfaction.

The complementary roles played by the health-care workers was acknowledged and valued by their organizations, as was the collaboration of all team members in developing trusting and meaningful relationships with clients. Because of their heavy involvement in the provision of health and social care, client care workers helped to contextualize client needs and to communicate undocumented health and social care needs. This in turned enhanced the ability of the care team to address changes in a client's condition. "The client care workers are very good at making them feel comfortable," explained a clinical coordinator, "so they open up to them."

Offering emotional support to co-workers. Participants indicated that supporting the emotional care needs of team members was part of the knowledge-exchange process. It enabled them to critically reflect on the meaning of their work in a safe and supportive environment and to integrate their experiences into their professional practice and build self-confidence:

> *When our clients are in bad shape, or end of life, we respect each other — we give moral [support to] each other.*

An environment of sharing and mutual support was also seen as important for team chemistry and for maintaining a positive culture.

Discussion

Contemporary nursing practice and education are centred on evidence-based practice. Sackett, Straus, Richardson, Rosenberg, and Haynes (2000) define evidence-based medicine as "the integration of best research evidence with clinical expertise and patient values" (p. 1) and as having three key components:

- research approaches that emphasize quality in the production of evidence, to avoid bias and to produce "the best research evidence" (p. 1)
- a view of expertise as "the ability to use our clinical skills and past experience to rapidly identify each patient's unique health state and diagnosis, their individual risks and benefits of potential interventions, and their personal values and expectations" (p. 1)
- the identification of patient values as "the unique preferences, concerns and expectations each patient brings to a clinical encounter and

> which must be integrated into clinical decisions if they are to serve the patient" (p. 1).

Through the use of these components, according to Sackett et al., health professionals and clients can "form a diagnostic and therapeutic alliance which optimizes clinical outcomes and quality of life" (p. 1). While the participants in the present study may not have received formal training and education in evidence-based practice, it is clear that they had integrated these components — in particular the second and third — into their practice. The nurses and client care workers indicated that research was welcome; they expressed an interest in research findings and education.

The findings show that nurses and client care workers do not rely solely on "hard evidence" when addressing health-care needs. Although chronic conditions and co-morbidities may have led them to focus on health status, the participants indicated that engaging clients and addressing barriers to compliance with treatment were a necessary first step. The findings further suggest that nurses and client care workers see the importance of supporting each other practically and emotionally and sharing knowledge about their clients' needs and experiences. Continuing education and professional development opportunities play an important role in the professional behaviour of health-care personnel. However, relationships among health-care workers who value experiential knowledge and demonstrate a willingness to incorporate such knowledge into their practice suggest that adaptations are being made to evidence-based practice. Such strategies are a response to the diverse care requirements of persons who face challenges in meeting basic needs, engage in high-risk behaviour, and lack access to health services. Nurses and client care workers providing services to homeless persons in shelters or in community settings are extending essential medical services to those who are traditionally underserved medically. These health professionals play an essential role in closing service gaps and reducing inequities in health-care delivery. The strategies described by the participants in the present study could be used by nurses and client care workers in mainstream settings to provide health services to homeless persons, thereby facilitating even greater access to care. This would be a small but important step in reducing the health inequities experienced by persons who are homeless.

Capacity-Building and Critical Approaches

These findings raise important questions for health professionals, academics, and health-services organizations. How can nurses and client care workers enhance their ability to provide care to homeless persons? How can the strategies described in this article be built upon to optimize service delivery and improve health outcomes? The literature on research utilization proposes a number of ways to help nurses and client care workers enhance their ability to use research, address knowledge deficits, and improve practice. These include contextualizing learning within the practice setting, encouraging reflective practice, identifying opinion leaders, and supporting communities of practice (Gabbay et al., 2003; Locock, Dopson, Chambers, & Gabbay, 2001; Schön, 1983; Senge, 1990; Wenger, McDermott, & Snyder, 2002). The participants in the present study worked collaboratively to improve client care, thus forming a community of practice based on client needs. An excellent approach is to consider how best to support the ability of health-care workers to play multiple roles by developing a community of practice.

Critical approaches that feature questioning and analyzing workplace arrangements and practices that facilitate new and evidence-based learning, or that address barriers, may be helpful. One example of a critical approach to knowledge exchange is the Registered Nurses Association of Ontario's (2002) *Implementation of Clinical Practice Guidelines* toolkit, which assesses environmental readiness for the implementation of clinical practice guidelines and identifies areas that need to be addressed in the implementation of health-care innovations. Areas that the tool identifies as important include workplace structure and culture, communication, leadership, knowledge skills and attitudes of the target group, commitment to quality management, availability of resources, and interdisciplinary relationships.

Conclusion

Capacity-building to serve homeless persons through evidence-based practice must consider not only the best available research evidence but also professional expertise and client preferences. The conditions necessary for the delivery of health care to homeless persons — such as relationships of trust among staff and between staff and clients — must be emphasized in nursing education programs and by health-care organizations. Knowledge exchange can be facilitated through critical reflection on the institutional and operational contexts of health-service delivery for this population. Knowledge exchange has the potential to improve care by accounting for the diverse needs and experiences of homeless persons and to equip health-care workers with the skills they need to face complex challenges and achieve improved outcomes. The application of the present findings to other health-care settings will require further research and the development of a transferable model of care.

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Résumé

Recherche sur les femmes soumises à une probation imposée par le tribunal ou à une ordonnance de probation

Jodi Hall et Lorie Donelle

Le cadre de vie des délinquantes constitue un bon exemple des inégalités sanitaires que l'Organisation mondiale de la santé a cernées comme étant d'importants déterminants de la santé. Au cours de la dernière décennie, on a noté une hausse importante des condamnations menant à une détention correctionnelle chez les femmes, ce qui fait ressortir la nécessité pressante d'entreprendre des travaux de recherche dans ce domaine. Pour répondre à cette nécessité, une étude pilote a été menée au Canada, plus précisément en Ontario, en vue d'examiner les besoins des femmes qui ont des démêlés avec la justice en ce qui concerne la promotion et les notions en matière de santé. Les auteures font ressortir les aspects du processus de recherche employé auprès de délinquantes en énumérant les difficultés professionnelles et personnelles auxquelles peut se heurter l'équipe de recherche lors du déroulement d'une telle enquête. Dans leur conclusion, elles formulent des recommandations pour les futurs travaux de recherche entrepris auprès des délinquantes en se servant des leçons tirées de l'étude pilote.

Mots clés : délinquantes

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Research With Women Serving Court-Mandated Probation or Parole Orders

Jodi Hall and Lorie Donelle

The life context of women offenders exemplifies the health inequities that the World Health Organization highlights as important determinants of health. In the past decade the sentencing of women to correctional detention has increased dramatically, prompting an urgent call for research in this area. In response to this call, a pilot study was conducted in the Canadian province of Ontario to investigate the health promotion and health literacy needs of women in conflict with the law. The authors highlight aspects of the research process with female offenders by recounting the personal and professional challenges experienced by the research team in carrying out an investigation with this population. They conclude with recommendations for future research with women offenders using lessons learned over the course of the pilot study.

Keywords: health promotion, women offenders, prisoners, research methods

Introduction

Over the past decade admissions to correctional detention centres have increased in Canada, with women representing 10% of admissions to provincial/territorial custody, 5% of admissions to federal custody, 11% of admissions to remand, and 17% of probation and conditional sentencing (Statistics Canada, 2006). The largest proportion of offences leading to incarceration relates to administration of justice (breach of probation conditions and failure to appear in court), theft and possession offences, and assault and related offences (K. Underhill, Statistics and Applied Research, Correctional Services Division, personal communication, October 1, 2008).

The lives of women in conflict with the law are characterized by poverty, abuse, homelessness, multiple health concerns, illiteracy, and lack of education (Cox, 2007; Simpson, Yahner, & Dugan, 2008). High-risk health behaviours (e.g., prostitution, substance abuse, sharing of IV drug paraphernalia) are characteristic of this population (Yasunaga, 2001). In fact, women in conflict with the law tend to have mental health concerns (e.g., schizophrenia, bipolar disorder, depression), high rates of communicable disease (e.g., HIV/AIDS), high mortality rates, substance use issues, and high incidence of chronic disease (Auditor General of Canada, 2003; Correctional Services Canada [CSC], 2004; Enders, Paterniti, & Meyers, 2005; Evans, 2006; Johnson, 2006; Robert, Frigon, & Belzile, 2007), all of which usually persist upon one's release into the community (CSC, 2004). Of women offenders, approximately two thirds are mothers with dependent children (Shaw, 1994) and over 90% serve sentences of less than 6 months (K. Underhill, personal communication, October 1, 2008). In fact, many women serving short sentences and probationary sentences (open custody arrangements) return to poor and/or unsafe housing, unemployment, unstable lifestyle, and extreme marginalization (Condon, Hek, & Harris, 2006; Evans, 2006), conditions that exacerbate their difficulty accessing appropriate health services in their communities (Whynot, 1998). Consequently, the promotion of health within this population has a reverberating effect as women return to their children, families, and communities (Condon et al., 2006; Freudenberg, 2004; Williams, 2007).

In this "health information age," inadequate health literacy constitutes a significant health-care hurdle. Health literacy is defined as the ability to access, understand, and use information in ways that promote and maintain good health (Nutbeam, 2000). Adequate health literacy skills are foundational to effective health promotion and are critical for the successful navigation of the health-care system (Health Canada, 2003; Institute of Medicine, 2004; Nutbeam, 2000). Health literacy also reflects one's ability to act on personal and community health by improving personal lifestyle and general living conditions. Because of its role in enhancing access to and ability to use health information, health literacy is critical to empowerment, which is in and of itself health promoting (Nutbeam, 2000).

It has been estimated that 70% of inmates in Canada read below the Grade 8 level (CSC, 2004). In practical terms, these individuals are challenged to read and comprehend information unless it is brief, simply laid out, and presented in a familiar context (Canadian Council on Learning, 2007; Human Resources Development Canada, 2003). Outcomes of health literacy (i.e., informed decision-making, self-efficacy, and personal empowerment), coupled with effective, accessible community services, are prerequisites for successful transition from custody to community (Evans, 2006; Nutbeam, 2000).

In effect, the life context of women offenders exemplifies the inequities highlighted by the World Health Organization ([WHO], 2008) as important determinants of health. In the past decade increasingly more women have been in conflict with the law (Statistics Canada, 2006), which has resulted in an urgent call for research in this area (Williams, 2007). In response to this call, we conducted a pilot study to investigate the health promotion and related health literacy needs of women offenders in the province of Ontario. While it includes a summary of our findings, this article focuses on the personal and professional challenges we encountered in our research with women offenders. We conclude with research recommendations based on lessons learned during the course of the study. Finally, we highlight our research process with women offenders in the hope of generating further research with this population.

Literature Review

We found a striking lack of research evidence regarding the health of Canadian women in conflict with the law. Of 786 possible publications of interest, 41 were related to the health of incarcerated women and women on probation/parole. While none of the publications addressed health literacy, health promotion, or health-seeking behaviour among women on probation/parole, five addressed the health of Canadian federal women offenders and one addressed the health-related concerns of provincially incarcerated women.

Researchers in the United States have focused on female offender assessment (Brunsman Lovins, Lowenkamp, Latessa, & Smith, 2007), substance use and mental health (Johnson, 2006), and re-integration challenges (Freudenberg, 2004; Hammett, Roberts, & Kennedy, 2001). Research conducted in the United States also reports on women's pathways to offending (see Simpson et al., 2008; Steffensmeier & Allan, 1996) and the impact of gender-neutral public policy on the lives of women offenders (Bloom, Owen, & Covington, 2004). Canadian research on female offenders addresses issues related primarily to federally incarcerated women and on the importance of defining, assessing, and managing a range of issues (e.g., recidivism, violence to oneself or others, escape) (Hannah-Moffat, 2004). After conducting interviews with 27 women incarcerated in a Canadian medium-security institution, Micucci and Monster (2004) conclude:

> Numbers incarcerated, all-time high correctional expenditures, unpredictable and degrading conditions currently faced by women in provincial prisons, shorter sentences and less serious offending compared with their federal counterparts, and methodological gaps in the existing Canadian data base on female corrections also combine to produce a desperate need now for some carefully prepared case studies involving female offenders in provincial correctional facilities. This type of research would assess progress and identify deficiencies in need of correction. (p. 515)

Women who have entered the criminal justice system are confronted with significant health challenges that existed before their initial criminal charge and extend well beyond it (Condon et al., 2006; Evans, 2006).

While evidence suggests that women's experiences of incarceration and probation are significantly different from those of men, women do not enjoy equal access to resources in the community upon sentencing or release (Hannah-Moffat, 2004). Despite the increasing presence of women in the Canadian criminal justice system, there remains a dearth of literature on women's unique experiences within the system, barriers to women's access to health care within the system, and the ways in which women attempt to have their health-related needs met in the face of such adversity (Micucci & Monster, 2004;Yasunaga, 2001).

Theoretical Framework

The project coordinator and principal investigator was a nurse educator-researcher with expertise in community health. One of the research assistants had worked as a counsellor with female survivors of abuse before embarking on doctoral studies in the health sciences.The other was an undergraduate health sciences student with experience in social health research and with marginalized communities. Consequently our philosophical underpinnings and research orientation were rooted in our collective personal, professional, and academic experiences.

Consistent with our pluralistic perspective, our research was situated primarily within the constructivist paradigm, according to which reality is socially co-constructed and the dynamic interaction between researcher and participant is central to capturing and describing lived experience (Weaver & Olsen, 2006). Our study was informed by a feminist theoretical perspective, which makes no single set of claims aside from some generalizations that constitute *feminist theory* (Harding, 1991); the research design is shaped by common themes such as the use of researcher reflectivity, an action orientation, a valuing of women's experiences from their own perspectives, and an acknowledgement that knowledge produced by the research process has the potential to facilitate change in the researcher and in the participants (Fonow & Cook, 1991; Harding, 1989). A feminist perspective also enabled us to remain mindful of the multiple and intersecting vulnerabilities of the research population and therefore to acknowledge the potential of women offenders to experience exploitation and re-victimization within a research context (Hlavka, Kruttschnitt, & Carborne-Lopez, 2007).

Method

The research process began with a comprehensive review of the research literature, which was followed by an investigation of the health promotion and health literacy needs of women offenders using a mixed-method design.

Literature Search

A search of the CINAHL, PubMed, Scopus, MEDLINE, and Sage Full Text: Nursing and Health Sciences databases was conducted using the following search phrases: women + probation, women + incarceration, women + prison, women + parole, women + offenders, and women + prison + health. All searches were limited to English and to the years 1995 to 2008. Reference lists were consulted for relevant journal articles, conference proceedings, government reports, and media releases. The review focused on literature related to health services, barriers to health, health literacy, health promotion, and health-seeking behaviours of incarcerated women and women on probation or parole.

Participant Recruitment

Research Ethics Board approval was obtained for the conduct of a mixed-methods study. Purposive sampling was used to recruit women over the age of 18 who were serving court-mandated probation or had completed probation within the preceding 18 months. Women were excluded from the study if they had an active, unmanaged mental health issue that compromised their ability to provide informed consent. Participants were given a $10 coffee shop gift card as a research stipend.

Recruitment strategies were focused on community services and organizations, including probation and parole services, the Children's Aid Society, a group-counselling program for women charged with domestic violence, and a drop-in centre for homeless women. In addition, recruitment posters were placed in strategic locations throughout the downtown core, including a methadone clinic, a sexual assault centre, a women's shelter, a shelter and a coffee house for homeless persons, and a health clinic serving high-risk populations. In order to engage in further community service networking, the researchers attended local workshops for women offenders; at the beginning of several sessions, time was provided for the researchers to discuss and raise awareness about the study.

Data Collection

Participants were asked to complete (1) a general demographic survey; (2) a researcher-administered functional health literacy assessment whereby the respondent reviewed a food label provided to her and verbally responded to six standardized questions (Weiss et al., 2005); (3) an e-health literacy assessment — a 10-question paper-and-pencil tool assessing self-reported skill in finding, accessing, and assessing online health information (Norman & Skinner, 2006); and (4) a semi-structured interview centred on issues of health promotion and health literacy, during which the respondent was invited to share information regarding her personal definition of health, her perceived health status, barriers to and facilitators of health care, her experiences with the health-care system, and perceived skills needed to engage in effecting change in her community.

Findings

Data were collected from 12 women ranging in age from 25 to 45 years, of whom 11 identified as Caucasian and one as Aboriginal. One participant was married and 11 were single. One participant was employed. All unemployed participants received government assistance because of mental health issues or physical disabilities. Most of the women reported an annual income of less than $15,000 (*n* = 8; 66.7%) and limited education (high-school completion: *n* = 6; 50%). Functional health literacy skill was limited (NVS mean = 2.25/6), yet most women (*n* = 9; 75%) self-reported good to excellent reading ability and numerical comprehension (*n* = 9; 75%).

Three themes emerged from the data: perception that participants' health was influenced by factors such as "people being judgemental"; participant access to health information ("community health clinic," or specialized health services for vulnerable populations); and recommended changes to the health-care system ("outreach…somebody from the ministry should…come out…and ask questions or see where we need our help…many times I've called on the phone, left my name, and gotten nothing back").

Challenges to the Research Process

During meetings of the research team, discussions tended to manifest around four themes: participant recruitment, data-collection methods, physical and emotional safety, and professional and personal tensions.

Participant Recruitment: Shifting Strategies

Members of the research team appreciated the importance of developing trusting and transparent relationships with study participants. Although women offenders are not a homogeneous group, we were aware of intersecting vulnerabilities (poverty, homelessness, substance use, mental illness, trauma) and the fact that mistrust of outsiders is sometimes bred through negative experiences with health and social service workers (Ensign & Panke, 2002; Hatton, Kleffel, Bennett, & Gaffrey, 2001; Zrinyi & Balogh, 2004). Consequently we solicited assistance from community workers who interacted directly and on a daily basis with this population. Although we had the support of most key persons and organizations working with women offenders, we did meet with some resistance. Influenced as we were by the tenets of feminism, we did not anticipate a lack of support regarding participant recruitment. However, this is what we encountered on the part of a few select community health-care providers; for example, a women's health clinic refused to display our recruitment posters in its waiting area.

Initially we relied on the obligatory interaction between probation/parole officers and women offenders as our primary means of recruitment (placing a poster in the probation office waiting room and raising awareness of the study among probation officers). Even with the strong support of the district manager of the local probation and parole office, we failed to recruit research participants in this setting. We then revisited our recruitment strategy and broadened our community outreach. A referral from our network of community services linked the research team to the local police service, specifically to an officer who served as coordinator of a program for persons at risk of offending (e.g., female prostitutes). This police officer played a gatekeeper role in linking us with potential participants. In order to "meet the women where they are at," members of the research team accompanied the officer on her rounds of at-risk neighbourhoods. She acted as an intermediary, introducing the researchers to at-risk community members. As a result of this experience, we focused our subsequent recruitment activity on a drop-in day shelter for women. Staff members at the shelter supported the research by raising awareness of the project among their clients. Two members of the research team (on a rotating basis) spent two full mornings a week at this location for 6 weeks, in order to minimize our "outsider" status among the clients and also to minimize the inconvenience associated with research participation.

Methods of Data Collection: Issues Related to Time, Space, and Place

The transient nature of the study population (Condon et al., 2006) made recruitment and data collection a challenge. Women frequenting the drop-in day shelter appeared curious about the researchers and the project. However, they were extremely reluctant to commit to a set meeting time, and when a meeting was scheduled they often did not show up as arranged. This inability to commit to a set interview time was complicated by the multiple engagements competing for the women's time, such as court appointments, probation meetings, counselling sessions, group activities at the day shelter, and informal gatherings with their peers.

Although the interview is currently the most widely used method in health research (Nunkoosing, 2005), the competing issues faced by many of the women made this data-collection method less efficient and effective than expected. Many of the women appeared to accelerate the interview process by responding without elaboration or saying such things as "next question." Many of the participants fidgeted throughout the interview, and many had trouble making or keeping eye contact. Experienced day shelter staff suggested that shorter interviews, lasting no longer than 20 or 30 minutes, would be more appropriate. Such a short time span challenged our ability to build the trust and rapport necessary to elicit participants' narratives and left us few opportunities to probe for explanation or clarification. Consequently the interviews took on the unanticipated tone of a question-and-answer session.

Because of participants' reluctance to modify their daily routines and their preference for meeting in familiar surroundings, the interviews were held in shared space at the day shelter. However, the limited space and lack of privacy posed limitations to the data-collection process. While participants stated that they were comfortable being interviewed in a semi-private space, our audio-recorders had difficulty picking up nuances in the conversation and some participants may have been inhibited from sharing details they might have disclosed in more private circumstances. On the other hand, some women might not have participated at all in unfamiliar surroundings and without the presence of trusted staff and peers.

Physical and Emotional Safety of the Research Team and the Participants

Qualitative researchers build relationships with participants as a means of exploring questions "about the experiences and meaning people give to dimensions of their lives and social worlds" (Hewitt, 2007, p. 1149). Furthermore, the skill required to facilitate such exploration is strengthened by the researcher's ability to empathize — recognizing, however, that this also renders the researcher/participant relationship more vulnerable (Hewitt, 2007). Our research team recognized the potential of the research context to trigger issues around their own personal or professional traumatic experiences. The team prepared for the study by exploring several questions: Are we equipped to deal with our own emotional responses to what the women might share? What would be the consequences for our participants if we became emotional during an interview? How can we learn to manage our own feelings and reactions so as to minimize any potentially unsupportive comments or body language during an interview? How can we best take care of ourselves and one another?

The team initially met on a weekly basis to discuss, de-brief, share successes, and support one another through some of the challenges of interviewing women offenders. We validated and supported one another's feelings as they surfaced. We kept in contact on a regular basis via e-mail and orchestrated availability to one another on data-collection days. After completing an interview, each researcher checked in with at least one other team member. Since the effect of a woman's story would not necessarily manifest until hours or even days after an interview, we decided that we would call team meetings as required in order to provide support and debriefing.

Meeting women offenders "where they were at" sometimes meant being in physically unsafe areas. Therefore as a team we discussed strategies for keeping ourselves and our participants safe during recruitment and data collection. To mitigate the hazards of the research process, we developed the following "rules of engagement" to maximize our emotional and physical safety and well-being: data collection would be conducted in a confidential space but in a public setting; each researcher would carry a cell phone; interview settings outside the day shelter were reviewed for safety and security; there would be no "home" visit interviews; and all researchers would be informed of when and where each interview was to take place.

Throughout recruitment and data collection, we were mindful of the vulnerability of the participants. Because of the social vulnerability of sex workers, women who have experienced violence, and women who are engaged in illegal or marginalized activities, we considered the potential for feelings of re-victimization through participation in the study (Liamputtong, 2007). Potential re-victimization was mitigated through respectful negotiation of interview locations, provision of access to appropriate and current information about community resources should a woman request further support, solicitation of feedback from day shelter staff with regard to the research process and potential challenges for participants, and reflexivity on the part of the research team throughout the study.

Professional and Personal Tensions

Throughout the research process we were aware of the potential for team members to witness activities or disclosures that could cause legal, ethical, or moral tensions. The team also grappled with personal feelings of guilt because of our position of relative privilege, as well as frustration or anger over the choices the women felt compelled to make given their life situation. The field notes of one of the research assistants included the following:

> *What was so interesting (yet infuriating) about what she [the research participant] shared was how grateful she was to be going on to probation (for a mischief charge) because she would get quicker access to substance use treatment…and would have the assistance of the probation officer in keeping on the straight and narrow. She had to leave a partner because he was too substance involved and she wanted to get off of drugs (opiates).*

> *She said numerous times that it was "a good thing for [her]"...and I thought how crazy that someone in this country should have to go to such lengths to get timely health care. Here she has a 2.5-year-old in [foster] care, and so of course you do what you need to do to get services. It made me think about all the ways in which people are resilient and yet demonized for being so, the ways that women cope with trauma (i.e., substance use), only to find themselves re-victimized by the very actions that they take to survive.*

One of the ways in which the team managed such feelings was to revisit the purpose and objectives of the study. Researchers reflected on the potential for the women to have positive experiences through their participation in the interview. Participation in research can give a voice to marginalized populations such as women offenders, as well as an opportunity to gain unanticipated benefits such as a sense of purpose and empowerment; by sharing their stories, the women might have a cathartic experience that serves to enhance their well-being and reduce their feelings of isolation and stigmatization (Hlavka et al., 2007; Hutchinson, Wilson, & Skodol Wilson, 1994).

Recommendations for Future Research With Female Offenders

Lessons learned through this pilot investigation were invaluable to us in revising our approach to research with women offenders. The limited literature on health promotion and health literacy among women offenders may be a reflection of the inherent difficulties and challenges of conducting research with this population. Women offenders often feel compelled to make themselves invisible because of the stigma and shame attached to their life experiences (Martel, 2004). They tend to live within tight networks limited to those they trust (e.g., mental health and outreach workers).

Our recommendations for future research with female offenders include careful attention to the selection of research setting, the methods of data collection, and the establishment of community collaboration.

Selection of Research Setting

We see several distinct advantages to conducting research with women offenders who are in closed custody (incarcerated) as opposed to open custody. Women in closed custody are less likely to engage in activities that may inhibit or preclude their participation in research (i.e., substance use). Correctional facilities have suitable space available for conducting confidential and safe data collection. Women in closed custody have periods of unstructured time and have greater time flexibility than those in open custody in terms of participating in research (Robert et al., 2007). Daily routines in closed custody make for a structured, less chaotic environment than open custody living arrangements. Finally, research participants in closed custody are afforded the time, space, and a secure environment in which to engage in self-reflection (Robert et al., 2007).

There are also drawbacks to conducting research with women who are incarcerated. These include the permission process attached to accessing the target population, the amount of time needed to develop effective working relationships at multiple levels within government correctional services, and the potential for correctional processes to impede the research process (Martel, 2004). In addition, incarcerated women may fear reprisal from prison officials. Finally, data collected in an artificial living environment such as a prison may not reflect the strengths, deficits, and resiliencies of women's health as fully as the reality of open custody or living arrangements that are unencumbered by legal conflict.

Methods of Data Collections

Alternative methods of data collection with this particular population include body mapping and photovoice. Body mapping is an arts-based method of data collection that entails participant creation and use of the traced outlines of participants' bodies to gather and share health-related information. It has the ability to facilitate change through awareness-raising and critical dialogue (Cornwall, 1992; Devine, 2008; Weinand, 2006). Researchers encourage women to use their body maps to elicit explanations of their health concerns and their sources of resiliency and support. By using people's own representations of their bodies as a starting point from which to explore particular health issues, body mapping can facilitate a less scripted interviewing style, allowing exploration of issues that are difficult to access through verbal discussion alone (Cornwall, 1992).

Photovoice is a promising method of data collection with women offenders. It was developed by Wang and Burris (Wang, 1999) to enable Chinese village women to photograph their "everyday health and work realities" and has been expanded to include other populations (Frohmann, 2005; Moffitt & Vollman, 2004; Oliffe & Bottorff, 2007). Regardless of the research topic, photovoice has three main objectives: to give people an opportunity to document and reflect on their community's strengths and weaknesses (Wang & Burris, 1997); to facilitate critical dialogue and knowledge regarding one's community; and to reach people who are in a position to effect change, such as policy-makers, program administrators, and health-care providers (Wang, 1999; Wang & Burris, 1997). Research has demonstrated that photographs can access memories that may not be accessible through a narrative method alone (Oliffe & Bottorff, 2007).

Community Collaboration

Recruitment of the women offender population requires the budgeting of adequate time to network and develop relationships (with substance abuse counsellors, mental health outreach workers, and the staff of drop-in centres or coffee houses for the homeless) within the communities in which women offenders find themselves. We found the social service personnel linked with this population of women to be very protective of them, and gaining the trust of these personnel was an essential but time-consuming task. A community advisory committee, if formed, could have assisted tremendously with the recruitment of participants. It could have ensured that our recruitment strategies were appropriate to the target population and could have assisted with the dissemination of findings among the target population, health professionals, and other stakeholders.

These observations are consistent with those of Logan, Walker, Shannon, and Cole (2008), who report that building trust and community collaboration is integral to the recruitment of women living in a context of trauma. Participants in their study confirmed that community collaboration gives credibility to a research study, as they were inclined to check with their community supports about a study before agreeing to participate.

Discussion

This pilot study of health promotion issues among female offenders was conducted with a small group of women serving time in open custody. The literature review indicated that there is limited interest in health promotion and health literacy among female offenders in Canada. The research team considered some of the relatively intangible but perhaps salient reasons for the lack of health promotion research with women offenders. Health promotion is defined as the "process of enabling people to increase control over, and to improve, their health" (WHO, 1986). The principles that have been established for the practice and promotion of health are founded on social justice and equity, such that differences in health status, opportunity, and access to resources are minimized through supportive environments, access to information, the development of effective life skills, and the opportunity to control choices.

Growing research evidence has begun to shift the health promotion dialogue from one of individual blame related to lifestyle choice to a consideration of the external influences underlying such circumstances as homelessness and poverty (Raphael, 2003). Yet the complex web of health determinants that characterize the lives of women offenders and the failure to acknowledge the circumstances that influence women's "choices" reinforce the idea of individual blame. Blaming the individual, rather than illuminating the complexity of factors that facilitate or impede "choice," obscures the need for health promotion researchers to fully explore the "web of causation" that guides the choices of women offenders (Bloom et al., 2004; Evans, 2006; Johnson, 2006).

Researchers, clinicians, and policy-makers are beginning to acknowledge the complex influences of hyper-consumption and obesity, smoking and cancers, and languor and heart disease. We are therefore hopeful that they will become more inclined to examine the complex conditions of poverty, abuse, addiction, and threats to mental and physical health that women offenders must navigate in order to survive (Covington, 2002; Evans, 2006; Johnson, 2006). Investigators can confront their deeply entrenched beliefs only by examining a woman's life from her own perspective, attending to the nuances that are not easily captured using traditional research designs.

Conclusion

The findings of this study with women serving time in open custody highlight important issues related to participant recruitment, methods of data collection, physical and emotional safety, and professional and personal tensions. Women offenders face myriad complex issues related to their psychological, emotional, and physical health (Evans, 2006). For women who are incarcerated, in the process of integrating back into their communities after incarceration, or coming to terms with the reality of living life under probationary supervision (Covington, 2002), their involvement in the criminal justice system has lifelong effects on their health status, extending well beyond the initial criminal charge (Evans, 2006). Fully understanding and appreciating the health promotion and health literacy needs of women offenders should be a priority for health researchers concerned with social justice and equitable access to services and resources, for these women are among the most vulnerable by virtue of their life circumstances.

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Résumé

Une intervention destinée à améliorer la santé et la capacité d'adaptation des jeunes sans-abri

Miriam Stewart, Linda Reutter, Nicole Letourneau et Edward Makwarimba

La vulnérabilité des jeunes sans-abri est souvent grande, en raison de la solitude et des ressources limitées à leur disposition. La présence des pairs peut s'avérer un soutien social précieux. Une intervention pilote destinée à cette population, conçue dans le but d'optimiser l'influence des pairs, a été mise à l'essai. On a d'abord procédé à une évaluation des besoins et des préférences après avoir consulté 36 jeunes sans-abri et 27 fournisseurs de services. Sur cette base, on a conçu un projet pilote de 20 semaines, qui comprenait quatre groupes d'entraide, soutien individuel facultatif, activités de loisir en groupe et repas. Ces activités étaient encadrées par des professionnels et des pairs mentors, dont d'anciens sans-abri. En tout, 56 jeunes sans-abri âgés de 16 à 24 ans ont pris part au projet; des mesures quantitatives et des entrevues qualitatives ont eu lieu avant, pendant et après. Malgré certains défis dus pour une large part à l'attrition, les jeunes ont rapporté avoir constaté des améliorations sur plusieurs plans : comportements liés à la santé, bien-être mental, solitude, réseau social, habiletés d'adaptation, consommation de drogues et d'alcool. Ce modèle pourrait être reproduit sur d'autres sites et avec un échantillon plus vaste dans le cadre de recherches ultérieures.

Mots clés : jeunes sans-abri, soutien social, intervention pilote, pairs mentors

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A Support Intervention to Promote Health and Coping Among Homeless Youths

Miriam Stewart, Linda Reutter, Nicole Letourneau, and Edward Makwarimba

Homeless youths are often vulnerable to limited support resources and loneliness. Peers are a potent source of social support. A support intervention for homeless youths was designed to optimize peer influence and was pilot tested. The intervention was based on an initial assessment of support needs and intervention preferences from the perspective of 36 homeless youths and 27 service providers. Based on the results, a 20-week pilot intervention program was designed, consisting of 4 support groups, optional one-on-one support, group recreational activities, and meals. Support was provided by professional and peer mentors, including formerly homeless youths. A total of 56 homeless youths aged 16 to 24 took part. Participants completed pre-, mid-, and post-test quantitative measures and qualitative interviews. In spite of challenges due primarily to attrition, the youths reported enhanced health behaviours, improved mental well-being, decreased loneliness, expanded social network, increased coping skills, enhanced self-efficacy, and diminished use of drugs and alcohol. Further research could focus on replication at other sites with a larger sample.

Keywords: homeless youths, community involvement, social support, pilot intervention, peer mentors

The estimated number of Canadian youths experiencing homelessness is 150,000, representing a third of Canada's homeless population (Public Health Agency of Canada [PHAC], 2006). Youth homelessness is caused by systemic and individual factors such as a shortage of affordable housing, reduced government support, poverty, poor physical or mental health, parental neglect, and violence or abuse in the home (Laird, 2007). Moreover, the street lifestyle exposes youths to high-risk behaviours that contribute to ill health (PHAC, 2006). One Canadian team of nurse researchers has investigated the plight of homeless adolescents. They report significant health challenges linked to sexual abuse, use of alcohol and other drugs, and suicidal behaviours (Reid, Berman, & Forchuk, 2005) and describe major barriers to health-related services connected to policies, insensitivity, and stigma (Haldenby, Berman, & Forchuk, 2007).

Many homeless youths experience depleted and deficient social support networks, often due to poor relationships with family members and schoolmates, the volatility of street-life relationships, aversion to authority (Johnson, Whitbeck, & Hoyt, 2005), and challenges coping with stresses linked to homelessness. Social support interventions, including support groups, can help youths build new social ties, extend their networks, expand their coping repertoire, reduce isolation and loneliness, and meet basic needs (Rew, 2000). However, few empirically based support interventions for homeless youths have been tested (Hwang, Tolomiczenko, Kouyoumdjian, & Garner, 2005). The purpose of this study was to pilot test a comprehensive support intervention for homeless youths that is intended to optimize peer influence, reduce loneliness and isolation, and enhance coping skills.

Support Resources and Coping Skills of Homeless Youths

One Canadian report indicates that over 70% of homeless youths retain some contact with their parents and between 65% and 70% have a social worker (PHAC, 2006). The social networks of homeless youths are generally smaller than those of other youths, leading to a reduced sense of belonging and self-esteem and increased isolation and loneliness (Harpaz-Rotem, Rosenheck, & Desai, 2006). Where family ties are lacking or tenuous, peers become homeless youths' proxy family, in an attempt to fill their need to belong (PHAC, 2006). Street friendships, while providing a sense of support, are often associated with increased substance use and violence (Johnson et al., 2005).

Most homeless youths lack the resources to engage in healthy practices or to access appropriate health services (Feldman & Middleman, 2003; Johnson et al., 2005). Often, street youths engage in survival sex to meet basic needs such as food and shelter and to attempt to fill nurturing needs (Feldman & Middleman, 2003). The views of female homeless youths regarding the consequences of high-risk sexual behaviour are often skewed due to past sexual abuse (Johnson et al., 2005). HIV infection, pregnancy, and parenthood are potential outcomes. Homeless youths tend to cope with stressful life circumstances by shunning stress management and self-medicating with alcohol and other mind-altering substances (PHAC, 2006).

Support Interventions for Homeless Youths

Social support is a protective resource and may help moderate the negative effects of homelessness, increase feelings of belonging, diminish isolation, and enhance social integration and satisfaction with support received (cf. Badr, Acitelli, Duck, & Carl, 2001). Individual therapy and counselling for homeless youths, typically delivered by professionals through shelters, mobile teams, crisis centres, and medical clinics, can reduce the incidence of sexually transmitted disease and substance use but may have an insufficient long-term impact (Karabanow & Clement, 2004). Some short-term crisis interventions have enhanced acquisition of housing and employment, increased self-esteem and perceptions of support, and decreased distress and psychiatric symptoms (Gardner, 1993; Karabanow & Clement, 2004). Support groups and group therapy programs for homeless youths are rarely reported, but a few reported group therapy interventions have increased the ability of homeless youths to share and control their emotions, increased their self-esteem, and helped them to develop friendships (Gardner, 1993). Support in the form of mentoring may help to improve academic performance, sense of worth, and relations with parents and to decrease substance use, violence, and absenteeism (Grossman & Garry, 1997). However, data on mentoring programs in Canada are limited and mostly pertain not to homeless youths but to children and young people in school and at risk of delinquency or domiciled youths involved in crime and violence.

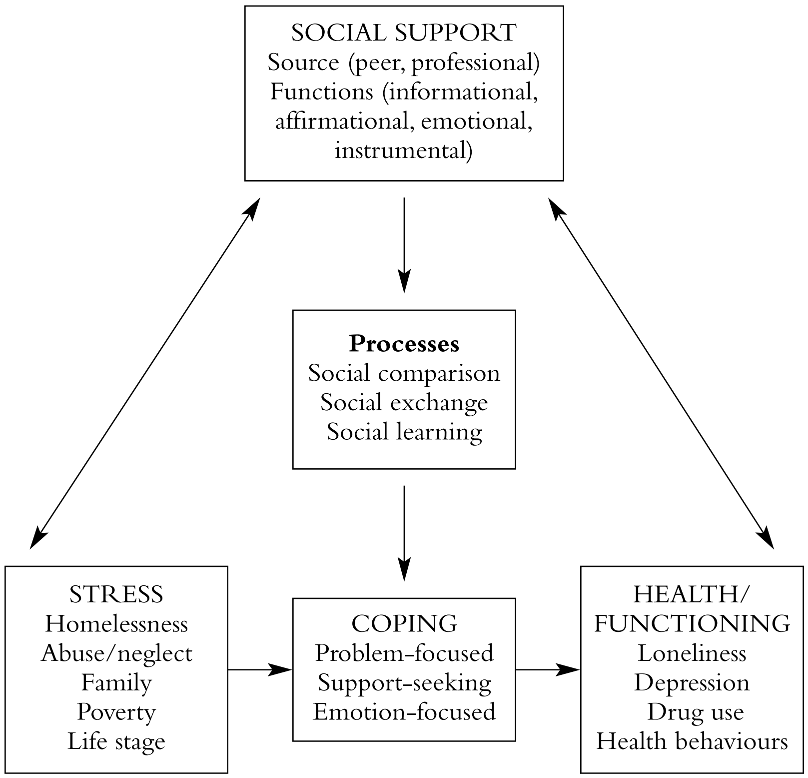
The support needs of homeless youths are difficult to address because of limited support networks (Johnson et al., 2005) and individual, familial, and systemic barriers (Feldman & Middleman, 2003). Although school-based interventions have some potential, they are few in number (Nabors et al., 2004); furthermore, homeless youths are unlikely to be enrolled at a school. Thus there is an acute need for support interventions designed for homeless youths (Harpaz-Rotem et al., 2006). Such programs that do exist tend not to utilize the skills and experiential knowledge of formerly homeless youths. Homeless youths are rarely included in research aimed at improving their lives. Haldenby et al. (2007) cite the potential of peer-led support groups. Our study engaged homeless youths using participatory and empowering strategies, and it designed and pilot tested a peer-led support group for homeless youths.

Conceptual Foundation

Social support was conceptualized in this study as interactions with peers and professionals that can improve coping, moderate stress, and alleviate loneliness and isolation (Gottlieb, 1998). Social support influences mental and physical health and health behaviours. It is a coping resource or source of assistance for coping with *stresses* associated with homelessness (e.g., abuse, neglect, poverty). *Coping* with homelessness can entail managing distress (emotion-focused) and completing instrumental tasks (problem-focused) (Unger, Kipke, Simon, Montgomery, & Johnson, 1997). Support seeking is a coping strategy that influences satisfaction with social support. In this study, a network of peers and professionals was formed to enhance and supplement the depleted resources of homeless youths by providing emotional, affirmational, instrumental, and informational support. Supplementary support through the building of new ties is appropriate when the existing network is impoverished, drained, or in conflict or when it reinforces undesirable behaviours (Gottlieb, 2000) — common situations among homeless youths.

Social support can moderate the impact of stressful situations like homelessness on outcomes related to mental health, including loneliness. Loneliness is emotional distress generated when people feel estranged from, misunderstood by, or rejected by others and when they lack partners necessary for social integration (Rook, 1987; Sorkin, Rook, & Lu, 2002). Peer and professional supporters can influence the health behaviour of homeless youths by providing information, encouragement, or advice and acting as role models, which can constrain youths from engaging in inappropriate or risky behaviour (see Figure 1).

Figure 1 ***Conceptual Foundation***



Preliminary Assessment

To guide the design of a relevant and acceptable support intervention, we launched a preliminary assessment. We also created a Community Advisory Committee comprising representatives of community agencies serving homeless youths and influencers of municipal and federal policy, to ensure the relevance and acceptability of the intervention. Semi-structured qualitative interviews were conducted with 36 homeless youths (19 in individual interviews and 17 in group interviews) and 27 service providers (18 in individual interviews and nine in a group interview) to assess the support needs and support-intervention preferences of this vulnerable population. The interviews revealed that the youths faced daunting challenges, including low self-worth, social isolation, inadequate and inappropriate support services, and poor coping strategies developed to manage the physical, social, and mental deprivations that characterize life on the street. This preliminary assessment confirmed the existence of major support needs and key barriers to accessibility of services for homeless youths, such as lack of information about the few resources/services available, rigid or unrealistic support structures, difficult or invasive procedures for accessing resources, and lack of understanding on the part of service providers. Participants provided guidance in the development of a support intervention to meet the needs of these youths and overcome barriers to their obtaining support. The findings from this assessment (reported elsewhere) informed the design of the follow-up pilot study, which is the focus of this article.

Research Questions and Hypotheses for the Pilot Intervention Study

The study was guided by seven research questions: What are the effects of the pilot support intervention on homeless youths with respect to (1) quality, composition, and size of social network; (2) satisfaction with support received; (3) loneliness and isolation; (4) support-seeking coping; (5) self-efficacy; (6) mental health; and (7) health-related behaviours? Based on our conceptual framework (Figure 1), our assessment study with homeless youths, and our previous social-support study with vulnerable groups — including people living on low incomes — it was hypothesized that, following the pilot intervention, participants would report (1) an expanded social network; (2) increased satisfaction with support received; (3) decreased loneliness and social isolation; (4) increased support-seeking coping; (5) increased self-efficacy; 6) improved mental health; and (7) more positive health behaviours.

Methods

We employed a one-group, within-subjects design for this multi-method study (Stewart, Makwarimba, Barnfather, Letourneau, & Neufeld, 2008) examining the effects of the pilot intervention over time. We did not choose a randomized controlled design because the intervention needed to be thoroughly piloted prior to implementation of a full trial, and our community partners were less interested in controlling exposure to intervention than in examining the effect of the intervention in a real-world setting. This approach is consistent with current thinking — that pilot intervention studies do not need to be overly controlled to be externally valid (Glasgow et al., 2006). Participants' perceptions of impacts and satisfaction with the intervention were determined through qualitative interviews with the homeless youths, as intervention study participants are rarely invited to identify valued outcomes and perceptions of interventions (Stewart et al., 2008). Quantitative data were elicited through standardized instruments for measuring intervention outcomes. Participants were assured of confidentiality, voluntary participation, and freedom to withdraw at any time without consequences. The study was approved by the university research ethics board.

Support Intervention

To facilitate the development of positive interactions and to help compensate for the limited social networks of homeless youths, a network of peers and professionals was formed to provide various types of support functions, including emotional, informational, and affirmational support.

The intervention consisted of four support groups that met once a week for 3 to 4 hours over the course of approximately 5 months in the western Canadian city of Edmonton, Alberta. This support intervention for homeless youths encompassed group and dyad (one-on-one) support. This mode was selected given homeless youths' reported preference for face-to-face support. Space for the program was provided in kind by two partner agencies serving homeless and at-risk youths and one community centre. The support groups were facilitated by professional mentors and included opportunities for one-on-one support delivered by both peer and professional mentors. *Professional mentors* (e.g., social workers, psychologists, therapists) were professionally trained, experienced in working with youths, and recruited from agencies that supported the program. They guided and supported both the peer mentors and the homeless youths by providing resource information, crisis intervention, and supervision. *Peer mentors* were youths who had experienced homelessness themselves and who would be appropriate role models for homeless youths.

Each session included a recreational activity as well as a free meal. Recreational activities were chosen by youths in each support group, with professional mentors facilitating the selection process. The research team was responsible for organizing the event with community recreational outlets/facilities. The most well-attended activities were swimming, picnics in the park, visit to a science centre, bowling, indoor wall climbing, paintball, and professional hockey games. Transportation to the support sessions was provided via bus tickets and transportation to the recreational sites was arranged. The youths could approach any of the mentors for support, and many took advantage of this offer, seeking help with such things as homework and information on job and educational opportunities.

Sample Selection, Recruitment, and Attrition

Recruitment was facilitated by partner agencies, including an employment program and drop-in centres, and by the Community Advisory Committee. Service providers at the agencies handed out cards with contact information inviting youths to get in touch with the researchers. Interviewers also regularly visited the agencies to facilitate recruitment, and they "hung out" to enhance accessibility. A total of 70 eligible youths were recruited and administered pre-tests. These youths were between 16 and 24 years of age and were either currently homeless or in transition from homelessness. Youths were considered homeless if they (1) had no home at all and were living on the streets (absolutely homeless); (2) were living in a place that was not intended as housing or was unsuitable for long-term residence; or (3) were at risk of becoming homeless through loss of their home, discharge from an institution/facility with nowhere to go, or loss of income. Of the 70 youths who were pre-tested, 56 participated in the intervention to some degree. Initial power analysis suggested that a sample size of 70 was necessary to support the findings. In spite of extensive effort, however, only 56 youths participated in the intervention after pre-testing. Given the pilot nature of the study, this number was deemed sufficient to examine trends associated with the intervention. This initial attrition reflects the transient and unpredictable nature of the lives of homeless youths. Moreover, attendance at the support sessions varied considerably: 17 youths participated in 10 or more sessions, 28 in six to nine sessions, and 18 in fewer than three sessions. Of the 29 youths who participated in both the pre-test interview and the mid-point interview (halfway through the intervention), 17 (59%) took part regularly in at least 10 support sessions. The dose of the intervention, therefore, was unevenly distributed, with further variation in attendance by site. The research team engaged in continuous recruitment efforts to boost attendance at weekly support groups.

Data Collection

Interviews were conducted pre-, mid-, and post-intervention. The interviewers were similar in age to the youths, experienced in working with at-risk youths, and trained by the investigators. The interviews were conducted face-to-face on the premises of the collaborating community agencies. These numbered 70 pre-test, 29 mid-point (approximately 12 weeks after the first session), and 14 post-test (at the end of the 20-week intervention). The interviews were audiotaped and transcribed verbatim. Following each interview, the youth was given a token of appreciation consisting of $20 in food vouchers, movie passes, and bus tickets.

Four standardized measures were administered pre-test, along with questions about demographics, living arrangements, size and characteristics of social network, satisfaction with support, high-risk behaviours, health promoting behaviours, and perceived health. The Social Provisions Scale was used to assess global perceptions of support (Cutrona & Russell, 1987). This scale incorporates six support functions: guidance, reliable alliance, reassurance of worth, attachment, social integration, and nurturance. The Revised UCLA Loneliness Scale assesses loneliness, social isolation, and satisfaction and dissatisfaction with social relationships (Russell, 1996). The Center for Epidemiological Studies Depression Scale (CES-D) is a screening instrument for depressive symptoms, including low mood, feelings of guilt, hopelessness, psychomotor retardation, loss of appetite, and sleep disturbances (Radloff, 1977). The Proactive Coping Inventory evaluates proactive cognition and behaviour as a positive facet of coping (Greenglass, Schwarzer, Jacubiec, Fiksenbaum, & Taubert, 1999); only the Proactive Coping Scale, the Instrumental Support Seeking Scale, and the Emotional Support Seeking Scale were included in the interview. These measures and their psychometric testing are summarized in Table 1.

Due to reported respondent burden for these vulnerable youths, several changes were made in data-collection protocols at the mid-intervention and post-test interviews. The CES-D and the Proactive Coping Inventory instruments, viewed as particularly difficult to answer by the youths, were replaced with semi-structured questions that elicited responses on the same outcomes of depression and coping. Quantitative questions on health behaviours were replaced with qualitative questions. *Qualitative questions on perceived impacts* focused on general "impact/outcomes," behavioural changes, personal outcomes, and social networks. Specific questions are given in Table 1. Questions related to demographics and health behaviours were adapted from those employed in the Community University Partnership study, Capacity Building as Crime Prevention: A Formative Analysis of Processes and Outcomes in an Employment-Based Social Development Program (Schnirer et al., 2007).

Table 1 *Quantitative and Qualitative Questions About Impacts of the Intervention*

	Quantitative				Qualitative
Construct/ Variable	**Measures**	**Content and Items**	**Scoring**	**Psychometric Properties**	**Questions**
Social support/ social networks	Social Provisions Scale	Global perceptions of support (24 items)	Four-point scale. Summative score *range* = 24–96. Higher scores indicate higher levels of global support. Normative sample *mean* = 82 (*SD* = 10).	Internal consistency alphas ranged from .65 to .76 for the Provisions Subscales and .92 for Global Support.	Do you think the program has affected your relationships with people outside of the group? What other supports or positive influences do you have in your life? At present, how many friends (i.e., peers, people you spend time with) do you have? Who is currently in your life that you could go to if you needed help or support?
Loneliness	Revised UCLA Loneliness Scale	Loneliness, social isolation, satisfaction/ dissatisfaction with relationships (20 items)	Participants indicate if they often, sometimes, rarely, or never feel as described in statements. Higher scores indicate a higher degree of loneliness, social isolation, and dissatisfaction with social relationships (norm score = 40; maximum score = 80).	Concurrent validity was confirmed by associations between scores on the Revised UCLA Loneliness Scale and other indicators of loneliness, social relationships, and affective states (e.g., Beck Depression Inventory, alpha r = .62). In studies using samples of college students, high internal consistency coefficients were obtained (r = .94–.96).	

(continued)

Construct/ Variable	Measures	Content and Items	Scoring	Psychometric Properties	Questions
Mental health	Center for Epidemiological Studies Depression Scale	Depressive symptoms in preceding 7 days (20 items)	Four response choices create a range of scores from 0 to 60. Clinically significant levels of depressive symptoms are indicated by a score of 16 or higher (Radloff, 1977).	Spearman-Brown halves of .85 (for general population) and .90 (for patient samples). Test-retest reliability: .45 to .70 (Radloff, 1977). Correlates well with other valid depression scales.	Do you think this program has had an effect on you or your life? In what way? What has changed in your life because of the program?
Coping	Proactive Coping Inventory	Assessment of cognitive and behavioural coping strategies. Subscales: Coping Overview (14 items), Instrumental Support Seeking (9 items), Emotional Support Seeking (5 items)	Scale of 1 (not at all true) to 4 (completely true) on all items. A higher score generally indicates enhanced coping. Some items are reverse scored.	Coping Overview Scale: Reliability α = .80 and .85; validity α = .22 to .73. Instrumental Support Seeking Scale: reliability α = .84 and .85; validity α =.17 to .65. Emotional Support Seeking Scale: reliability α = .73 and .64; validity α = -.17 to .60 (Greenglass et al., 1999).	Since you started coming to the group, have you looked for any other sources of support (e.g., programs, agencies, people)? Does this group help you cope with other things that are going on in your life? What kinds of things does it help you with? How does it help you cope with these things? What would be something that would help you cope with other things going on in your life? Does this group help you cope with other things that are going on in your life?

Health behaviours	Investigator-prepared Health Behaviour Questionnaire	Assessment of high-risk behaviours (violent/criminal behaviour, tobacco use, marijuana use, alcohol use, illicit drug use, attempted suicide, high-risk sexual behaviour), self-perceived health, chronic illness, and health promoting behaviour (leisure activities, exercise, nutrition, sleep, counselling) (15 items)	Compilation of questions derived from multiple sources with varied response choices.	N/A	Do you think you are more or less involved in "drug use, crime and high-risk activities" — we talked about at the beginning of the program — since you started the program, or is it about the same? Do you think you are doing more or less healthy things since you started attending this group, or is there no difference? Since starting the program, have you made a personal change (achieved a personal goal)?

Data Analysis

Quantitative data were analyzed with measures of central tendency and parametric statistics, including paired *t* tests and repeated measures analysis of variance (ANOVA). Nonparametric statistics were also used as appropriate. Repeated measures ANOVA was conducted with participants who completed all of the pre-, mid-, and post-test interviews using Statistical Package for the Social Sciences. Assumptions (i.e., normality, skewness, kurtosis, homogeneity of variance) were assessed prior to parametric testing. The tests utilized are robust to violations of assumptions; nonetheless, when assumptions were violated (as occurred often due to the small sample size), the nonparametric equivalent tests were performed. Only statistically significant findings are reported. Qualitative data from the interview questions (Table 1) were analyzed using a qualitative descriptive approach (Sandelowski, 2000). A coding framework was developed inductively from data in the initial interviews and revised as analysis proceeded.

Findings

Profile of Participants (Pre-test N = 70)

At pre-test, the mean age was 19 years (*n* = 10; *SD* = 2.5 years), with ages ranging from 16 to 24 years. Slightly more males (54%; *n* = 38) than females (46%; *n* = 32) were recruited. Of the sample, 60% were Aboriginal, reflecting the high rate of homelessness among Aboriginals living in this city, where, in 2002, 43% of all homeless people were Aboriginal (Edmonton Joint Planning Committee on Housing, 2002). Only 27% were Caucasian (*n* = 19), followed by 13% (*n* = 9) visible minority. Of the youths, 15% (*n* = 11) were parents, of whom most had one child (11%; *n* = 8) and a few had two children (4%; *n* = 3). Only four youths lived with their children. The mean level of education was Grade 10 (*n* = 70; *SD* = 1.3). Levels of education spanned Grade 5 to high school, with only 19% (*n* = 13) having completed high school. Of the sample, 14% (*n* = 10) were still in school (an alternative outreach school based at a drop-in centre), 42% (*n* = 29) had dropped out, and 16% had been expelled. Of the youths, 30% were employed and 27% claimed employment as their main source of income. Parents were a main source of income for 23% of participants. Some youths (6%) reported illegal activity as a source of income.

Close to half of the sample lived at times with a mother, father, or relatives. Almost 20% were living with friends or partners. The next-largest category was the absolute homeless (14%). Fewer youths lived in shelters (4%), in semi-independent or independent living arrangements (4%), or with "homeless" roommates (1%). Nearly half (45%) reported that they were continuously moving or transient. About one third (36%) had been in their current living arrangement for less than 6 months. The transitory nature of their housing arrangements is reflected in the fact that 20% had been at their current location for less than 1 month, 11% for 1 or 2 weeks, and 4% for less than 1 week; 9% had been living at their current location for 6 to 12 months and 10% for over 1 year.

The majority of these young people described their peers as not attending school (64%) or not working (71%). Most youths reported that their peers had been arrested (77%), had been incarcerated (57%), and used alcohol (63%) and/or drugs (69%). Almost half indicated that their peers made money illegally (40%) or got into fights (40%). Most of the youths at pre-test (59%; n = 41) felt that they were *somewhat healthy,* while only 29% (n = 20) reported that they were *very healthy.* Half of the sample (51%; n = 36) reported having chronic psychological (30%) and physical (41%) health problems.

Change in Size and Composition of Social Network (Research Question/Hypothesis 1)

The youths were asked how many friends they had (including peers and people they "hang out with") at pre-, mid-, and post-test. At pre-test (n = 70), they had an average of 25 people in their support networks. Paired t tests revealed a mean increase of 11 persons from pre- to mid-test for the 29 youths interviewed at mid-point. The mean network size at mid-point was 46. For those youths completing the post-test (n = 14), a mean increase of 19 was reported from pre-test to post-test. However, repeated measures ANOVA revealed no statistically significant difference across time points (n = 14). Given attrition, it is useful to compare pre-test and mid-point using the available data. This also provides evidence for the necessity/utility of delivering a shorter intervention to homeless youths, as discussed in the final section of this article.

Some youths commented that their expanded social network contained new people who cared, which resulted in increased interest and trust in others. Youths were asked to describe the composition of their support network. The majority named friends as their main source of social support at pre-test (61%), mid-point (76%), and post-test (78%). The second-largest reported source was mothers at pre-test (57%), mid-point (66%), and post-test (43%). The third-largest source was siblings and aunts/uncles at pre-test (46% and 41%, respectively). Interestingly, this last source changed at mid-point, with 48% of responses indicating peer and professional mentors as key supporters, surpassing aunts/uncles at 41%. At post-test, 42% cited mentors as supporters (the third most frequently reported source of support).

Despite the reported increase in social network size, the results of the Social Provisions Scale did not reveal statistically significant differences in means over time: pre-test, 74 (n = 60); mid-point, 75 (n = 25); post-test, 75 (n = 14). A repeated measures ANOVA used to analyze pre-, mid-, and post-test means (for only n = 14) (pre-test, 76; mid-point, 75; post-test, 75) indicated that the means did not fluctuate and stayed below the normative mean of 82. The repeated measures model was not statistically significant.

Increased Satisfaction With Support Received (Research Question/Hypothesis 2)

During the pre-test (n = 69), mid-point (n = 29), and post-test (n = 14) interviews, participants were asked to rate their satisfaction with support over the preceding 2 months on a Likert scale, with 1 representing *not at all satisfied* and 5 *very satisfied*. The percentage of youths *not at all satisfied* decreased at mid-point from 10% (n = 7) to 3% (n = 17), with no youths reporting *not at all satisfied* at post-test. The percentage of youths *very satisfied* increased from 17% (n = 12) at pre-test to 29% (n = 4) at post-test. However, the Friedman test to examine differences over time (pre-, mid-, post-test; n = 14) was not significant, indicating that levels of satisfaction did not significantly change. Some youths indicated that the intervention affected relationships external to the support group, as new friends eliminated the need to spend time with the "wrong crowd." Still others noted decreased conflict with friends or family due to the intervention. However, some youths stated that the intervention did not affect their external relationships. Some youths observed differences in their friends' behaviours within the intervention versus outside of it; their friends discussed new topics and acted differently in the support group. Thus the intervention seemed to influence the nature of their friendships. Youths added that it was good to see their friends being active instead of just "hanging out." Those with low expectations of other participating youths were surprised that they had made friends and had changed. Consistent with research pointing to the importance of both increasing positive relationships and decreasing negative interactions and relationships (Newsom, Rook, Nishishiba, Sorkin, & Mahan, 2005), these youths removed themselves from detrimental relationships:

> *I don't really hang out with anybody down here and stuff like that; I stopped. This whole group thing has given me ideas, like you don't need to go out and you don't need to do drugs and crime to have fun and stuff, so I've kind of dropped everybody that I used to hang out with and everything.* (19-year-old)

> *My personality has changed, like, dramatically. I'm more open, more funnier, I do more funnier stuff. I've got new friends and stuff.* (23-year-old)

Decreased Loneliness (Research Question/Hypothesis 3)

A repeated measures model revealed a significant decrease in loneliness over time (F = 4.6 [2, 26]; p = .04). The means ranged from 43 at pre-test (just above the norm of 40) to 41 at mid-point and 39 at post-test (n = 14). Qualitative data reinforced participants' perceptions of decreased loneliness following the support intervention. According to these youths, interacting with peers in the group improved their mood, increased mutual respect, diminished sense of isolation, and decreased loneliness:

> *I guess you could say I got to know more people, so, like, there's always someone I could, like, see that I know. Not feel so lonely, I guess.* (16-year-old)

Increased Support-Seeking Coping (Research Question/Hypothesis 4)

At pre-test, the mean for the Proactive Coping subscale of the Proactive Coping Inventory was 42 (n = 64; SD = 4.4), very close to the normative mean of 43. Similarly, the Emotional Support Seeking Scale (subscale) mean of 15 (n = 68; SD = 3) was almost identical to the normative mean of 16. The Instrumental/Practical Support Seeking subscale produced a less optimistic picture, with a mean of 23 (n = 68; SD = 4), well below the normative score of 31. Due to respondent burden, this instrument was not used beyond the pre-test. At the mid-point and post-test interviews, participants were asked about changes in their support-seeking behaviours (see Table 1). At mid-point (n = 29), over one third of participants (35%; n = 10) reported seeking more support. At post-test (n = 14), 57% (n = 8) reported increased support seeking. Additional sources of support sought included community agencies, teachers, dentists, and counsellors.

Youths reported that emotional and informational support from mentors created a safe place to discuss problems and offered a different perspective. This in turn helped them to cope with relationship challenges and life situations. Moreover, youths reported acquisition of general knowledge (e.g., housing, personal life goals) and learning opportunities provided by mentors:

> *It really helped me…to cope with the fact that my mom and dad don't want me around… It's given me people to hang around with…it was just basically, it was able to help me cope with it, actually having people there…*

> *I'm basically erasing the memories of…old and…really bad experiences with my family and replacing them with better ones.* (23-year-old)

> *…conversations with people, or just, like, talking and venting to people about a situation I'll be in and then ways to overcome that situation without having more issues to overcome.* (16-year-old)

Youths described an increased ability to cope with their lives, as the intervention provided a drug/alcohol-free option, which helped them to avoid negative influences, remain off the streets, and manage boredom in alternative contexts. They also stated that they could cope better because the intervention supported their personal goals, such as continuing with school:

> *In some ways, [professional mentor] helping me with my homework, it's helping me finish my school.* (16-year-old)

Some youths indicated they had improved their social and support-seeking skills. Interacting with mentors helped them to develop their social skills, which boosted their self-esteem and self-confidence. They reported becoming more social and engaging in conversation. They were less shy, which in turn affected those around them. Enhanced social skills affected the youths' relationships outside of the intervention. At post-test, participants reported being more positive in their relationships. They explained that their new peers within the intervention context caused them to increase their social and interpersonal skills:

> *More open, more outgoing with other people… I'm not the one that's quiet, sitting there…I'm actually in the conversation, talking along with them, something like that.* (23-year-old)

> *I'm a bit more outgoing and, like, I'll go do more things now. I'm not so shy. I used to be really shy.* (19-year-old)

Increased Self-Confidence and Efficacy (Research Question/Hypothesis 5)
The support intervention helped youths to try new activities and succeed, increasing their perceived self-efficacy. Although no quantitative measure was administered, relevant qualitative data were elicited by questions about personal success and goals. The intervention helped youths to achieve personal goals, including college acceptance, completion of courses, and improved parenting. Housing was considered a way to achieve success. At mid-point and post test, some youths reported that they had a place to stay because of information received from group mentors:

> *I'm trying more. I want to try more to get off the streets. And the program helps me there. And…[mentor] told me if I get a job and all that stuff, I*

> *can do this with my own money. Go actually out and do laser tag and all that stuff and have fun myself.* (23-year-old)

Some participants experienced a personal change during the intervention, such as a desire to return to school or complete studies that were already underway. Some youths attributed their increased confidence and self-esteem to participation in the intervention. They reported having grown stronger and more assertive.

Improved Mental Health (Research Question/Hypothesis 6)

When the CES-D was applied, participants at pre-test had a high mean score of 23 (n = 68; SD = 11). Scores above 16 may be indicative of clinical depression. At pre-test, many youths anticipated that their mental and emotional well-being would improve with the intervention. Participants were asked about their future personal goals and how they would measure success. One of the measures of success they gave was mental and emotional well-being, which included achieving a goal, having positive feelings, identifying direction in life, and doing something positive. When asked about barriers to success, they spoke of psychological challenges, such as depression, anxiety, and negative emotions. In general, the qualitative data revealed that the participants experienced overall enhanced mood and relaxation and stress relief in the positive environment created by the mentors, which was a welcome respite from street life. At post-test, some participants said that their goal of controlling anger and "de-stressing" was supported by the intervention. Some youths reported that the intervention gave them an opportunity to relax, forget about problems and worries, and dwell on good memories:

> *I feel more energetic. I have a lot more energy.* (19-year-old)
>
> *[I'm starting to] look at the good side of my life instead of the bad side.* (18-year-old)

At mid-point and post-test, some youths reported increased happiness and improved attitudes, enhanced personal strength, more assertiveness, and "open-mindedness." At post-test, youths described how their goal of controlling anger was supported through the intervention. In the words of one youth: "More of a belief in myself, that I can keep something going."

Improved Health Behaviours (Research Question/Hypothesis 7)

At pre-test, 14% of youths reported sexual encounters with three to 10 partners in the preceding 2 months. Just over half had used a condom in their last sexual encounter. Many youths (69%) received counselling for various personal issues, but only 34% received counselling for drug/alcohol addiction. Most participants used tobacco either daily (43%) or almost daily (40%); 53% had attempted tobacco cessation in the previous 12 months. Of the sample, 80% reported using marijuana and about one third used alcohol once or twice in the preceding 2 months.

In terms of health promoting behaviours or activities, the majority of the youths reported that they exercised regularly (69%; *n* = 48), played sports (44%; *n* = 31), watched movies or television (75%; *n* = 53), used reading and writing skills (72%; *n* = 50), or spent time with friends (69%; *n* = 49). However, most youths reported no involvement in team sports (62%; *n* = 43), video/computer games (48%; *n* = 34), or musical instruments (66%; *n* = 46). Only about a quarter ate three meals a day (26%; *n* = 16) or had breakfast daily (24%; *n* = 17). The majority (86%; *n* = 61) ate "junk food." Only 3% (*n* = 2) had no food almost every day, while about half of the sample (51%; *n* = 36) did not eat on some days. Close to half of the sample (46%; *n* = 25) reported going hungry on a daily basis. Many youths (41%; *n* = 29) reported difficulty getting enough sleep.

At mid-point and post-test, participants were asked about changes in health behaviours since starting the program (see Table 1). Many participants (55% [*n* = 16] at mid-point [*n* = 29]; 29% [*n* = 4] at post-test [*n* = 14]) reported decreased use of drugs and alcohol or complete cessation of both. Being substance free was considered a measure of success by the participants. Youths reported that the intervention supported their personal goals of decreasing substance use or abstaining from drugs/alcohol or that it "removed" them from access to these substances. A favourite element of the program was the decreased need for drugs/alcohol because of the alternatives provided (e.g., somewhere fun to go).

> *I use it [the intervention] more just to stay off the drugs, really…it's really hard, 'cause I'm at the point where I'm just about over the wall… I've been doing good, and it gives me something else to think about.* (19-year-old)

> *Basically, Wednesday [when the support intervention took place] did something more than just make me stop doing drugs; it stopped me selling drugs a little bit too, 'cause…most of my dealers wanted me to do it around the clock…so I told [them] that I am stopped dealing now, 'cause I wanted to go into the program and actually have fun.* (23-year-old)

Many participants (45% [*n* = 13] at mid-point [*n* = 29]; 36% [*n* = 5] at post-test [*n* = 14]) stated that they were less involved in risky behaviours (e.g., having unprotected sex). At post-test, two youths attributed their decreased involvement in unprotected sex to intervention activities.

One 22-year-old stated, "Well, since I've joined…I haven't really been doing any high-risk activities."

Youths believed that the intervention fostered positive health behaviours. The opportunities for physical activity helped some of them to sleep better. A few participants commented that they were taking better care of their health. Overall, at post-test the majority reported that they were engaging in more health-promoting behaviours since starting the intervention:

> *…healthy food, yeah…. Actually…the first time I ate broccoli was, like, here. My whole life I thought I didn't like it, 'cause I didn't try it.* (24-year-old)
>
> *I'm doing a lot more healthier things… I'm playing basketball every now and then…and I go swimming with my kids, brother and sister, play pool.* (19-year-old)

Discussion

The findings of this pilot intervention study with vulnerable youths are important for several reasons, despite irregular attendance and attrition. Qualitative and quantitative data were triangulated to reveal a significant decrease in loneliness over time. The health, emotional, and behavioural problems encountered by the homeless youths who participated in the study point to the need for appropriate support strategies. The potential effects of this support intervention reveal encouraging trends, including expanded social network, improved emotional and mental well-being, decreased loneliness, acquisition of support-seeking coping and social skills, decreased use of drugs and alcohol, and adoption of healthier behaviours.

While interactions with other homeless youths, peer mentors, and professionals facilitated the building of new ties and extended participants' social networks, the youths also developed social skills. Participants reported being more social, engaged, and positive in their relationships and more frequently seeking support from persons outside the intervention. One possible key benefit of peer and professional mentorship is enhanced social skills. The acquisition of social skills supplements the coping repertoire of homeless young people. Some youths described an increased ability to cope with their lives, as the intervention served as a drug/alcohol-free option, which helped them to avoid negative influences, stay off the streets, and manage boredom. For these homeless youths, a program offering support for coping with addictions and other health-related challenges was important. Prior to the intervention, these youths used coping styles widely reported in the literature, such as substance use, unprotected sex, and violence, to distance themselves from stressors.

The participants reported improved attitude and increased personal strength. Harpaz-Rotem et al. (2006) argue that interventions targeting homeless youths should promote self-esteem and competence. The support offered by mentors may have enhanced self-esteem and self-efficacy through social comparison and social learning. The youths described how their goal of controlling anger through "de-stressing" was supported in the intervention. These findings attest to the beneficial effects of social support in moderating stressful situations. They supplement emerging evidence on the beneficial role of mentoring in decreasing substance use and violence and instilling a sense of self-worth (Badr et al., 2001; Grossman & Garry, 1997).

Several limitations associated with this pilot study have implications for the findings. Attrition over time was a major challenge, leading to a small sample size and differential doses at data-collection points. Moreover, the transient nature of the study population made it impossible to discover reasons for this attrition. Our data at mid-test and post-test reflect different doses of the intervention, in that some participants attended more sessions than others at these time points. We also used different data-collection methods over time to reduce respondent burden based on youth feedback regarding some standardized measures, which may have influenced our findings. In particular, the appropriateness of the quantitative measures used with this population requires further exploration. Nevertheless, our findings suggest that there were positive outcomes for those youths who did participate in the intervention on a regular basis.

For research on homelessness, identification of the needs and priorities of those affected is important and timely (Frankish, Wong, & Quantz, 2005). This intervention study was based on an assessment of the support needs and preferences of homeless youths. It went one step further, with a participatory approach to research (Heenan, 2004). It included formerly homeless youths as peer mentors and service providers from the community as professional mentors, and it engaged a Community Advisory Committee in the development of the intervention. A participatory approach engaging stakeholders serves to empower vulnerable populations, reduce distrust, and extend the application of research knowledge (Heenan, 2004). Youths are rarely consulted about their health needs and priorities, and programs that do consult them are more effective than those that do not. The youths who participated most fully in this support intervention seemed to experience improvements, as indicated by qualitative self-report and most quantitative measures. Qualitative and quantitative methods increased the richness of the data by capitalizing on the strengths of each method (Creswell, 2003).

The findings of this study, as well as its identified limitations, point to the need for further research. We believe that a participatory approach and participation by community agencies are necessary and vital elements of any study involving homeless youths. Given the high rate of attrition, a shorter, more concentrated intervention time frame could be explored. To illustrate, a 12-week support intervention, the typical duration tested successfully in our research and recommended by others (e.g., Gottlieb, 2000), or even a shorter program, may be ideal for a vulnerable population such as homeless youths. Our experience with quantitative measures suggests that future research should carefully consider the type and number of measures used, including literacy level and sensitivity to particular needs and situations. In this study, the participants had difficulty with some of the quantitative measures and appeared to be better able to express their views through open-ended questions. However, interviewers reported that some youths had difficulty describing their thoughts and feelings in depth. Finally, further research with larger samples drawn from several cities and using a comparison or control group is needed to confirm the findings of this pilot study conducted in one locale.

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Happenings

A Major Canadian Initiative to Address Mental Health and Homelessness

Myra Piat, Jayne Barker, and Paula Goering

Over the past 20 years homelessness has emerged as a significant social problem affecting thousands of people every night in cities across Canada (Bégin, Casavant, & Chenier, 1999; Hwang, 2001). The prevalence of mental health problems and addictions is considerably higher among homeless people than among the general population (Aubry, Klodawsky, & Hay, 2003; Canadian Institute for Health Information [CIHI], 2007; Hwang, 2001; Paterson, Somers, McIntosh, Shiell, & Frankish, 2008). The Mental Health Commission of Canada has launched a multi-site research demonstration project in mental health and homelessness. In February 2008 the federal government allocated $110 million to support the growing number of homeless people who have a mental illness. The overall goal of this innovative project, titled Research Demonstration Project in Mental Health and Homelessness, is to provide housing and support services to people who are homeless and have mental health problems. The 4-year project, the first of its kind in Canada, will be conducted in five cities: Vancouver, Winnipeg, Toronto, Montreal, and Moncton. The Mental Health Commission has awarded funding to consortia involving researchers, service providers, and persons who have experienced mental illness and homelessness in these cities. Although the project is managed by the Commission, consumer representatives and consumer researchers, as part of a special consumer panel, will be offering their perspectives throughout the design and implementation process.

Research Objective

The objective of the Research Demonstration Project in Mental Health and Homelessness is to produce relevant policy and program evidence about what service and system interventions best achieve housing stability and improved health and well-being for people who are homeless and have a mental illness. The specific goals are to (a) contribute to the development of best practices and lessons learned that can be applied to future efforts with respect to mental health and homelessness across Canada, (b) identify cost-effective approaches to integrating housing supports and other supports and services that promote long-term quality-of-life changes for this population, and (c) identify unique problems and solutions for diverse ethno-cultural groups within this population. Interventions will include the provision of housing and complementary services (assertive community treatment or case management), implemented through collaboration with key stakeholders, including governments, service providers, and homeless persons.

Housing First is the overarching philosophy and model under which the programs have been funded. This model is one approach to ending homelessness and helping previously homeless persons to achieve community integration. It entails the provision of housing (through rent supplements) and support services. In this project, a comparison of Housing First approaches to care-as-usual will be required in all cities, each of which may also study particular populations of interest. The overall goal is to identify best practices that could be adopted on a national scale.

Core Research Design

It should be pointed out that this multi-site project must meet both service objectives and research objectives using the same core research design for all sites. This approach is necessary for the aggregation and comparison of data from the five cities. Four of the five sites will have a minimum of four groups, two experimental (Housing First for high and moderate need) and two comparison (care-as-usual for high and moderate need). Due to its smaller population, Moncton will have just one intervention and one comparison group. For each group, 100 individuals will be recruited, with the expectation that at least 75 of these will remain for the duration of follow-up. Data for the common measures across sites will be collected at baseline and then every 6 months for a 2-year period.

In addition to the quantitative process and outcome evaluation of the intervention, there will be an extensive qualitative component. This complementary research process will gather in-depth information about the intervention, the participants in the intervention, and usual care conditions. The following aspects of the initiative will be studied qualitatively: (1) the planning/proposal development phase, (2) the personal stories of consumers at baseline, (3) the implementation of the intervention, and (4) the personal stories of consumers at 18-month follow-up. The goal is to provide an in-depth description of and lessons learned about the planning/proposal development and implementation phase of the initiative that might be useful for planners and practitioners in other jurisdictions who wish to pursue a similar initiative.

Guiding Principles

As this demonstration project gets underway, it is worth highlighting its guiding principles:

- Ensure that people who have experienced mental illness and homelessness are collaborators in the planning and delivery of all supports and services and in informing the research questions and methods used in the demonstration projects.
- Strive for long-term improvements in the quality of life of participants.
- Seek a bridge to transition and support participants after the end of the demonstration projects.
- Develop a knowledge base from the research demonstration projects in order to ultimately support more effective interventions for homeless people who have a mental illness.
- Build on work undertaken by the cities and provinces and on other promising practices in order to maximize the scope of the results and the impact of the study.
- Ensure that research is conducted in a manner that is ethically sound and meets generally accepted standards and practices of excellence.
- Support the knowledge-exchange component of the mandate of the Mental Health Commission of Canada.
- Establish mechanisms to collaborate with Aboriginal communities to ensure that approaches are culturally relevant.
- Work with communities to ensure lasting results and buy-in.
- Address fragmentation through improved system integration, including cross-governmental collaboration.
- Collaborate with partners to develop a plan for sustainability.

Timeliness of the Initiative

The United Nations special report on adequate housing describes the homelessness situation in Canada as a "national crisis" (United Nations, 2007). Recent reports have cited the significant health consequences and costs of homelessness in Canada (CIHI, 2007; Paterson et al., 2008). To date, there have been few studies examining the effectiveness of housing and support interventions for people with mental illness who are homeless, and the studies that have been conducted all originate in the United States (Nelson, Aubry, & Lafrance, 2007).

Challenges: Building Capacity and Sustainability

The Research Demonstration Project in Mental Health and Homelessness is a unique nationwide initiative aimed at improving the lives of the most vulnerable Canadians. The challenges of implementing this project are numerous. How we go about developing and supporting collaboration and partnerships with federal, provincial, and municipal governments, and with the not-for-profit and private sectors, while leveraging funds, avoiding duplication of efforts, and building a foundation for sustainability, will be key to the long-term resolution of this social problem.

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Résumé

Meilleures pratiques en matière de recherche

L'importance de procéder à une étude pilote pour les essais cliniques aléatoires en matière d'intervention

Nancy Feeley, Sylvie Cossette, José Côté, Marjolaine Héon, Robyn Stremler, Geraldine Martorella et Margaret Purden

L'étude pilote fournit une occasion unique de déterminer les difficultés que pose l'évaluation d'une intervention et de s'y préparer. Au bout du compte, cette façon de faire permettra d'améliorer la rigueur et la valeur scientifique de l'étude à grande échelle. Bien que certaines revues publient les comptes rendus d'études pilotes, on accorde très peu d'attention à ces types de questions et de thèmes de recherche qui sont propres à ces mêmes études. Le présent article porte principalement sur l'utilité de procéder à un essai clinique pilote sur un échantillon aléatoire comme première étape avant d'effectuer un essai clinique aléatoire. On y décrit les principaux objectifs d'un essai clinique pilote sur un échantillon aléatoire : à savoir, évaluer la faisabilité et l'acceptabilité de l'intervention, du plan de recherche et des méthodes ainsi que déterminer plus facilement les valeurs des effets à des fins de calculs pour la taille de l'échantillon.

Mots clés : études pilotes, essais cliniques aléatoires, méthodes, faisabilité, acceptabilité

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Best Practices for Research

The Importance of Piloting an RCT Intervention

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Robyn Stremler, Geraldine Martorella, and Margaret Purden

The pilot study provides a unique opportunity to identify and prepare for the challenges of evaluating an intervention. Ultimately, it will enhance the scientific rigour and value of the full-scale study. Although some journals publish reports of pilot studies, little attention has been given to the types of research questions and issues specific to these studies. This article focuses on the utility of a pilot randomized controlled trial (RCT) as a first step towards conducting an RCT. Three major objectives of a pilot RCT are discussed: assessing the feasibility and acceptability of the intervention, assessing the feasibility and acceptability of the design and procedures, and facilitating the determination of effect sizes for use in sample-size calculations.

Keywords: pilot studies, randomized controlled trials, methods, feasibility, acceptability

Introduction

Evidence-based practice is currently a goal of the nursing profession and is thought to achieve optimal outcomes for patients (Melnyk & Fineout-Overholt, 2005). Meta-analyses of randomized controlled trials (RCTs) are considered the strongest source of evidence on which to base practice (Melnyk & Fineout-Overholt, 2005). Thus the RCT is an important evidence-building tool for nursing practice and is increasingly being utilized in nursing research. As noted by Sidani and Braden (1998), the evaluation of nursing interventions is challenging because numerous factors can hinder one's ability to implement the experimental design and deliver the intervention as planned. The pilot RCT provides the researcher with an invaluable opportunity to identify these challenges before conducting a full-scale RCT. Moreover, the pilot study can be an important first step in securing funding for a full-scale RCT. Since RCTs are expensive, evidence that a procedure is feasible will be invaluable (Gardner, Gardner, MacLellan, & Osborne, 2003).

Although nurse researchers usually learn how to conduct experimental studies during their training (Bennett, 2005), they do not learn about pilot studies, and the majority of research textbooks fail to address this topic. Moreover, although a small number of nursing journals publish reports of pilot studies, the types of research questions that can be addressed in a pilot study have received little attention (Gardner et al., 2003; Jairath, Hogerney, & Parsons, 2000). In this article we outline the potential objectives of a pilot study and strategies to address these in order to assist investigators with the planning and conduct of an RCT.

Objectives of Pilot Studies

A pilot study precedes and is closely related to a full-scale study (Hinds & Gattuso, 1991; Perry, 2001). It is used to assess the design, methodology, and feasibility of the larger study (Gardner et al., 2003). Pilot studies should have well-defined objectives, or questions, to ensure methodological rigour and scientific validity (Lancaster, Dodd, & Williamson, 2004). Although the pilot study is often designed in much the same way as the subsequent full-scale study (Jairath et al., 2000), its research questions are different, with refinement of the processes and methods being the central focus (Campbell et al., 2007; Oakley et al., 2006).

When developing a pilot study as a preliminary step in an RCT, the researcher has several design options from which to choose. Myriad factors may influence this decision. However, we advocate a pilot RCT as the best option because only this design can fully test the feasibility of the main features of an RCT, such as random assignment of participants to a group. Hence in this article we focus on the pilot RCT and describe three major objectives: (a) assessing the feasibility and acceptability of the intervention, (b) assessing the feasibility and acceptability of the design and procedures, and (c) facilitating the determination of effect sizes to use in sample-size calculations for a full-scale trial. We conclude with a discussion of the issues surrounding the publication of pilot RCTs.

Defining Feasibility and Acceptability

While many published pilot studies assess feasibility and acceptability, these terms have not been explicitly defined, and many authors do not differentiate between the two. This may be partly because the terms are closely intertwined. For example, if an intervention is not acceptable to participants, then it is unlikely that it will be feasible, and vice versa. Nonetheless, it is helpful to distinguish between the two terms in the interests of conceptual clarity. Feasibility is defined as the ease or convenience of execution (Soanes & Stevenson, 2005), while acceptability is defined as the suitability or favourability of reception ("Acceptableness,"

Table 1 *Definitions*

Assessment of feasibility	Determines whether the intervention, study design, and procedures can be successfully executed by the researcher and delivered to the participants as planned.
Assessment of acceptability	Determines the suitability of the intervention and the study procedures from the perspective of the clinical population of interest, the intervention providers, or the health professionals who provide care to the population of interest.
Assessment of intervention fidelity	Determines the extent to which the intervention can be provided as intended. These data can be used as indicators of feasibility in a pilot RCT.

2008). Therefore, we propose that feasibility is primarily concerned with the researcher's ability to execute the plan — that is, to provide the intervention and complete the study procedures — whereas acceptability is concerned with the suitability of the intervention or the research design from the perspective of the recipients, the intervention providers, or health-care professionals (Table 1).

Assessing the Feasibility and Acceptability of the Intervention

Before a pilot RCT can be conducted, the experimental intervention must be developed to the point where pre-testing is possible. The process of intervention development has been described by others (Conn, Rantz, Wipke-Tevis, & Maas, 2001; van Meijel, Gamel, van Swieten-Duijfjes, & Grypdonck, 2004) and is beyond the scope of this article. Feasibility and acceptability issues need to be considered early in the process of intervention development and should be systematically assessed in the pilot RCT, because non-significant results in the full-scale RCT might be a result of problems with feasibility (e.g., ineffective delivery) or acceptability (e.g., ineffective uptake) rather than ineffectiveness of the intervention itself (Santacroce, Maccarelli, & Grey, 2004).

Feasibility

Many different aspects of intervention feasibility can be examined, including the dose (i.e., number, frequency, and timing), content, and methods of delivery. One indicator of intervention feasibility is the percentage of sessions delivered to participants. In a pilot study assessing an intervention with mothers of very low birth-weight (VLBW) infants, one objective was to determine the feasibility of delivering the intervention in six sessions while the mothers were in the neonatal intensive care unit (NICU) (Feeley et al., 2008). The intervention began shortly after the mothers had given birth, a time often marked by high levels of maternal psychological distress and precarious infant health. The number of sessions received by each participant was documented, and findings revealed that the intervention was feasible, since 83% of mothers received all six sessions. Although the percentage of sessions delivered is an indicator of feasibility, it also reflects (to some extent) the acceptability of the intervention for the study population. In cases where the researcher has reason to believe that one element of the intervention might be of particular importance for intervention effectiveness, the percentage of sessions provided may not be the best indicator; it may be more appropriate to determine whether the critical elements of the intervention have been provided.

Intervention fidelity is defined as the extent to which the intervention can be delivered as intended (Bruckenthal & Broderick, 2007). Most researchers will be familiar with the notion of monitoring intervention fidelity in a full-scale RCT. However, Bruckenthal and Broderick (2007) propose that intervention fidelity be assessed in a pilot RCT. This can reveal problems related to implementation that can be remedied and thus lead to improved delivery in the full-scale RCT. For example, in a pilot study for a coping skills intervention, Bruckenthal and Broderick assessed whether nurse providers implemented the intervention content according to the manual. Audiotapes of intervention sessions were analyzed using a checklist that included the essential content of each session. Although the findings indicated that most of the content (i.e., 86%) was delivered, one important element was omitted: the providers often failed to ask whether participants practised their new skills. To address this problem the researchers extended provider training and placed greater emphasis on how to follow up on participants' use of the coping skills they had been taught. It is hoped that enhanced training will translate into improved implementation of the intervention in the full-scale RCT.

Acceptability

There are many stakeholders in an RCT, and therefore a pilot RCT should examine the acceptability of an intervention from the perspective of several key groups, including patients, intervention providers, and health professionals. The nursing literature includes many examples of pilot RCTs that examine intervention acceptability. When researchers measure acceptability, they typically assess satisfaction, or perceptions of the helpfulness, credibility, comprehensibility, and user-friendliness of the intervention (Vandelanotte & De Bourdeaudhuij, 2003). For example, Dennis (2003) administered a reliable and valid questionnaire to assess mothers' perceptions of a peer-support program. The measure examined the quality of each mother's relationship with the peer intervener and her satisfaction with the support. It also examined the peer interveners' perceptions of their experience in providing the intervention. In a pilot RCT for an intervention to help mothers manage their preterm infants' health problems, researchers assessed the usefulness of the intervention from the perspective of the participating mothers, the infants' primary health-care provider, and the nurses who delivered the intervention (Pridham et al., 2006). These data pointed to the need for modifications to the intervention. For instance, written guidelines on how to manage infant health problems were seldom used, and mothers suggested how these could be modified to enhance their utility.

It is evident from these examples that feasibility and acceptability assessment may reveal the need for some adjustment to an intervention. If careful attention has been paid to these issues in the early stages of intervention development, the RCT should require only fine-tuning, such as minor changes to the content and methods. As van Meijel and colleagues (2004) suggest, if the pilot study leads to a major modification of the intervention, the researchers should continue with the pilot procedure, until the intervention is optimized, before proceeding to the full-scale RCT.

Assessing the Feasibility and Acceptability of the Study Design and Procedures

Another major objective of a pilot RCT is to determine the feasibility and acceptability of the design and procedures (van Teijlingen & Hundley, 2002). This assessment determines if and how the design should be modified for the full-scale RCT (Hinds & Gattuso, 1991). It can also reveal threats to validity, such as contamination (Becker, Roberts, & Voelmeck, 2003). Although many design features can be examined, in this article we will focus on those most pertinent to RCTs.

Feasibility

Questions concerning the recruitment of participants need to be considered in the pilot RCT (Friedman, Furberg, & DeMets, 1998). An obvious indicator of recruitment feasibility is the percentage of eligible persons agreeing to participate. Of course this may also reflect the acceptability of the intervention or study procedures, as a person's willingness to take part will be influenced by his or her perception of these factors. To assess the extent to which the acceptability of the intervention and procedures may affect recruitment, a questionnaire can be administered at the time of recruitment to identify the specific reasons for refusal (i.e., study procedures too time-consuming or intervention not appropriate).

Data concerning the rate of recruitment can be useful in determining the overall timeline for the full-scale RCT as well as in drawing up a budget (Lancaster et al., 2004). They may also be used to confirm the adequacy of proposed recruitment sites and the need for additional sites for the full-scale study. As well, they can be useful for assessing the effectiveness of recruitment methods, revealing obstacles to recruitment, and revising methods accordingly.

Inclusion and exclusion criteria can be scrutinized (Hinds & Gattuso, 1991) to determine whether the study population, as defined by the inclusion and exclusion criteria, is sufficiently large. If the pilot study reveals otherwise, revision of the criteria may be advisable, to capture a narrower or broader range of participants. Nevertheless the researcher will have to ensure that the intervention is appropriate for the revised sample. In pilot testing an intervention with caregivers of Parkinson's patients, Habermann and Davis (2006) found that many caregivers were in their 50s whereas the inclusion criteria stated that they had to be 60 or older. For the full-scale RCT, modifications were made to allow for the enrolment of caregivers in their 50s, in the knowledge that the intervention would be relevant for younger as well as older caregivers.

An important feature of RCTs is the blinding of participants, research staff, or clinicians — meaning that one is unaware of whether a participant has been assigned to the intervention or the control arm of the study (DiCenso, Guyatt, & Ciliska, 2005). A double-blind study design (i.e., both the participants and the outcome assessors are blind) is not usually possible in nursing intervention studies because in such studies participants are often provided with information or are assisted in changing their behaviour (Sidani, Epstein, & Moritz, 2003). However, single-blind studies, in which the assessors of outcomes are blind to group assignment, are often possible in nursing research. Pilot work can be an opportunity to determine the feasibility of blinding outcome assessors, if this is part of the protocol. For example, research staff who assess the primary outcome can be asked if they have any knowledge of the participants' group assignment. The same approach can be used, if applicable, to determine whether the clinicians caring for participants are aware of group assignment. If the pilot study reveals that assessors or clinicians have learned of participants' group assignment, then strategies can be devised to correct this problem in a full-scale study.

Reduction of bias in an RCT hinges on successful randomization. Randomization consists of two elements: (a) the generation of a random allocation sequence, and (b) the implementation of that sequence in such a way that it is concealed until the participant is assigned to a group — that is, allocation concealment (Schulz & Grimes, 2002). Allocation concealment prevents research staff members who enrol participants and others from knowing the subsequent group assignment. A variety of allocation concealment methods are considered adequate. They include opaque, sequentially numbered, sealed envelopes; centralized randomization via a telephone service; and randomization via a Web site (Schulz & Grimes, 2002). When the pilot study includes random assignment of participants to a group, information can be gleaned as to the effectiveness of the allocation concealment method as well as how randomization will be received by potential participants (Lancaster et al., 2004).

Some participants may be reluctant to agree to random assignment, a difficulty that has been noted in nursing intervention studies (Fogg & Gross, 2000; Gross & Fogg, 2001). Some people may not wish to participate because they have a clear preference for one intervention and wish to choose which intervention they receive (Miranda, 2004). It is critical for the researchers to determine whether this might be the case before conducting a full-scale RCT.

If the pilot reveals that too few participants will agree to be randomized, then investigators may consider other design options, such as a partial RCT, random assignment by site, or the Zelen design. The partial RCT design allows participants who have a treatment preference and do not wish to be randomized to choose their group assignment, while those with no preference are randomly assigned (Sidani et al., 2003). The partial RCT design is prone to selection bias, of course, due to the lack of random assignment. If random assignment by site is utilized and the sites are not comparable, there is the threat of selection bias. With the Zelen design, participants are randomly assigned to groups before they are approached and give their consent (Homer, 2002). This option is controversial due to ethical concerns and the potential for loss of power if a large portion of participants decide to withdraw after randomization.

Patients' reluctance to take part in an RCT may indicate a lack of equipoise regarding the benefits and risks of the intervention. First proposed by Freedman (1987), clinical equipoise means that there is no consensus within the scientific community about the comparative merits of the intervention being tested in an RCT. There is evidence demonstrating that the acceptability of clinical equipoise can be crucial in determining whether participants will consent to randomization and accept their group allocation (Mills et al., 2003). For example, if potential participants feel strongly that the experimental intervention is more effective than the control, they may not agree to accept an equal chance of being assigned to the control group. It is important that willingness to accept randomization be established in a pilot study, before the investigators embark on a full-scale RCT.

Two particular issues that may warrant careful appraisal in a pilot study are contamination and co-intervention. Contamination occurs when participants in either group receive the intervention intended for those in the other group (DiCenso et al., 2005). When participants in the control group are exposed to the intervention, even in part, they may experience change in the desired outcomes (Becker et al., 2003). In a pilot study, researchers can devise ways to assess contamination and determine whether it needs to be addressed. For example, in the pilot study with mothers of VLBW infants, the research staff asked participants not to discuss the information they were acquiring in the experimental program with other mothers of infants in the NICU (Feeley et al., 2008). Post-intervention, mothers were asked if, and with whom, they had shared the information they acquired during the intervention. If contamination is a concern, the researcher might consider revising the design to randomize sites rather than individuals (Gross & Fogg, 2001); alternatively, randomization could be limited to one participant per patient care room.

Co-intervention occurs when interventions other than the experimental intervention, but affecting the target outcome, are administered differentially to both the experimental and the control group (DiCenso et al., 2005). Co-intervention can be an issue in nursing intervention studies, and a pilot study can determine whether this is problematic. Data can be gathered from participants about the use of services that might constitute co-intervention. For example, a pilot study for an intervention to promote maternal and infant sleep in the early postpartum period assessed mothers' sources of sleep information by asking them if they sought additional sleep-related advice (Stremler et al., 2006). This allowed the investigators to assess the pervasiveness of co-intervention and to determine whether there was an imbalance between groups in the amount of co-intervention. Excessive use of co-interventions or imbalance between groups may reflect a lack of confidence among participants in the potential usefulness of their assigned condition and indicate a need for future trial investigators to tailor the intervention to participants.

A pilot RCT can also be useful for scrutinizing the appropriateness, timing, and sequencing of study measures. For example, in a pilot test for an intervention for caregivers of Parkinson's disease patients, researchers assessed whether it was more effective to administer a questionnaire before or after an in-depth interview with participants (Haberman & Davis, 2006). The findings indicated that the questionnaire should be administered before the interview, as this would allow participants to develop rapport with the interviewer. The feasibility of observational measures can be a particularly important consideration. In the pilot study with mothers of VLBW infants, the plan was to observe mother-infant interaction in the NICU before the intervention (Feeley et al., 2008). However, it was unclear whether it would be possible to observe such interaction so soon after preterm birth. In fact, the pilot study revealed that there was very little interaction, due to infant sleep or health status. Based on this finding, it was decided not to measure pre-intervention interaction in the RCT. As a result, a change from baseline to post-intervention could not be examined.

A pilot study can also examine the possibility of unexpected outcomes, which may prompt the investigators to include additional outcomes in the full-scale RCT — ones that initially had not been considered. Conversely, the pilot study may identify outcome measures that are inappropriate, lacking in sensitivity, or unfeasible (Hinds & Gattuso, 1991; van Teijlingen & Hundley, 2002). Pilot work also allows the researcher to determine which outcomes may be amenable to change, and at what time points (Campbell et al., 2007), facilitating the selection of the best outcome measures. For example, in their pilot study Stremler and colleagues (2006) found that, at 6 months postpartum, mothers who received the experimental intervention slept more than mothers in the control group. Given the evidence of the short-term efficacy of the intervention, a future RCT will examine longer-term outcomes.

Acceptability

A pilot study also provides an opportunity to assess the acceptability of data-collection procedures (Hinds & Gattuso, 1991), such as gauging participants' willingness to complete the study procedures or determining whether the data can be collected in a reasonable span of time. It is particularly important that the burden to participants be assessed in the pilot RCT study, as both the intervention and the study procedures place demands on participants. Moreover, in nursing studies participants are often ill or in the midst of dealing with a health crisis. Reviewers of the grant application for the full-scale RCT may have concerns about these issues that could well be assuaged by the pilot data. If the pilot study reveals that the procedures are unacceptable to participants, then the researcher can explore means of reducing the burden, such as shorter instruments, shorter data-collection sessions, or telephone interviews. For example, in the pilot study with mothers of VLBW infants, mothers completed post-intervention questionnaires, infant development was assessed, and mother-infant interaction was videotaped (Feeley et al., 2008). Mothers were willing to participate in a 1-hour home visit, and the pilot study found that data collection could be completed within this time-frame if carried out by two research assistants.

Determining Effect Sizes

Researchers have used pilot RCT estimates of outcome variance or proportion to determine the sample size for the full-scale RCT (van Teijlingen & Hundley, 2002). This is a particularly useful option when there is scant literature on which to base effect-size estimates and when the pilot RCT uses the same design and outcome measures as the full-scale RCT (Hertzog, 2008). However, it should be kept in mind that the pilot RCT may lead to an over- or underestimation of effect size and the possibility of over- or underpowering the full-scale trial (Kraemer, Mintz, Noda, Tinklenberg, & Yesavage, 2006). Ideally, effect-size estimates or outcome variance estimates from pilot studies are supported by the literature as well as by estimates of clinically meaningful differences between groups. Alternatively, a conservative approach to the use of such estimates in sample-size calculations should be used, in order to ensure adequate power for the future trial (see Hertzog [2008] for a detailed discussion of these methods). Since pilot studies typically have small sample sizes and are often underpowered to reveal statistically significant differences between groups, investigators and funding agencies should resist viewing small effect sizes in pilot studies as reason to reject moving forward to the full-scale RCT.

Regardless of the outcome estimate used in calculating sample size for a future RCT, attention must be paid to the issue of clinical significance. While an intervention may lead to statistically significant differences between groups, it will be useful in practice only if that translates to a clinically meaningful difference in health outcomes. Ideally, clinical consensus will indicate what difference in participant outcomes merits the time, expense, and effort of the proposed intervention. Although estimates of clinically significant differences in outcomes should be elicited from expert clinicians, a pilot RCT offers an excellent opportunity to elicit participants' opinions about what they would consider meaningful. This information can be invaluable in interpreting outcomes from the pilot study (Oakley et al., 2006) and can also be helpful in planning future RCTs. Sample-size calculations are more difficult to complete when the relationship between statistically significant and clinically meaningful differences is unknown. Pilot work can be useful in this regard.

Since the pilot study is not expected to be powered to detect differences between groups, there is no universally accepted calculation for pilot study sample size. However, Hertzog (2008) provides a statistical approach to determining sample size for pilot RCTs. This approach is aimed at obtaining estimates of variance in an outcome when an important difference between groups has already been identified. In such cases, it is suggested that 10 to 20 participants per group will suffice. However, if a meaningful group difference is unknown and the pilot study is intended to establish an effect size for sample-size calculation, then 30 to 40 participants per group is suggested. Ultimately, the decision regarding sample size for a pilot RCT must also take into account the research timeline, human and financial resources, and the research objectives.

Publication of Pilot RCT Findings

Researchers wishing to publish the findings of their pilot study may encounter difficulties, since there is currently much controversy over the usefulness of such publications. Opinions vary regarding whether the report should focus on the process of implementing the study (i.e., feasibility and acceptability objectives, as discussed in this article), the study outcomes (i.e., hypothesis testing as to whether the intervention was efficacious), or both implementation and outcomes. We agree with those who argue that pilot RCT findings should be published, but with the stipulation that they should contribute meaningfully to the literature (Watson, Atkinson, & Rose, 2007). The publication of feasibility and acceptability findings of a pilot RCT serves to inform other researchers about the methodological or practical challenges of designing such studies (Gardner et al., 2003) and constitutes a meaningful contribution to nursing knowledge. However, we would also agree with van Teijlingen and Hundley (2002), who argue that the outcomes of pilot RCTs should be published only if they are interpreted with caution. For example, in the pilot RCT for the mother-infant sleep intervention, statistically significant differences in amount of maternal night-time sleep and number of infant awakenings were found between the experimental and control groups at 6 weeks postpartum (Stremler et al., 2006). The investigators published the results, reporting on both the process and the outcomes, but were careful to ensure that any conclusions about the efficacy of the intervention acknowledged both the small sample size and the limited generalizability. Furthermore, for these reasons they indicated that they would proceed to a full-scale RCT to enrol a more diverse sample.

A last issue regarding the publication of pilot RCT outcomes relates to knowledge transfer. Lancaster and colleagues (2004) reviewed pilot studies published in seven major journals and found that only a few reported that their purpose was to prepare for a future RCT. Thus clinicians may take the positive outcomes of a pilot RCT to mean that the intervention should be applied in practice, particularly if this is the best published evidence. Although various groups, such as the Centre for Evidence-Based Medicine at Oxford (InfoPOEMS, 2007), have developed systems to grade evidence, they do not mention pilot studies, thus leaving it unclear how these studies should be considered. In any publication of a pilot RCT, the researcher should explicitly state that the purpose of the study was to prepare for a future full-scale RCT, so that clinicians do not conclude that the pilot RCT results can be interpreted as final.

Conclusion

In this article we have outlined the key objectives of a pilot RCT in order to assist investigators with the design of their own pilot studies. As noted by Hinds and Gattuso (1991), pilot studies are different from full-scale studies not in sample size but in purpose. Pilot studies can address a variety of methodological and practical questions and can be an invaluable first step in conducting feasible, scientifically sound, full-scale RCTs that will provide high-quality evidence on which to base practice. The pilot RCT study represents an excellent opportunity to assess the acceptability of an intervention and fine-tune the content and format, through feedback from participants and others. The dissemination of pilot findings can contribute to knowledge by furthering researchers' understanding of the methodological and practical challenges of designing and conducting intervention studies.

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Résumé

Les conséquences de présenter d'importants antécédents familiaux de cancer du sein

Christine Maheu

Les constations formulées dans le présent article sont tirées d'une étude qualitative au cours de laquelle des données ont été recueillies auprès de 20 femmes qui avaient reçu des résultats non concluants à la suite d'un test génétique pour mesurer une susceptibilité héréditaire au cancer du sein. Avant de parler de la signification qu'elles accordaient à leurs résultats, toutes les participantes ont décrit comment elles vivaient le fait de présenter d'importants antécédents familiaux de cancer du sein. Le présent article porte principalement sur l'expérience des femmes présentant des antécédents personnels et familiaux de cancer du sein. Pour ces femmes, de tels antécédents sont devenus une réalité qu'il est impossible d'ignorer. À partir des données recueillies, trois thèmes ont été dégagés : *anticiper un diagnostic de cancer du sein et y réagir, se protéger et protéger les autres,* et *avoir à subir davantage d'examens de dépistage du cancer.* Ces thèmes portent sur la réalité fondamentale qui entoure le fait de présenter des antécédents personnels et familiaux de cancer du sein, c'est-à-dire qu'il ne s'agit pas d'une situation isolée, mais plutôt d'une partie du parcours d'une personne dans le choix de se soumettre ou non à des tests génétiques en vue de déterminer une susceptibilité au cancer du sein.

Mots clés : cancer du sein, antécédents familiaux

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Implications of Living With a Strong Family History of Breast Cancer

Christine Maheu

The findings presented here are from a qualitative study in which data were gathered from 20 women who had received inconclusive genetic testing results for inherited breast cancer susceptibility. Before describing the significance, for them, of their genetic test results, all of the participants related what it was like to live with a strong family history of breast cancer. The focus of this article is the women's experience of living with a personal and strong family history of breast cancer. For these women, having such a history had become a fact of life that could not be ignored. Three themes were identified in the data: *expecting and dealing with a diagnosis of breast cancer, protecting oneself and others,* and *increasing exposure to cancer screening procedures.* These themes address the underlying reality that having a personal and family history of breast cancer is not an isolated situation but part of one's journey in choosing to undergo genetic testing for inherited breast cancer susceptibility.

Keywords: breast cancer, family history, qualitative, interpretive description

A family history of the disease is recognized as one of the most important risk factors for breast cancer (Emery, Lucassen, & Murphy, 2001; Yang & Lippman, 1999). A family history with the following characteristics indicates probable genetic susceptibility: breast and/or ovarian cancer in two or more first-degree relatives (mother, sister, or daughter); young age at diagnosis; and breast cancer appearing on the same side of the family, among same-blood relatives. Genetic testing for inherited breast cancer susceptibility is usually reserved for individuals who are assessed at risk of predisposition because of their personal and strong family history of the disease. Three types of result are possible with such genetic testing. The individual can be found to carry an inherited mutation and therefore receives a *positive* test result. When a mutation has been identified in a family, those family members who opt for testing can either be found to carry the familial mutation or be told that they do not carry it; hence, they receive the second type of result, a *true negative.* The third type of test result is *inconclusive.* The result is inconclusive when a mutation is not detected in individuals with a past personal cancer diagnosis, from a family at high risk of the disease, who have no prior identified familial mutation (Carter, 2001; Dorval et al., 2005).

The data-based literature shows that individuals from families with a strong history of breast cancer demonstrate intense interest in genetic testing (Bottorff et al., 2002). While this population shows great interest in genetic testing, it also exhibits a high degree of psychological cancer distress (Friedman et al., 2006). Zakowski et al. (1997) and Zakowski, Valdimarsdottir, and Bovberg (2001) report that individuals from families with a history of cancer are known to experience symptoms of general distress, to have frequent intrusive thoughts, and to at times deny their risk of cancer. According to Baum, Friedman, and Zakowski's (1997) theoretical model of stress and genetic testing for disease risk, individuals who perceive themselves to be at increased risk of cancer because of a strong family history but who have no identifiable mutations may experience stress similar to that exhibited by those who are found to carry an inherited cancer mutation. Baum et al. postulate that, for the former population, an inconclusive genetic test result does not reduce their uncertainty about the etiology of their cancer history, with the resultant distress adding to the distress from perceived risk of an inherited mutation. To date there have been few studies describing this unique pool of individuals: those who have a personal and family history of breast cancer and who have received inconclusive genetic test results for inherited susceptibility (Frost, Venne, Cunningham, & Gerritsen-McKane, 2004; Hallowell, Foster, Eeles, Ardern-Jones, & Watson, 2004). In the large qualitative study on which this article is based, 17 of the 20 women interviewed took their inconclusive results to mean that there was still a possibility they carried a breast cancer mutation (Maheu & Thorne, 2008).

Consequently, empirical research looking at the implications of living with a personal and family cancer history indicating a probable inherited genetic susceptibility seems warranted. We need to better understand how such implications create unique health and illness experiences in the context of clinical genetics. The present article addresses this gap by describing women's experiences of living with both a breast cancer diagnosis and a strong family history of breast cancer that indicates probable inherited susceptibility. The findings presented here are from a qualitative study with women who received inconclusive genetic test results (Maheu & Thorne, 2008).

Method

The study was guided by the interpretive description approach (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). This approach recognizes the contextual and constructed nature of the health and illness experiences of those who come into contact with clinical settings and relates how clinical context can influence an individual's subjective interpretation of their experience. The purpose of interpretive description is to identify common clinical phenomena that, within individuals' contexts, generate new understandings and new meanings of the phenomenon under study (Thorne et al., 1997).

Recruitment and Sampling Procedures

Recruitment took place within one Hereditary Cancer Program (HCP) in Canada. A sample of 21 women was drawn from a pool of 250 who spoke English, had a previous breast cancer diagnosis, had already undergone genetic testing for inherited breast cancer susceptibility, and were considered to have a strong family history of breast cancer (having met eligibility criteria for genetic testing that predicted a 10% to 20% chance of finding a mutation). The women were selected with the assistance of genetic counsellors and the HCP's educational nurse. They had been identified by the health professionals because of their openness during genetic counselling about their views on genetic testing for inherited breast cancer susceptibility and because of their divergent cancer backgrounds. First, the health professionals sought the women's permission to be contacted for research. Next, I contacted interested individuals to further describe the goal of the study and to seek their participation. Of the 21 women who were approached, one declined, as she was experiencing a second primary breast cancer. Once verbal consent was obtained, the 20 women were sent an information letter, the interview guide, and an informed consent form to be signed on the day of the interview. Clearance to conduct the study was obtained from the Behavioural Research Ethics Board at the University of British Columbia and from the HCP.

Data Collection

In this study, semi-structured interviews captured participants' experience of living with a personal and strong family history of breast cancer. Each interview began with the interviewer asking the woman to describe, in a story format with a beginning, middle, and end, her personal experiences with breast cancer and the experiences of others in her family. I strategically used this opening segment to help the participant feel comfortable telling her story in the open-interview format. During the course of the interview, I used prompts to guide the woman in exploring her experience of living with a personal and family history of breast cancer. These prompts included the following: *How has breast cancer affected your life? How did you feel when a family member was diagnosed with breast cancer? Did this influence your thoughts of your own risk or the risk of others in your family? Do you have an explanation for the appearance of breast cancer in you and in your family members?* All but three of the interviews took place in the participant's home. The interviews lasted 60 to 90 minutes on average. All participants were asked to choose a code name to safeguard their anonymity. All transcribed interviews were transferred to QSR N5 software for qualitative analysis, for ease of data management and retrieval.

Data Analysis

Data collection and analysis were conducted iteratively over 1 year. The analysis consisted first of identifying key statements that spoke to the implications of living with a strong family history of breast cancer. These key statements were recurrent beliefs and ideas cited by the participants while telling their stories. These key statements served as initial identification of themes. While searching for themes in the interview data, I asked myself: *What led this participant to respond in this way? What am I hearing and not hearing? What is different and similar within the interviews conducted thus far?* I marked these insights as *outstanding questions* in my field notes, to be either tested or negated by the next interviewees.

The reflection allowed for clarification of other emerging themes. In subsequent interviews, the woman was asked to reflect on the meaning of emergent themes for her lived health and for her illness experiences with breast cancer. This strategy contributed to the validity of the findings. I also contrasted identified themes with individual and aggregate stories in order to assess how context influences and alters the experience of living with a personal and family history of breast cancer. After comparing the themes in the 20 different experiential contexts, I could see a pattern in the overall experience of deciding to undergo genetic testing for inherited breast cancer susceptibility. As one participant explained, the women had not "arrived at the decision to have genetic testing overnight" but had been led, by certain factors, to become open to this new technology. One major factor was the implications of having a personal and family history of breast cancer.

Findings

The 20 women ranged in age from 41 to 70. More than half were married and more than half had a relatively high level of education. All except one were Caucasian. Nine of the 20 had received a breast cancer diagnosis while under the age of 40. Twelve had a mother diagnosed with breast cancer and seven had a sister diagnosed with breast cancer. For 11 of the women, three or more family members in the last two generations, on the same side of the family, had been diagnosed with breast cancer.

Three themes associated with the implications of living with a family history of breast cancer ran through the interviews: *expecting and dealing with a diagnosis of breast cancer, protecting oneself and others,* and *increasing expo-*

sure to cancer screening procedures. Each of these themes will be discussed separately.

Expecting and Dealing With a Diagnosis of Breast Cancer

Having been in close contact with family members who had developed breast cancer, the women had come to expect that they would get the disease themselves at some point. One woman, Juniper, had seen her mother develop breast cancer while Juniper was still a preteen. She described her own experience: "I basically prepared myself to have cancer all those years. It was like I knew that probably at some point I would have cancer." The following contextual description of Juniper's life reveals how she became comfortable with the word "cancer."

When Juniper's mother was diagnosed with breast cancer at the age of 45, she pulled Juniper and her sister out of school so they could look after their younger brother, feeling that she was no longer able to do so herself. Juniper said that her mother went into a depression and showed the many facets of the illness to her three young children. The children became their mother's only support system. Juniper stated that her mother's mental pain was more difficult for the children to deal with than her physical pain, even when she showed them the gruesome scars from her radical mastectomy.

Like her mother, Juniper was diagnosed with breast cancer at the age of 45. She explained that, although she had not expected to get breast cancer one day, she felt that she had already experienced the diagnosis through her mother's cancer, and she did not fear it; in fact when Juniper received her breast cancer diagnosis, she did not experience intense shock.

This one participant expressed the cancer risk awareness of many of the others. The women explained that it was difficult to let go of their perception of increased cancer risk. They feared a recurrence or another primary cancer, knowing that this was a real possibility, as they had seen it happen to other family members. The women described how they looked to past generations for possible scenarios of how breast cancer would strike their generation — themselves as well as their family members. Those with daughters also worried that they would be diagnosed with breast cancer. Interestingly, one woman reported that her daughter did not fear cancer but had come to accept it as inevitable. Another participant, Donna, related a conversation between herself and her daughter:

> *My daughter said, "I know what happened to my grandmother and to you. I expect it to happen to me, but I don't really want to think about*

> *that now." My daughter has kind of accepted that this is something that's going to happen. She's just waiting for the other shoe to drop.*

The women's awareness of their family disease and their learning to live with the heightened risk help to explain why many of them were comfortable with the word cancer and saw it as the family norm. The women explained that it was an accepted topic of conversation at family gatherings, triggered either by a recent diagnosis or by the many reminders of breast cancer in the homes of family members. Those reminders, they said, became part of their family history. One woman made an analogy between the expectation of breast cancer diagnoses in her family and society's expectation of car accidents because there are so many cars on the road: "There's always the thought that . . . someone else in the family will be diagnosed."

Nineteen of the 20 women said that their perceived high risk made their cancer diagnosis less stressful than it otherwise might have been. The one exception, Erika, had immigrated to Canada relatively young and had little contact with her extended family. Her mother had not been diagnosed with breast cancer and was unaware of any other breast cancer diagnoses in the family except for her grandmother. Erika herself had been diagnosed at 35.

In Stephanie's case, conversely, both her mother and her grandmother had been diagnosed with breast cancer in their early 30s. Stephanie commented, "What else was I to assume?" Stephanie was diagnosed with precancerous cells in her cervix at 20, received a second cancer diagnosis at 35 when she developed uterine cancer, and was diagnosed with breast cancer at 50. Stephanie not only had come to expect a diagnosis of breast cancer one day, in light of her family history of cancer, but had become comfortable with the word cancer.

Although some of the women had become comfortable with the word cancer, two said that they experienced difficulty with losing their breast. They explained that, although images of breastless women were not strange to them, they still felt ill at ease:

> *Having most of my adult life seen my mother with no breast, it wasn't as if I didn't know what it was going to look like. You get used to the word cancer and are almost comfortable with it, even when one gets a diagnosis. But what has been harder is losing the breast. It's like there [are] two different issues happening. I had a harder time with losing my breasts [than with] having cancer.*

Four other women spoke of losing a part of themselves and their femininity when they had their breasts removed as part of their cancer treatment. They described the event as a disruption of their self-identify;

living with breastlessness or with reconstructed breasts forced them to rebuild their self-identify. For two other women, however, breast removal was a positive event. These participants explained that they had, as they put it, finally got "rid of it" — the source of their fear and anxiety. Gilligan said that her mastectomy decreased her personal risk of cancer while permitting her to take on more risk in other aspects of her life, such as her professional life.

The accounts above concern how women dealt with their own cancers. Coming from families with a high prevalence of cancer, they also had to learn to deal with cancer diagnoses and deaths among family members. More than three quarters of the women explained that they had to deal with disrupted plans due to new diagnoses or deaths. These are further implications of living with a strong family history of cancer. The participants said that when they made plans, unlike people with no family cancer history, they often had to ask, *What if someone gets a diagnosis?* For example, Gladys said that her own vacation plans and those of her eldest sister were sadly derailed when the middle sister received her fourth cancer diagnosis. For Emma, disrupted plans meant broken dreams. The following is Emma's biographical account of broken dreams after her two sisters died from breast cancer. It is constructed from segments of her interview.

It was only recently that Emma was able to speak about the death of her sisters. Emma had planned to grow old with them. Instead, she found herself nursing both of them to their deaths from breast cancer. One of Emma's sisters had been like a mother to her. When this sister received her diagnosis, Emma and her husband decided to sell their home and move closer to her. Soon after the move, Emma took her sister into their new home, where she cared for her until the end. Following the death of her two sisters, Emma was diagnosed with breast cancer as well, at the age of 43. At the time of the interview she was still suffering from survivor guilt.

Protecting Oneself and Others

Individuals who believed that cancer was the norm in their family viewed themselves as the family guardian. They made it their responsibility to oversee the cancer screening behaviours of their siblings and sometimes of extended family members as well. Who was guarded in the family and who was not seemed to depend on one's geographical and emotional proximity to the guardian. Some women explained that, as family guardian, they had genetic testing on behalf of family members who did not meet the eligibility criteria for testing, such as having a previous cancer diagnosis. In their role as family guardian, these women expressed a need for ongoing professional support to keep up to date with information on breast cancer.

For many of the women, receiving an inconclusive genetic test result left them uncertain about the etiology of their cancer. To understand it, the women compared themselves to others in their families, seeking family risk factors for breast cancer. Three women specifically posed an interesting question: If they could not determine why they had developed breast cancer in the first place, how could they know whether they were being diligent enough to prevent another cancer? Many of the participants, perhaps as a result of being family guardians and aspiring role models, were proactively trying to reduce their risk of breast cancer. Erika reported becoming highly aware of anything that could be carcinogenic; at one point she had almost stopped eating for fear of consuming carcinogenic agents. Victoria had decided to grow an organic garden in the summer and to avoid all non-organic vegetables and fruits during the rest of the year.

Increasing Exposure to Cancer Screening Procedures

The women's accounts suggest that they had gone through much more cancer screening and testing than undergone by the average woman. As one woman explained, "I understand that my lumpy breasts are not the same as your lumpy breasts." The participants commented that, in their case, a suspicious lumpy breast or fibrous cyst would be investigated more thoroughly because of their family cancer history. For some of the women, before they received their first diagnosis of breast cancer they had already experienced much cancer screening and testing:

> *By the time I was barely 30 years old I had already experienced my first mammogram. By the time I was 40 I had [had] about five or six done. And by the time I was 41 I had [had] one breast aspirated for a fibrous cyst. Yes, I had been thinking about cancer for a long time. Then you also have those "worrisome mammograms" that tend to lead to other mammograms soon after.*

As well, a breast cancer diagnosis in the family often served as a sharp reminder to others to get screened, whether or not they were due for their regular checkup. One woman described how her breast cancer diagnosis prompted her three sisters to have their mammograms redone. As a result two sisters were told that their mammograms were normal and the other was found to have a suspicious lump; this led to more tests, which revealed a malignant tumour.

Participants explained that a strong family history of breast cancer made them eligible for clinical trials. A few said that they were at times solicited and encouraged to participate in clinical trials because of their family history. Some women linked their eligibility for trials and their eligibility for genetic testing: just as they had easily met many of the criteria for different clinical trials, they easily met criteria for genetic testing for inherited breast cancer susceptibility.

All but three of the women interpreted meeting eligibility criteria for genetic testing as confirmation of their high cancer risk and their likelihood of carrying a genetic mutation. About half of the sample explained that agreeing to be genetically tested was a way for them to gain control over what they saw as their "chronic illness." Approximately a third perceived their high cancer risk as a constant in their lives, concluding that living with high cancer risk was like living with a chronic illness.

Discussion

This study explored the experiences of 20 women who had grown up in families with a strong history of breast cancer. Each participant had received a breast cancer diagnosis. The women's knowledge of their strong family history of breast cancer appears to have provided them with time to adapt to their own risk and that of others in their family. Analysis of the women's experiences of living with a family history of cancer revealed contexts for their experience of genetic testing for inherited breast cancer susceptibility. It became apparent in the larger investigation of which the present study was a part that the decision to undergo genetic testing did not take place in a vacuum but occurred in the context of the women's lives; for example, the women attached meanings to living with a personal and strong family history of breast cancer.

In their experience of expecting a diagnosis of and dealing with breast cancer, all of the women described how they became comfortable with the word cancer. Kenen, Ardern-Jones, and Eeles (2003) theorize that this ease mimics coping strategies among individuals with chronic illness. Kenen et al. describe the expectation of disease onset as "living with a chronic risk perspective." The participants in the present study experienced two types of chronic risk: the risk of breast cancer diagnosis, and the risk of inherited mutation of breast cancer. Although theories of uncertainty in illness have been developed (Mishel, 1988, 1990), they pertain to chronic illness, not chronic risk. Therefore, much remains to be discovered about the impact of living with chronic disease risk and with an (unconfirmed) inherited risk of a disease.

For the participating women, having a personal and family cancer history was a concrete and constant reminder of their increased risk of the disease. The women were reminded of the risk when other family members received a cancer diagnosis or when they saw photographs of family members who had been diagnosed in the past. Because of their heightened risk of cancer, the participants in the present study and in the study conducted by Hallowell et al. (2004) commented that they could conceptualize their futures only as the eternal present — that is, plans had to be moved forward because *What if a family member is diagnosed with cancer?* In the context of the study by Hallowell et al. and the present study, the concept of chronic risk for a disease could be said to encompass disruptions in one life, uncertainty about one's future, and uncertain timetable of one's life (Hallowell et al., 2004).

One grave consequence of cancer distress is a tendency to avoid cancer screening. Although this tendency was not the focus of the present study, the women's accounts indicated that they both were offered and accepted *more* cancer screening as opposed to *less*. Hallowell et al. (2004) suggest that accepting one's increased cancer risk serves to reduce anxiety, which in turn can positively affect adherence to cancer screening and interest in genetic testing. Perhaps those participants for whom cancer in the family was the norm and part of their upbringing were adapting to their increased risk of breast cancer and were therefore less likely to exhibit cancer-specific distress. The interviews revealed that cancer was a frequent topic of conversation at family gatherings. Nonetheless, the perception of increased risk among one's family members can lead to uncertainty and distress (Baum et al., 1997; Lerman et al., 1993; Schwartz et al., 2002).

The themes identified in this study show that having a personal and family history of breast cancer is not an isolated situation but part of a woman's journey in choosing to undergo genetic testing for inherited breast cancer susceptibility. For example, when the women spoke about being family guardians, they were acknowledging the breast cancer expertise they had acquired — expertise that enabled them to decode ambiguous information about breast cancer risk. Future research could investigate what specific needs and supports are required for individuals to be effective family guardians. Such support could be virtual or in person.

The main themes derived from the experiences of the 20 participants in living with a personal and strong family history of breast cancer, along with their individual stories, could be used to guide oncology nurses in applying aggregate knowledge to individual cases (Thorne et al., 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). As with Clements et al. (2007), this study explored concepts associated with living with a personal and strong family history of breast cancer; it focused on identifying emotional and cognitive experiences of this history, as opposed to quantitatively measuring the intensity of the experience. Further research is needed to compare this experience with the experience of living with other prevalent cancer diagnoses for which there is probable inherited genetic susceptibility.

Conclusion

The identified themes of living with a personal and family history of breast cancer provided context for the 20 participants who underwent genetic testing for breast cancer susceptibility. The findings show that gathering information on family history of cancer as part of initial genetic counselling can be used not only to guide assessment of cancer risk and risk of a probable inherited mutation, but also to increase our understanding of individuals' reaction to a strong family history of breast cancer. Whether they work in the community, in cancer screening programs, or in cancer genetics programs, health professionals can use the themes presented here as prompts when assessing whether individuals have learned to cope with a family history of cancer.

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Résumé

Traitements contemporains pour les traumatismes psychologiques du point de vue des Casques bleus

Susan L. Ray

L'objectif de cette étude phénoménologique herméneutique consiste à examiner les méthodes contemporaines de traitement pour les traumatismes psychologiques du point de vue des Casques bleus. Des données ont été recueillies à l'aide d'entrevues enregistrées sur bande audio et réalisées auprès de dix Casques bleus d'aujourd'hui qui ont été déployés en Somalie, au Rwanda et dans l'ancienne Yougoslavie. On a demandé aux participants de décrire l'expérience qu'ils ont vécue lors des différents traitements reçus pour un traumatisme psychologique. On a invité les participants à passer en revue les comptes rendus ayant été faits à partir des transcriptions d'entrevues et à les commenter à des fins de rigueur et de vérification du sens. Une analyse thématique du texte, laquelle a été entreprise en vue d'examiner comment les méthodes contemporaines de traitement aident les Casques bleus à surmonter un traumatisme, a permis de révéler trois thèmes : *les médicaments qui ont été les plus utiles, la compréhension de ce qui se passe* et *l'autoguérison en tant que suite de découvertes.* À la suite d'un traumatisme chez les Casques bleus d'aujourd'hui, la nature corporelle de la guérison ne devrait pas être négligée. Il faut entreprendre d'autres études sur l'efficacité des différentes méthodes de traitement des traumatismes psychologiques, y compris les thérapies complémentaires esprit-corps.

Mots clés : traumatisme

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Contemporary Treatments for Psychological Trauma From the Perspective of Peacekeepers

Susan L. Ray

The purpose of this hermeneutic phenomenological study was to examine contemporary treatment approaches for psychological trauma from the perspective of peacekeepers. Data were collected via audiotaped interviews with 10 contemporary peacekeepers who had been deployed to Somalia, Rwanda, or the former Yugoslavia. The participants were asked to describe their experience with various treatments for psychological trauma. Narratives from the transcribed interviews were reviewed with the participants and their comments solicited for rigour and verification of meaning. A thematic analysis of the text, conducted to examine the ways in which contemporary treatment approaches help peacekeepers to heal from trauma, revealed 3 themes: *medications as helping the most, understanding what is going on,* and *self-healing as a journey of discovery.* The embodied nature of healing from trauma among contemporary peacekeepers should not be overlooked. Studies on the efficacy of different treatment modalities for psychological trauma, including mind-body complementary therapies, are needed.

Keywords: adult health, intervention effects, mental health/pyschosocial, trauma

Canadian military peacekeepers have been involved in United Nations peacemaking, peacekeeping, and peace-building and in North Atlantic Treaty Organization (NATO) peace enforcement in more than 65 missions. They have suffered more loss of life than peacekeepers from any other country (Renner & Ayres, 1993).

Nurses in all practice settings are increasingly working with military personnel as dedicated health services are being eliminated from military bases. In Canada, nurses are providing care for contemporary peacekeepers experiencing post-traumatic stress disorder (PTSD) in Operational Stress Injury clinics operated by Veterans Affairs Canada on an outpatient basis at Ste. Anne's Hospital near Montreal, Quebec, and satellite clinics in several provinces. Included in the network are the Department of National Defence's five Operational Trauma and Stress Support centres located across Canada. These clinics provide assessment, treatment, prevention, and support services for Canadian Forces personnel. If nurses are to provide knowledgeable and sensitive care, it is vital that they be informed about whether contemporary treatment approaches are helping peacekeepers to heal from psychological trauma.

The purpose of this article is to address the research question *Are contemporary treatment approaches helping peacekeepers to heal from psychological trauma?* The data presented here are part of a published doctoral dissertation on the experiences of contemporary peacekeepers healing from trauma (Ray, 2009). Data on approaches to the treatment of trauma from the perspective of peacekeepers will be presented and discussed.

Literature Review

Quantitative research studies have focused on recovery from military trauma by measuring the efficacy of different therapeutic interventions for reducing symptoms of PTSD, depression, anxiety, and related conditions (Bormann et al., 2005, 2006; Creamer, Morris, Biddle, & Elliot, 1999; Foa et al., 1999; Keane & Barlow, 2002; Taylor, Thordarson, Maxfield, Fedoroff, & Ogrodniczuk, 2003). In a review of the literature on relaxation therapies for PTSD, Taylor et al. (2003) found that, in a sample of 60 participants, eye movement desensitization and reprocessing (EMDR) and relaxation did not differ in speed or efficacy whereas exposure therapy produced significant reductions in symptoms. In the field of anxiety-management training for PTSD, Keane and Barlow (2002) describe an assortment of approaches that have been studied, including relaxation (Taylor et al., 2003; Watson, Tuorila, Vickers, Gearhart, & Mendez, 1997), biofeedback (Peniston, 1986; Watson et al., 1997), controlled breathing, cognitive restructuring, and anger management (Chemtob, Novaco, Hamada, & Gross, 1997). Evidence from these studies suggests that skills-training approaches have a favourable impact on PTSD symptoms.

Quantitative pilot studies with American veterans of the Korean, Vietnam, Gulf, and Iraq wars have produced evidence supporting the benefits of "mantram repetition" (the repetition of a mantra) for reducing psychological distress, including the symptoms of PTSD (Bormann et al., 2005, 2006). The veterans reported a reduction in stress, PTSD, anxiety, and anger as well as improvements in quality of life and spiritual well-being.

Meta-analyses of numerous psychotherapy studies conducted between 1980 and 2005 have found that approximately two thirds of patients with PTSD completing courses of various forms of cognitive behavioural therapy (CBT) or EMDR improve or fully recover; however, some 30% of patients in all available psychotherapy studies showed little or no improvement (Vieweg et al., 2006).

The results of qualitative studies provide an in-depth, richly contextualized picture of healing from psychological trauma from the perspective of survivors. However, qualitative studies on healing from military psychological trauma are limited to veterans of the Vietnam war, Soviet veterans, and Israeli soldiers (Karner, 1994; Kroch, 2004; Magomed-Eminov & Madrudin, 1997). The significance of the present hermeneutic phenomenological study rests with the opportunity to gain a richer and deeper understanding of contemporary treatment approaches from the perspective of peacekeepers.

Method

Theoretical Underpinnings

The methodological framework guiding the study was philosophical inquiry of a hermeneutic and phenomenological nature as articulated by Merleau-Ponty (1962) and van Manen (1998). The phenomenological philosophy of Merleau-Ponty defines "embodiment" as how we live in and experience the world through our bodies: embodied time, space/motility, sexuality, and speech. Thus interpretive phenomenology is committed to an inter-subjective understanding of the body: historically situated, relational, and defined by Merleau-Ponty as a "being-to-the-world" (p. 46). Such a term suggests that human knowledge is relational, temporal, and present in the world, as opposed to objective, static, and independent of the questioner. When the human subject is viewed as embodied and the body is viewed as a body-subject, suffering while healing from trauma is understood as a composite and complex whole that is experienced in the world in a concrete way. Van Manen (1998) discusses the four philosophical life existentials — lived body (corporeality), lived space (spatiality), lived human relations (relationality or communality), and lived time (temporality) — as fundamental lifeworld themes. These became guides for reflection in the research process.

Sample

The study was approved by the appropriate institutional ethics review board. A letter outlining the study was distributed to Operational Stress Injury Social Support groups for Canadian Forces veterans and enlisted personnel throughout Ontario. The study comprised a purposive sample of contemporary peacekeepers aged 37 to 46 years with a diagnosis of PTSD. The participants had been deployed to Somalia, Rwanda, or the former Yugoslavia. These deployments were chosen because they represent intrastate conflicts (civil wars) that have erupted since the collapse of the Berlin Wall. All the participants had received treatment for psychological trauma for a minimum of 2 years. A 2-year time span was chosen so that interviewees would be able to describe ample experience with treatments for psychological trauma. The 10 participants comprised six soldiers (Luke, Simon, Peter, James, John, and Tim), two chaplains

(Thomas and Matt), one medical assistant (Paul), and one female nurse (Mary). Pseudonyms are used for the purpose of anonymity. All participants provided written consent.

Procedures

Data were collected via one audiotaped interview with each of 10 contemporary peacekeepers who had served in Somalia, Rwanda, or the former Yugoslavia. The participants were first asked: *Are contemporary treatment methods for psychological trauma helping peacekeepers to heal?* They were then asked to describe if and how current treatment approaches were helping them to heal. The phenomenological method seeks to uncover the meanings of phenomena experienced by individuals through analysis of their descriptions. Van Manen (1998) describes six interactive approaches for hermeneutic phenomenological inquiry and data analysis: orienting oneself to the phenomenon of interest and explicating assumptions and understandings; investigating experiences as lived through conversational interviews rather than as conceptualized; reflecting upon and conducting thematic analyses that characterize the phenomenon and interpreting through conversation; describing the phenomenon through the art of writing and re-writing (re-thinking, re-flecting, re-cognizing), which is intended to create "depthful" writing; maintaining a strong relationship to the fundamental question about the phenomenon; and balancing the research context by considering parts and wholes.

I interpreted verbatim transcriptions and used reflective journaling to clarify the data and better understand the experience. Reflective journaling served to reinforce the rigour of the study. I was made aware of my personal biases and unique perspective as a Clinical Nurse Specialist who had provided comprehensive holistic care, which included body-mind therapies for peacekeepers suffering from psychological trauma. I reviewed narratives from the transcribed interviews with the participants and solicited their comments in order to enhance rigour and verify meaning.

Results

The research question *Are contemporary treatment methods for psychological trauma helping peacekeepers to heal?* elicited three themes: *medications as helping the most, understanding what is going on,* and *self-healing as a journey of discovery.* Each excerpt from the transcript will be followed by a description in the words of the researcher.

Medications as Helping the Most

> *I'm getting the most out of the medications. They seem to be working. The doctor prescribed these to turn down the volume a little bit. Am I stuck on*

> *these medications forever? I don't know. I don't care. If I was a diabetic I would take insulin.*

Simon stated that medications to stabilize his PTSD symptoms had helped. He went on to explain that there had been no "therapy." During the interview Simon said that the injury or illness resulting from the trauma had eradicated a range of emotions, leaving him feeling only mad, sad, or glad. His limited range of emotions was what propelled him to start treatment. However, he was told by the doctor that "this is as good as it gets." That was the turning point for Simon, prompting him to cope and get on with his life. However, the lack of "therapy" to deal with his sense of numbness and limited range of emotions begs the question *Is this as good as it gets for those trying to recover from psychological trauma?*

> *I'm on Paxil. Double-edged sword. They tell you there may be some sexual side effects. I'm glad I'm not married. The medications certainly have helped. I'm getting them to the right level.*

Matt described his medications as a double-edged sword because they had many side effects. He used the analogy of a rope that burns your hands if it slides through your fingers when thrown to a drowning person. The burns on your hands are like the side effects of medications. However, the rope, like medications, could save a life. The medications had saved his life, but at what cost? For Matt, they were a constant reminder that he was "sick" and "broken." He wanted to be like everyone else — "normal," with his own parish, functioning and contributing to society. However, the side effects of the medications were one of the tradeoffs he had made. The drug therapy made it impossible for him to perform his job and live a full life. Matt had tried EMDR therapy only twice because he found the memories and feelings too disturbing to process within a 45-minute session. Thus his therapy remained limited to regulation of his medications. The inability to process memories and to reattach with his feelings and emotions begs the question *Is this as good as it gets?*

> *The most effective treatment for me right now is the right doses of medication. What a struggle — the side effects, the sleepiness, the sedativeness, and then trying to get up and go to work in the morning. I had to get a late arrival for work. I can see an improvement, and so can my family, since the medication. My kids actually like me now. Two years ago they didn't want to be anywhere near me. Now when I come home they can walk up to me and say, "Hey, Dad!"*

Tim explained that so far the most effective treatment approach had been medication. Like the other peacekeepers, Tim experienced many side effects, making it difficult for him to perform his job. For him, the trade-off was the ability to relate better with his wife and children, which he attributed to the medication. Would Tim heal even more if he engaged in therapy to help him process the memories of the trauma and reattach with his feelings and emotions?

> *I didn't want drugs. I do have PTSD. I finally accepted my first trial of medications. I went through a lot of reading and stuff. The psychologist helped me go from not ever leaving my house to I'm in uniform again. I got posted here. I just started couple counselling again because my wife has to live with this too.*

John described his treatment with a civilian psychologist who referred him to a psychosocial group. The group did not work for John because it included people with a variety of mental health issues, not just those with PTSD. John said that he would rather be with his peers — his "band of brothers" — than to heal from his military trauma with a heterogeneous group. Throughout history "brother" and "band of brothers" have been the most common verbal symbols of the bond between soldiers, which is even stronger than the bond between a soldier and his biological family because soldiers face life-and-death situations together (Shay, 1994). The psychologist worked with John to increase his knowledge and understanding of PTSD and the medications used to treat it. Eventually John accepted his medications, which he now believed had helped him to leave his house. He was back in uniform, working at a military base. Like Tim, John was beginning to reconnect with his civilian family through counselling together with his wife.

Understanding What Is Going On

> *A lot of cognitive restructuring to look at the way I think about him being shot and me being the survivor. We restructure in a way that it's not a bad thing to think that way but why are you taking responsibility for it? It's fate. Presently, I have a psychiatrist, and that's mostly for medications and to talk about how things are. My sleep patterns are a lot better but I have irritable bowel as a result of all the stress. I always know that around the corner for me it's depression around the time of year that he was shot.*

James described his cognitive restructuring therapy with a psychiatrist to deal with his survivor guilt. A soldier was shot and seriously wounded when he relieved James on duty overseas. Cognitive restructuring therapy had helped James to learn not to take responsibility for the shooting of the soldier. Although this type of therapy deals with the mind, it does not deal with the feelings and emotions surrounding the trauma. James still suffered from depression around the time of year when the soldier was shot. He had cognitively processed the memory of this incident but not the feelings and emotions surrounding it, so each anniversary of the shooting was emotionally difficult for him.

> *I was avoiding and giving the psychologist the* Reader's Digest *version. I have to go back over the incidences, and I haven't really tapped into my feelings. I don't really think that's avoidance. I just don't know how to get into the feelings yet. I think another side of it is grappling with the understanding that your career is over after 20, 25, 35 years. What do I do? This is all I know. You started down the path of not being that soldier any more. You're left with the wife, the kids, and the dog. You have to learn how to be a person again. It's taken a long time for even me and my wife to sit down. We're going to couple therapy. After 2 years of therapy I still feel very much alone.*

Peter, like most traumatized contemporary peacekeepers, was caught in the so-called *Reader's Digest* version of his traumatic experiences. This was a way for him to shield others, including his therapist, from the suffering. The *Reader's Digest* version of events cognitively processes the trauma but in a way that avoids the fullness of the memories of an incident and one's feelings about it. Peter was still unable to understand his feelings and emotions about the traumatic incidents. His suffering in silence continued, as he had not been able to fully tell his story. According to Shay (1994), the communalization of trauma is necessary for healing to take place. Peter explained that his aloneness was due to the loss of his "band of brothers" — his military family — and his inability to tap into his feelings and emotions. Learning how to become a person again in civilian life means understanding and verbalizing one's feelings and emotions.

Self-Healing as a Journey of Discovery

> *Through Personal Growth and Life Coaching, I found a lot of answers… You have PTSD. You get angry, stressed, so you need to know what you're going to do when you get that way. I just have to find the answers in my head or get some help to search [for] them… don't feel guilty about getting help. Visualization and meditation [are] more effective. There's some writing, Pilates, and some self-talk. I accept that I have that condition. I have to live with it and control it with the tools for any occasion. I'm not on medication right now. If I have to take them again, I'll take them for*

> *sure. I'm confident that I'm far from taking them. I have a lot of tools. I know myself a lot better now.*

Paul saw a psychologist for maintenance therapy, which was an opportunity for him to ventilate about events during the preceding week. Paul felt that this was not "real therapy," as he was not moving forward. Two or three sessions of EMDR did not make a great difference. Paul described self-healing through training in Personal Growth and Life Coaching. The use of tools such as visualization, meditation, writing, Pilates, and self-talk had been the most effective therapy for Paul. These self-healing tools had helped him to understand and express his feelings and emotions. Currently he was not on medications because he had these other tools instead.

> *In the beginning it was all about PTSD and the army. PTSD has struck me particularly hard. Then it wasn't all about having two accidents. It was also about those other relationships and conflicts in my life — my ability to ground myself, to identify and protect myself when I get in those anxious set of circumstances. Visualization and EMDR and those types of things were effective in my circumstances. I know that there's something greater than myself…to draw on that spirituality and to draw on feelings and to feel sad, to cry and to do other things are all good things. This has been a real journey for me. It's turning that around and putting "the man before the mission rather than the mission before the man."*

Luke described his therapy with a civilian nurse psychotherapist in a trauma clinic. Together they had been peeling away the layers so that Luke could learn about himself. Luke realized that there was much more to resolve than his PTSD, such as the multiple losses of his military career — including his "band of brothers" — his civilian relationships, and conflict in his life. He believed that holistic approaches such as visualization, EMDR, and grounding had been the most effective for his healing journey. Luke had been able to connect with his feelings and emotions as well as with something greater, his spirituality. He explained that he had many issues to resolve, such as being driven in his civilian job to the point of a "broken heart" and a "burnt soul." Luke was well along on his healing journey. A holistic approach that included spirituality, combined with a strong therapeutic relationship, had provided him with an excellent opportunity to heal from the trauma of peacekeeping and of being abandoned by his military family.

> *Narrative therapy has broadened to include how Buddhism and Zen fit in with psychotherapy. The intrusive memories for the most part are manageable. However, there are times I try to avoid them, suppress them until*

> *I'm able to start working through them. Partly because I think I felt abandoned by the medical system, the military, and the spiritual branch, I'm probably spending more time self-healing. I have a drive to become whole and the abilities and the knowledge…to do it. I did some Jungian workshops and looking at the role of grief and journaling. I've learned relaxation techniques, the Buddhist concept of mindfulness and meditation.*

Thomas had turned to self-healing after feeling abandoned by the military medical system and by his military and spiritual families. He had turned to Jungian workshops, the role of grief, journaling, relaxation techniques, the Buddhist concept of mindfulness and meditation. Thomas was spending more time self-healing than with his psychiatrist because he had a drive to become whole. His self-help comprehensive holistic approach to healing had helped him to begin healing from both the trauma of his peacekeeping deployments and the abandonment by his military family.

> *It is a journey of self-discovery. A labyrinth is a meditative tool for soothing and for rebalancing your energy. The labyrinth is similar to a maze except you go in and out only one opening. I could feel myself rebalancing. I generally experience a tingling, pleasant sensation throughout my body. I assume that the sensation is a result of all of my molecules shifting around to where they're supposed to be. I can feel my body when walking the labyrinth. Initially the idea is to focus on the physical act of going around the labyrinth. You should be focusing on putting one foot in front of the other, be aware of what your body is doing and let your mind go blank. Clearing your mind and focusing on the "physicality" will often allow fresh ideas or solutions to come to your mind once you have settled into the middle space of the labyrinth to "meditate." I find that walking back out gives me closure and leaves me feeling relaxed (I re-balance on my way in). A large labyrinth to walk around is more "powerful" than a lap labyrinth that you run your finger through (possibly because my whole body is involved while walking the large one), but the lap labyrinth is still a good therapeutic tool. You're more focused on the physical rather than things in your brain taking over.*

Mary felt that knowledge is the key in any recovery program. She had tried a multitude of approaches on her healing journey. These included CBT, grief work over the loss of her military career, exposure therapy, trauma and addiction courses, and walking, as well as lap labyrinths. The word "labyrinth" comes from the Latin *labyrinthus* and the Greek *labyrinthos,* which mean "maze," a large building with intricate passages; in English it also means "maze" — in the figurative sense, "a confusing state of affairs" (Skeat, 1983, p. 389). The labyrinth may represent the intricate and confusing process that the peacekeepers had to go through in order to obtain help with healing from the trauma of peacekeeping. For Mary it was an intricate passageway through which she was finding a sense of closure from the trauma of peacekeeping and from the trauma of being abandoned by her military family; it was a tool connecting her body and mind to her feelings and emotions.

Discussion

For Simon, Matt, and Tim, treatment was limited to one aspect of holistic care, the use of prescribed medications to reduce their PTSD symptoms. Despite the side effects, the peacekeepers found medications to be the most helpful means of reducing their symptoms of PTSD. John found that medications helped him to put on his uniform and return to work in the military. James found cognitive restructuring helpful in dealing with his survivor guilt. However, he was unable to process the emotional impact and as a result experienced depression around each anniversary of the shooting of his comrade. Similarly, Peter had cognitively processed the trauma but not his feelings and emotions. Peacekeepers whose therapy was limited to medications and/or CBT had not resolved their traumatic memories and thus remained disconnected from their feelings and emotions. There remained a profound disturbance in how they reacted to the world around them. They lacked the comfort and taken-for-grantedness that untraumatized people experience in the "entwining of their body in the world" (Merleau-Ponty, 1962, p. 45). It has been reported that approximately 30% of patients in all available psychotherapy studies show little or no improvement in healing from trauma (Vieweg et al., 2006).

Paul, Luke, Thomas, and Mary had tried many different holistic therapies, such as EMDR, visualization, meditation, grounding techniques, and journaling, and thus were further along than the other participants on their journey of healing from the trauma of peacekeeping and subsequent abandonment by their military family. Thomas and Mary spoke about self-healing for both types of trauma. Mary found the labyrinth to be a very effective tool for rebalancing and connecting her body and mind to her feelings and emotions. Research findings on the full range of physical and mental changes following trauma indicate that a single psychotherapeutic pathway to recovery may be less effective than different treatment modalities, which may modulate the system in different ways. It could be that drug treatments of various kinds act primarily via a subcortical (bottom-up) approach and psychotherapeutic approaches primarily via a cortical (top-down) approach (Vieweg et al., 2006). Therefore, to help peacekeepers fully recover from their traumatic experiences a comprehensive holistic approach that considers the whole person, including mental, emotional, spiritual, physical, social, and environmental factors (*Merriam-Webster's Collegiate Dictionary,* 2003), would be preferable to a sole reliance on medications or CBT.

Phenomenology provides a lens through which to explore the body in time, space, and relation and to understand these elements as intertwined and inseparable (van Manen, 1998). From a phenomenological perspective, we perceive the world with our bodies and thus are never able to be out of our bodies (Ray, 2009). The lived body is a physical self that senses the qualities of the world in which it is immersed and situated. Nurses spend time bridging the monadic (gnostic) body known to science with the dyadic (pathic) body that expresses itself (Cameron, 2006; van Manen, 1999). They seek to understand the particularity of each suffering body and to alleviate the suffering of the pathic body, where we live our lives and where healing takes place (Cameron, 2006). Traumatic memories may be stored differently in the body (van der Kolk, Herron, & Hostetler, 1994). Whereas non-traumatic memories are stored in a verbal, linear narrative, traumatic memories are fragmented by a disruption in the unifying thread of time (Stolorow, 2003; Stolorow, Atwood, & Orange, 2002). From a phenomenological perspective, healing begins with the establishment of safety and self-care; first the focus is on the body but then it gradually moves to the external environment. The body is a tremendous resource that often goes underused in trauma therapy. The therapist can use non-touch techniques to help the client access this resource (Ogden & Minton, 2000). Body-awareness techniques used in therapy for psychological trauma include grounding, which can help peacekeepers gain mastery over flashbacks and other intrusive phenomena. In order to heal, asserts Rothschild (2000), trauma survivors need to feel and identify their bodily sensations, and need to learn to use language in order to name and describe these sensations and articulate their meaning. According to Rothschild, the goals of therapy should be to reconcile implicit and explicit memories stored in the body into a comprehensive narrative of traumatic events and their aftermaths, to eliminate hyper-arousal in connection with those memories, and to incorporate traumatic events into one's personal narrative.

Implications for Nursing Practice, Education, and Research

Discourse on healing from psychological trauma often overlooks or minimizes the importance of embodiment. When caring for peacekeepers suffering from psychological trauma, nurses must not forget the embodied nature of healing in order to understand how trauma is lived (Ray, 2006). The body's storage of traumatic memories and the impact of those memories on the body are essential features of psychological trauma and must be addressed as part of the healing journey. Embodied healing is performed *by* traumatized peacekeepers, not *to* them, as the presence of the body in life situations gives the other life existentials their meaning — that is, time, space, and relation (Ray, 2006). In order for nurses to be truly present, embodiment and embodied engagement need to be incorporated into the development of best practice guidelines for the nursing care of contemporary peacekeepers (Ray, 2009).

Nursing programs, including specialty programs for advanced practice nurses, should include curricula for all forms of psychological trauma — military-related as well as other forms — so that nurses are adequately prepared to assess the care needs of enlisted personnel and veterans. Specialty programs are needed so that advanced practice nurses can acquire the knowledge and expertise necessary to provide care to psychologically traumatized military personnel.

Future studies, both quantitative and qualitative, are needed to address the efficacy of different treatment modalities, including mind-body complementary therapies, in order to ensure that the best care is delivered to those who are suffering while healing from the trauma of peacekeeping deployments. For nurses and other health professionals, whether in clinical practice, education, or research, human science inquiry offers a way to understand the experience of contemporary treatment approaches for healing from psychological trauma.

Conclusion

Nurses and other health professionals need to enhance their understanding of military psychological trauma and support those affected in their search for proper treatment. Treatment approaches must be focused on grieving multiple losses, which include the loss of deceased military "brothers," being separated from the "band of brothers," and losing one's career upon discharge from the military following a psychiatric diagnosis. Research studies are needed to test the efficacy of treatment approaches for PTSD, especially those that incorporate embodied healing such as mind-body complementary therapies. The ongoing deployment of Canadian troops to Afghanistan and elsewhere requires studies that respectfully address the findings of the present investigation in order to determine the best treatment approaches for military personnel upon their return home.

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Happenings

Centre for Innovation in Research and Knowledge to Action in Nursing

Judith A. Ritchie and Ann Lynch

A new nursing research centre emerging at the McGill University Health Centre (MUHC) in Montreal, Quebec, Canada, will bring an innovative approach to the bridging of the research-practice gap. Application of research results in nursing practice has been an issue since the early 1970s, and the MUHC's nurse researchers have successfully completed a number of projects in this area. The new initiative will respond to the call for fresh approaches to research in order to increase the probability that clinical, administrative, and policy decisions will be informed by research evidence. In Canada, agencies for the funding of health research, such as the Canadian Institutes of Health Research (www.cihr.ca) and the Canadian Health Services Research Foundation (www.chsrf.ca), are developing incentives and requirements for researchers to work with "decision-makers." The intention is that, instead of a group of "creators" and "users" of knowledge, we will have research teams that co-create knowledge in context. This so-called Mode 2 knowledge production is a "novel way of producing knowledge" (Kitson & Bisby, 2008). We believe that evidence-informed decision-making (EIDM) will lead to improved nursing care and more efficient utilization of research findings, as well as better integration of new knowledge, clinical practice, and patient preferences. The ultimate goal of such changes, and of the new Centre for Innovation in Research and Knowledge to Action in Nursing, is improved patient outcomes.

For over four decades the MUHC, one of the clinical agencies affiliated with McGill University, has maintained synergistic symbiotic relationships with the McGill School of Nursing. Nursing at McGill has a remarkably strong history of active involvement across the academic environments of the clinical agencies and the School itself. For more than three of those four decades, some of the MUHC's hospital sites have included nurse researchers within their nursing departments. Currently, the MUHC's own Nursing Department includes scientists and research consultants who are primarily hospital-based and scientists who are based primarily in the School of Nursing but spend at least 1 day a week at the MUHC. This legacy has resulted in a thriving climate of inquiry. Active, successful research programs have developed in specific areas, and many members of the Nursing Department at all levels are raising questions about practice, conducting research, and seeking ways to extend evidence-informed practice. The Department is ripe for a move to the "next level."

The MUHC's impressive record of research and evidence-based practice will be used to establish the Centre through innovative research, knowledge translation strategies, and support of undergraduate and graduate education and continuing education. The main objective of the Centre will be to link theory, research, and clinical and administrative decision-making in order to improve the delivery and work environment of nursing care and, ultimately, to improve patient care. A distinct advantage of the Centre will be the linkage of researchers and practitioners/administrators in exchanges that will benefit both research and practice. The Centre will increase the interaction between knowledge creation and knowledge application and will move knowledge into action.

The Centre for Innovation in Research and Knowledge to Action in Nursing is being established with funding from the Newton Foundation, the Montreal General Hospital Foundation, the Research Institute of the MUHC, and the MUHC itself. Its mission is "to be recognized as a world leader in evidence-informed nursing by linking clinical and administrative practices with theoretical and research results to improve patient care and outcomes while creating a magnet environment that recruits, retains, and retrieves nurses. The Centre's research clusters will obtain high-value research grants and contribute to enhancing nursing education at the undergraduate, graduate, and continuing education levels." Some of its strategic objectives are to:

- implement EIDM research and training activities
- prepare and encourage researchers, clinicians, and administrators to become world leaders in research and knowledge translation
- improve the quality and efficiency of nursing care and improve patient outcomes through evidence-informed practice
- improve nurses' work environment and become a magnet centre: attracting, retaining, and retrieving staff

Based on the population needs of the MUHC's patients and families, and on areas of experience, expertise, and critical mass in nursing research within the MUHC, the leadership of the Nursing Department has identified six clusters in which the research programs will focus:

- comfort and healing
- women's health
- nursing services
- chronic illness management
- cancer care
- patient safety

Each of these clusters will develop interprofessional research teams, but the core of the clusters will include nurse scientists (100% research time), clinician scientists (50% research time), clinicians and/or administrators, patients and families, students, and knowledge brokers. The scientists will develop innovative knowledge translation strategies and incorporate "embedded KT" approaches into their research. The knowledge brokers will help to ensure, particularly in the early phases of development, the smooth flow of traffic between the "two solitudes" of practice and research. Each of the clusters will also have infrastructure support, in the form of coordinators, secretaries, research assistants, information managers, an editor, and access to core facilities within the Research Institute of the MUHC for design and analytic consultation.

In addition to the innovation of linking research activities and EIDM in nursing care and administrative practices, the Centre will expand current Nursing Research Consultant levels for clinicians and managers and will uniquely give a focus to training and education in EIDM. This focus makes a critical link with the Centre's aim of having the MUHC use EIDM as "a way of doing business." Central to this focus will be the knowledge brokers, who will provide direct support to interprofessional teams developing organizational capacity within the EIDM process.

The Centre's collaboration with other Montreal-based nursing initiatives is a key element in the setting of its goals. The Centre will be reinforcing its strong relationships with the McGill School of Nursing and the Sir Mortimer B. Davis Jewish General Hospital and, as it grows, will be forming liaisons with other research centres in the McGill network and intensifying the MUHC's current levels of collaboration with the Faculté des sciences infirmières of the Université de Montréal and the research centres of the Centre hospitalier de l'Université de Montréal. The MUHC and its Research Institute are collaborators in the Centre FERASI (regional training centre in nursing services administration research), the initiatives of GRIISIQ (Quebec Interuniversity Nursing Intervention Research Group), and the joint doctoral program in nursing offered by McGill and the Université de Montréal.

The principal objective of the Centre will be to improve the quality of patient and family care while optimizing the use of scarce resources. The application of findings from the research programs will enable patients — initially those of the MUHC and the McGill hospital network and eventually all patients — to benefit in a more timely fashion from innovations in nursing care and administration. By collaborating with other nursing research and education initiatives in Montreal, the Centre will enable the Montreal nursing community to become a world leader in evidence-informed nursing. Because of its unique approach, linking research with clinical and administrative decisions and practices, the Centre will be in a class of its own.

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