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3. *Social Workers in Health Care Management: The Move to Leadership*, edited by Gary Rosenberg, PhD, and Sylvia S. Clarke, MSc, ACSW (Vol. 12, No. 3, 1988). “Social workers interested in hospital social work management and the potential for advancement within the health care field will find the book interesting and challenging as well as helpful.” (Social Work)

4. *The Changing Context of Social Health Care: Its Implications for Providers and Consumers*, edited by Helen Rehr, DSW, and Gary Rosenberg, PhD (Vol. 15, No. 4, 1991). “Required reading for every student and practitioner with a vision of improving our health care delivery system.” (Candyce S. Berger, PhD, MSW, Director of Social Work, University of Washington Medical Center; Associate Professor, School of Social Work, University of Washington)

5. *Women's Health and Social Work: Feminist Perspectives*, edited by Miriam Meltzer Olson, DSW (Vol. 19, No. 3/4, 1994). “[Chapters] explore how social workers can better understand and address women's health, including such conditions as breast cancer, menopause, and depression. They also discuss health care centers and African-American women and AIDS.” (Reference & Research Book News)

6. *Social Work in Ambulatory Care: New Implications for Health and Social Services*, edited by Gary Rosenberg, PhD, and Andrew Weissman, DSW (Vol. 20, No. 1, 1994). “A most timely book dealing with issues related to the current shift in health care delivery to ambulatory care and social work's need to position itself in this health care arena.” (Barbara Berkman, DSW, Director of Research and Quality Assessment, Massachusetts General Hospital; Associate Director, Harvard Upper New England Geriatric Education Center, Harvard Medical School)

7. *Social Work Leadership in Healthcare: Directors' Perspectives*, edited by Gary Rosenberg, PhD, and Andrew Weissman, DSW (Vol. 20, No. 4, 1995). Social work managers describe their work and work environment, detailing what qualities and traits are needed to be effective and successful now and in the future.


10. *Fundamentals of Perinatal Social Work: A Guide for Clinical Practice with Women, Infants, and Families*, edited by Regina Furlong Lind, MSW, LCSW, and Debra Honig Bachman, MSW, LCSW (Vol. 24, No. 3/4, 1997). “A knowledge summation of the essence of perinatal social work that is long overdue. It is a must for any beginning perinatal social worker to own one!” (Charlotte Collins Bursi, MSSW, Perinatal Social Worker, University of Tennessee Newborn Center; Founding President, National Association of Perinatal Social Workers)
11. **International Perspectives on Social Work in Health Care: Past, Present and Future**, edited by Gail K. Auslander, DSW (Vol. 25, No. 1/2, 1997). “The authors explore the need for new theoretical and practice models, in addition to developments in health and social work research and administration.” (Council on Social Work and Education)

12. **Social Work in Mental Health: Trends and Issues**, edited by Uri Aviram (Vol. 25, No. 3, 1997). “Suggests ways to maintain social work values in a time that emphasizes cost containment and legal requirements that may result in practices and policies that are antithetical to the profession.” (Phyllis Solomon, PhD, Professor. School of Social Work, University of Pennsylvania)


14. **Behavioral and Social Sciences in 21st Century Health Care: Contributions and Opportunities**, edited by Gary Rosenberg, PhD, and Andrew Weissman, PhD (Vol. 33, No. 1, 2001). “Stimulating and Provocative. . . . The range of topics covered makes this book an ideal reader for health care practice courses with a combined health/mental health focus.” (Goldie Kadushin, PhD, Associate Professor, School of Social Welfare, University of Wisconsin-Milwaukee)

15. **Clinical Data-Mining in Practice-Based Research: Social Work in Hospital Settings**, edited by Irwin Epstein, PhD, and Susan Blumenfield, DSW (Vol. 33, No. 3/4, 2001). “Challenging and illuminating. . . . This remarkable collection of exemplary studies provides inspiration and support to social workers. This book will be valuable not only as a guide to practitioners, but also is an important addition to the teaching materials for courses in social work in health care and in social research methodology.” (Kay V. Davidson, DSW, Dean and Professor, University of Connecticut School of Social Work, West Hartford)


17. **Social Work Visions: Around the Globe: Citizens, Methods, and Approaches**, edited by Anna Meteri, MSocSc, Teppo Kriiger, PhD, Anneli Pohjola, PhD, and Pirkko-Liisa Rauhala, Dr. Habil, DSW (Vol. 39, No. 1/2 and 3/4, 2004). “VALUABLE to practitioners in health and mental health. . . . Shows in a practical way how citizenship can be an inclusive practice related to social justice, rather than a way of excluding people from opportunities and resources in our societies.” (Heather D' Cruz, PhD, MSW, Senior Lecturer in Social Work., School of Health and Social Development, Faculty of Health and Behavioral Sciences, Deakin University, Geelong, Victoria, Australia)


19. **The Geometry of Care: Linking Resources, Research, and Community to Reduce Degrees of Separation Between HIV Treatment and Prevention**, edited by Debbie Indyk, PhD (Vol. 42, No. 3/4, 2006). An examination of ways to link bottom up and top down activities to further care, services, resources, training, theory, and policy analysis for AIDS treatment and prevention.

20. **International Social Health Care Policy, Program, and Studies**, edited by Gary Rosenberg, PhD, and Andrew Weissman, PhD (Vol. 43, No. 2/3, 2006). “Exemplifies how social work attempts to understand and respond creatively to the specific social issues of different countries from a clinical, programmatic and policy perspectives. . . . Contributors are experts in their respective areas of work and share their views and experiences through this wonderful book.” (Dr. Daniel Fu Keung Wong, PhD, Associate Professor, Department of Social Work and Social Administration, The University of Hong Kong)

21. **Social Work, Health, and International Development: Compassion in Social Policy and Practice**, edited by Serge Dumont, PhD, and Myrielle St-Onge, PhD (Vol. 44, No. 1/2 and 3, 2007). Leading international experts from a range of disciplines provide the latest in research, theory, and practical solutions to advance social work in health care issues while focusing on compassion and empathy.
Social Work, Health, and International Development: Compassion in Social Policy and Practice

Serge Dumont, PhD
Myreille St-Onge, PhD
Editors

Gary Rosenberg, PhD
Andrew Weissman, PhD
Series Editors

Social Work, Health, and International Development: Compassion in Social Policy and Practice has been co-published simultaneously as Social Work in Health Care, Volume 44, Numbers 1/2 and 3 2007.
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Social Work, Health, and International Development: Compassion in Social Policy and Practice

CONTENTS

PART I
Introduction: Social Work and the Development of a More Compassionate World: Experiences and Knowledge to Share 3
  Serge Dumont, PhD
  Myreille St-Onge, PhD

SECTION 1: COMPASSION AND SOLIDARITY
The Fourth International Conference on Social Work in Health and Mental Health Welcoming Remarks 13
  Serge Dumont, PhD

Compassion and Solidarity 17
  Fr. Florenzo María Rigoni

Ethical Preferences for the Clinical Practice of Empowerment Social Work 29
  Karla Miley, MA, LSW
  Brenda DuBois, MSW, PhD

SECTION 2: HIV-AIDS
Cultural Competence in HIV Prevention and Care: Different Histories, Shared Future 45
  William Rowe, DSW

We Care Don’t We? Social Workers, the Profession and HIV/AIDS 55
  Nigel Hall, BS, BSW, MSW
An Investigation of the Practice of Unsafe Sex
Yet Repeated HIV Testing

Naama Patinkin, BSc, BSW
Ben Werner, MD
Israel Yust, MD
Yaron Yagil, MSW
Margalit Drory, MSW
Michael Burke, MD

SECTION 3: AGING

Promoting the Psychosocial Health of the Elderly—
The Role of Social Workers
Alice Ming-lin Chong, PhD

Promoting Older People’s Voices—The Contribution
of Social Work to Inter-Disciplinary Research
Jackie Powell, MA

PART II

SECTION 4: PRACTICE

Do Culturally Sensitive Services for Chinese In-Patients
Make a Difference?
Joseph Ng, MSW, RSW
Svetlana Popova, MSW
Myra Yau, BA, RSW
Joanne Sulman, MSW, RSW

Does Difference Matter? Diversity and Human Rights
in a Hospital Workplace
Joanne Sulman, MSW, RSW
Marylin Kanee, MSW
Paulette Stewart, MN, PhD Candidate
Diane Savage, MSW, RSW

Best Practice Case Management for Improved Medical Adherence
Betsy Vourlekis, PhD
Kathleen Ell, DSW
Improvement of Return Rates in a Neonatal Hearing Screening Program: The Contribution of Social Work

Maria de Fátima de Campos Françozo, PhD
Juliana Cristina Fernandes, MSW
Maria Cecília Marconi Pinheiro Lima, PhD
Tereza Ribeiro de Freitas Rossi, PhD

Physicians' Ability to Influence the Life-Style Behaviors of Diabetic Patients: Implications for Social Work

Revital Gross, PhD
Hava Tabenkin, MD
Anthony Heymann, MB, BS
Miriam Greenstein, MA
Ronit Matzliach, MA
Avi Porath, MD
Basil (Boaz) Porter, MD

Perceptions of Online Support for Hospitalized Children and Adolescents

David B. Nicholas, PhD, CSW
Jane Darch, BA, BEd, CCLS
Ted McNeill, PhD, RSW
Leanne Brister, BA, CCLS
Kimberly O’Leary
Deborah Berlin, BSW, MSW, RSW
Donna Koller, PhD

Clinical Practice Standards and Ethical Issues Applied to a Virtual Group Intervention for Spousal Caregivers of People with Alzheimer’s

Julie Dergal Serafini, MSc, PhD Candidate
Thecla Damianakis, MSW, PhD
Elsa Marziali, PhD

An Evaluation of Dyadic Peer Support for Caregiving Parents of Children with Chronic Lung Disease Requiring Technology Assistance

David B. Nicholas, PhD, RSW
Krista Keilty, RN, MN, ACNP
Knowledge and Social Work in Health Care—
The Case of Finland

Johanna Björkenheim, MSS

Index
PART I
Introduction:
Social Work and the Development of a More Compassionate World:
Experiences and Knowledge to Share

Serge Dumont, PhD
Myreille St-Onge, PhD

In May 2004, the city of Quebec welcomed nearly 800 delegates from forty countries and five continents within the scope of the 4th International Conference on Social Work in Health and Mental Health. Hosted by the Laval University School of Social Work and the Social Work Department of the Hôtel-Dieu-de-Lévis Hospital, this event took place under the umbrella theme: Social work and the development of a more compassionate world; experiences and knowledge to share.

This fourth major gathering has confirmed the emergence of a tradition that is deeply rooted in the international community of social workers working in the areas of health and mental health. Although they are all extremely committed to the various highly specialized fields in which they work, they are bound by a real need to meet with their counterparts to share experiences and further the development of knowledge. They are especially aware that the illnesses currently afflicting both individuals and their communities are signs of social inequalities and the current imbalance between human beings and their environment. The
fight to alleviate human suffering and the causes and consequences of illness thus enriches humanity as a whole. The Fourth International Conference on Social Work in Health and Mental Health provided them with the precious opportunity to reflect together on how social work can contribute to the development of a world that values compassion and solidarity.

The scientific program was structured so as to maximize the sharing of knowledge and views within each area of interest, with the hope of stimulating the emergence of new partnerships. Conference objectives were:

- Offer a unique occasion to promote the development of knowledge and practices in health and mental health care.
- Foster convergence among the creative, leading-edge actors in research and development related to the social aspects of health and mental health.
- Encourage the formation of international partnerships in order to promote the development of research and training in healthcare and mental health care.
- Offer graduate students in social work an opportunity to expand their professional network by establishing valuable contacts with colleagues, researchers and clinicians from many regions around the world.

Holding this event made it possible to bring together, under the same theme, internationally renowned speakers, experienced experts, as well as researchers, clinicians and graduate students from different countries of the world, thus contributing to the reinforcement of collaborative links, the dissemination of new knowledge, and to increase research capacity within the field of health and mental health.

The quality of the communications was ensured through the presence of internationally renowned speakers providing feature addresses, plenary speeches and satellite symposiums. A scientific committee comprised of 93 members assessed nearly 800 abstracts regarding their innovation and their contribution to the development of knowledge. Five hundred (500) participants were invited to speak or to present poster communications. The Conference themes were addressed by twenty-one keynote speakers (five feature addresses and sixteen plenary speeches). Moreover, within the scope of the conference’s main theme, seven sub-themes were addressed through satellite symposiums: social policies,
mental health, violence, aging, HIV-AIDS, cancer, and mobility of populations—mobility of health related knowledge.

Of the five feature addresses, sixteen plenary speeches and 500 communications that were presented in the conference, sixty-nine were submitted to be considered for publication. Over the following year, these manuscripts were reviewed by external reviewers. This current volume includes two feature addresses, three plenary speeches and thirteen original articles. The issue is comprised of four sections: Compassion and Solidarity, HIV-AIDS, Aging, and Practices. These sections are summarized here.

**COMPASSION AND SOLIDARITY**

To start with, this volume presents the reader with the welcoming remarks delivered made by Serge Dumont, Vice President of the conference and President of the scientific committee. Dr. Dumont explains that the choice of the conference theme—Sharing experiences and knowledge: How social work can contribute to building a compassionate world—intertwines with the challenges now confronting social workers in the health field where major forms of suffering are often a reflection of inequities and imbalances in the relationship between individuals and their environment. Furthermore, the magnitude these inequities and imbalances is generally compounded by the presence of disease. Based on the works of Peter Kropotkine on mutual aid as a development factor of humanity, Dumont argues that the modern society has given social workers the mission of promoting social development and ensuring the well-being of individuals. Moreover he asserts that it is by building and strengthening solidarity that social workers acquire the capacity to establish compassionate social relationships.

After spending twenty years on the southern border of Mexico and working with migrants in Italy, Mozambique, Angola, and South Africa, the Padre Flor Maria Rigoni has learned that when a migratory trend begins, history follows suit, regardless of any rejection, discrimination and attempts to enforce borders. For him, it’s a living tide that represents a wager on the future. He evokes that the 245,000 dispossessed people who have passed through Casa del Migrante located in the Chiapas, Mexico, in the last twenty years have infused his work with meaning. It is through sharing the misery and suffering of migrants or other refugees that he explores with us the themes of compassion and solidarity. To him, compassion is a sister to empathy, a feeling of to-
getherness and a perception that the other person’s world is partly one’s own world too. Moreover, compassion is a positive attitude, it is an option in favor of the other person [. . . it is to embody here and now the person facing me and in whom I have decided to take an interest]. Solidarity is even broader than the concept of compassion and embraces unity, assistance, sharing, assuming the cause of the other and making it one’s own. He explains that the concept of solidarity rather has social overtones and very often refers to citizens’ duties and rights or to the notion of union harmony. He asserts that speaking of vulnerable categories, many times in the no-face, no-name daily dealings with people such as the undocumented, the sick or the handicapped, there is a dire need for an option that goes beyond the socio-political arena or even professionalism, and resides fundamentally in the dimension of gratuitousness and human brotherhood.

Karla Miley and Brenda DuBois invite social workers to revisit the ethical foundations of their practice. They list sixteen principles of ethics based on fundamental values of the profession that should embody our preferences in terms of ways of thinking and ways of conducting social work practices. These ethical principles remind us of the essential critical functions of the profession and enable us to situate our actions within issues related to the promotion of justice and the defense of rights, to the social development of communities, to solidarity between nations and people and finally, respect for dignity and self-determination. They assert that the simultaneous focus on human well-being and human rights is central to empowerment social work, as practice from this perspective contributes to building a more compassionate world.

**HIV-AIDS**

Social workers have been hailed by the HIV-AIDS epidemic since its initial manifestations. William Rowe reminds us that social work practitioners, researchers, and educators from around the globe gathered in Montreal on the occasion of the Joint Meeting of the International Federation of Social Workers and The International Association of Schools of Social Work in 2000 to dialogue on the unique and shared challenges we face in our respective regions concerning HIV. One of the outcomes of this gathering was a Manifesto on HIV Prevention and Care which was widely distributed around the world. One of the central tenants of this Manifesto was the critical need for cultural competence in responding to HIV-AIDS pandemic. In his article, Rowe uses the lens of cultural com-
Serge Dumont and Myreille St-Onge

petence to depict and analyse the reality in two countries, the United States and Indonesia, regarding the epidemic progression of this disease. Despite the fact that their experiences with HIV have been remarkably different, Rowe explains how future experiences may turn out to be very similar. Such evolution would be mainly attributable to cultural factors and he argues that social workers who value diversity must have the capacity to understand the socio-cultural dynamics related to the epidemic progression and must also promote programs and services in HIV prevention care that reflect an understanding of culture diversity.

In this regard Nigel Hall shares his thoughts about how social workers can help build more compassionate and ethical caring strategies that improve the lives of those living with the disease. In order to do so, he illustrates, with examples from his extensive experience, how the action plan proposed by the Southern Africa HIV/AIDS Information Dissemination Service can make a real impact. The core of this comprehensive action plan includes: Tackling the issue of poverty; tackling gender inequity, power issues and the roles of men and women; building an effective coalition through a multi-sectorial approach; and finally, tackling stigma and discrimination.

Within the prevention perspective, experiences in testing clinics have shown that the larger part of the population who request HIV tests can be classified into several main groups which are now well-documented and studied, such as homosexual people and injection drug users. However, Naama Patinkin and her colleagues from Israel have examined the behaviors and motivation of young heterosexual men and women who, without belonging to an at risk group, nonetheless go to testing clinics because they feel they engage in unsafe sexual behaviors. Results reveal several possible explanations for risky sexual behavior, such as applying of a variety of risk management mechanisms, refraining from impulse control behaviors, and self-destructive motives.

AGING

In her plenary speech, reported in this volume, Alice Ming-lin Chong highlights the trend of population ageing in the world, and in the People’s Republic of China in general, and Hong Kong in particular. She argues that due to improvements in hygiene and medical technology, people nowadays can live much longer. However, Dr. Chong is
concerned about the inconsistency in psychosocial indicators in elderly populations where simultaneously high levels of life satisfaction and high suicidal rates, as well as the weakening of social support networks, are observed. With respect to this phenomenon, she shares meaningful insights and analyses the recent scientific knowledge in this field of research. Finally, she makes some suggestions for promoting elderly people's mental health through different levels of intervention, including individual, family and social network, community and international levels.

Involving people in decisions about both their own needs and broader issues of service development, reflects an empowerment perspective promoted by health social workers. Jackie Powell examines the contribution of social work to an interdisciplinary research agenda designed to promote increased involvement of older people in issues of service quality in health settings. Based on research experiences in the United Kingdom, she asserts that social workers have many opportunities for rethinking research relationships and forging partnerships that promote the diverse voices of older people. For instance, involving older people in the research audit process, mixed-methods including focus groups or in-depth interviews, and an interactive research approach illustrate some meaningful opportunities in this area.

**PRACTICE**

**Culture**

According to a growing trend, hospitals in large cities must provide services to an increasingly diverse linguistic and cultural clientele. Some strategies have been adopted to improve services to foreign speaking populations. This new phenomena represents a challenge for social workers. Joseph Ng and his colleagues from the Mount Sinai Hospital in Toronto conducted a study to identify deficiencies in culturally sensitive care within this Canadian teaching hospital. A survey among a sample of 279 Chinese in-patients allowed them to determine their satisfaction with their hospital experience. An analysis of results provide meaningful insights that are relevant for health care providers who are interested in improving services for patients and families from diverse cultural and linguistic groups. A few years ago, the Toronto Mount Sinai Hospital es-
Serge Dumont and Myreille St-Onge established an office of Diversity and Human Rights staffed by a social worker. The office provides education, training, policy development and complaints management. Moreover, the administration also convened a hospital-wide committee to advise on the outcomes and to plan a process for diversity and human rights organizational change. This committee conducted a focus group to explore the perspectives of hospital staff. Joanne Sulman and her colleagues share in a second article from this group, the lessons learned from this process, which have the potential to increase overall cultural competency of staff, which in turn can translate into more sensitive work with patients.

**Adherence to Care**

For many diseases and health problems, longer-term adherence to recommended treatment programs, including medication compliance, regular periodic screening, diet control, and follow-up on referrals is required. However, it seems that even in developed countries where health care facilities are readily available, only 50% of patients adhere to treatment recommendations. Betsy Vourlekis and Kathleen Ell explain that despite the fact that inadequate and non-existent health care resources are an important contributing factor, many other barriers influence patient adherence, thereby impacting on morbidity, mortality, as well as health care costs. Socio-cultural factors are involved in this issue, which is a complex phenomenon resulting from the interplay of a number of potential barriers operating in the patient, provider and wider health care system. Indeed this issue challenges social workers in health care settings. Vourlekis and Ell argue that this issue needs to be addressed with a comprehensive evidence-based and cost-sensitive approach. They suggest a generic “best practice” case management approach to improve patients’ adherence and illustrate the key components of this program. Within a similar perspective, Maria de Fátima de Campos Françozo and colleagues describe the implementation of a neonatal hearing screening program in a Brazilian school hospital, focusing on return rates among infants who failed the first screening. An evaluative research protocol has shown both the need for an adequate way of imparting information to the mothers of newborns about hearing screening in economically underprivileged populations, as well as the role of social work in this process.

Adherence to treatment is also a great challenge for diabetic patients and their health care team. Long term morbidity and mortality are
strongly associated with life-style, such as inappropriate diet, lack of physical activity and smoking. During the last two decades, counseling among diabetic patients has become the key component in diabetes treatment. Revital Gross and colleagues examine the perceived self-efficacy of primary care physicians in their counseling practice among diabetic patients. Their findings suggest that only a small percentage of physicians feel capable of influencing their patients’ life-style behaviors. They recommend that social workers expand their role to include training physicians in counseling techniques. In return physicians could improve their capacity to influence life-style related behaviors of diabetic patients.

**Practice Development**

Advances in technology have improved access to health and social services by offering more abundant and convenient choices for clients. Social services in health are not exempt from developments in new technologies. On the contrary, several colleagues assess the relevance and efficacy of these in regard to the attainment of psychosocial intervention objectives in the field of health. David B. Nicholas and his colleagues share their findings from a study which identified perceived outcomes following hospitalized children’s participation in a pediatric online support network. They conclude that developments in pediatric support initiatives, that integrate advanced technology, contribute to effective and accessible child-centered pediatric health care delivery and constitute an important and promising endeavour for social workers in this area.

In the same perspective, Julie Dergal Serafini and her colleagues have implemented and evaluated an Internet-based intervention for spousal caregivers of persons with dementia. Based on a four year project, a psychotherapeutic group intervention was delivered via the Internet to three groups of spousal caregivers. The authors identify some of the key practice standards and ethical issues that arise when using computer technology to deliver a psychotherapeutic group intervention. This project illustrates the relevant issues related to maintaining practice standards and ethical procedures that need to be addressed during the application of a computer-based group intervention.

Social workers in the field of health evolve within a universe where the most avant-garde technologies are developed to ensure optimal treatment of patients. However, the implementation of these technologies sometimes has non-negligible impacts on family and friends and
raise new challenges for social workers. David B. Nicholas and his colleague Krista Keilty carried out an evaluative study on a dyadic peer support pilot intervention for parents of technology-assisted children with chronic lung disease. Although the study’s findings were not very conclusive, they attest to the need for mutual support among parents of medically-fragile children who are living at home and require continuous or intermittent assistance from technological supports such as home oxygen, respiratory or cardiac monitors and/or mechanical ventilators. The principal benefits of dyadic peer support included feeling understood, decreased isolation, and enhanced learning. However, few parents experienced limited or negligible benefits. Lack of time, lack of motivation, incompatibility and other constraints explain such results.

Developments in health social work practices also call upon the issue of training and research. The origins of social work are intimately tied to the charity movement and its development as a discipline is relatively recent. As such, a strong tradition of learning in the field has always permeated the training culture of social workers. Johanna Björkenheim observes that social workers make use of research in their everyday practice to a very limited extent only. On the other hand, she notes evidence that social workers feel they need knowledge, but not necessarily in the same form as that produced by the researchers. She conducted a study among Finnish social workers to learn more about how professional competence in health social work is acquired and maintained as well as how knowledge and research are perceived by health social workers. Her findings are meaningful and relevant for those who are interested in continual education.

The 4th International Conference in Social Work in Health and Mental Health held in Quebec in May 2004 aimed to significantly contribute toward the development of knowledge and practices in social work in health and mental health care within a solidarity enhancement perspective. During the conference new partnerships emerged between representatives from northern and southern countries. A critical review of the North-South relationship allowed us to recognize the limits of the approaches traditionally adopted in the field of humanitarian aid and developmental assistance. In effect, politically targeted assistance of some donor countries or the paternalism, unfortunately characterise North-South relations, should make room for cooperation based initiatives and real partnerships that favour local community participation which also respects cultural differences. Our initiatives will be successful if we respect human rights and dignity, the underlying values of social work.
The series of articles presented in this volume offers readers with a comprehensive overview of the wealth of the scientific content of the 4th International Conference. As editors for this collection, it is with pleasure and pride that we invite you to read on. Our next rendezvous took place in Hong Kong from December 10th, 2006 through to the 14th for the 5th International Conference in Social Work in Health and Mental Health.

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SECTION 1: COMPASSION AND SOLIDARITY: The Fourth International Conference on Social Work in Health and Mental Health
Welcoming Remarks


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SECTION 2: HIV-AIDS: Cultural Competence
in HIV Prevention and Care: Different Histories, Shared Future

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With all these experts and so much money why are we not making a difference? There were so many people at the 2002 HIV/AIDS Conference in Barcelona, but where were the social workers and what are they doing to fight the pandemic?" (a social work colleague).

The title of this article asks the rhetorical question-do social workers care about the pandemic and if so, what are they doing about it? Of course you will say—how could they not? Despite the challenge of my colleague,

I believe committed social workers do care deeply about this crisis, but some are not really sure exactly what to do about it and what their contribution could be. The problem seems to require a "mega" response from our profession and from all of us and leaves us feeling inadequate. Yet all though it may appear as if we are doing little, social workers are involved
in projects around the world that contribute a great deal. I want to high
light some of these because they are examples of good practice. But I also
want to urge us all to think strategically about what we as social workers
and professionals could do more of, because of the enormity of the prob-
lem and the consequences for so many. CONTINUING SPREAD OF HIV/AIDS IN THE WORLD
HIV/AIDS is a global development emergency and continues to spread unabated in many parts of the world where it is wiping out the
development gains achieved over the past decades, threatening the
peace and stability of nations and regions, and sending whole communi-
ties into destitution. The epidemic primarily affects the world's poorest
communities, those countries with greatest gender inequalities, dispari-
ties in income and access to productive resources, the marginalized,
stigmatized and disempowered.
Worldwide, over 60 million people have contracted HIV and 22 mil
lion have died of AIDS since the epidemic began in the late 1970s. Ex-
perts believe that the rate of new HIV infections could escalate 25% or
more by 2005, with the number increasing to 100 million by 2010 (from
the 40 million presently) according to recent predictions. In 2003 alone,

5 million people became HIV positive, while 3.1 million globally died from AIDS (UNAIDS, 2003).

In the developing world heterosexual activity remains the primary mode of transmission of the virus, particularly in Africa where thirty million Africans have HIV-and AIDS has so far led to the deaths of 17 million people. Although Africa has been the center of the AIDS epidemic for more than twenty years, this may be changing. For instance, UNAIDS (2003) estimates that there are at least one million HIV-positive people in China presently and that this number could grow to 20 million people by 2010. These staggering figures—representing so much misery and suffering in the world—demand a powerful response from the social work profession.

Sex between men remains an important aspect of the epidemic in most high-income countries, although an estimated one-third of new infections is now occurring through heterosexual contact (UNAIDS, 2003). An unfortunate development has been the resurgence of sexually transmitted infections in Australia, Japan, Western Europe.
and the USA, pointing to the revival of high-risk sexual behavior, especially among young people. Prevention programs that had achieved notable success in limiting HIV transmission in the 1990s appear to have been shifted to the back burner. The role of injecting drug use in the HIV epidemic is also significant in many countries, particularly among vulnerable populations—including those in prison and those who belong to marginalized minorities.

It is vital that prevention, treatment and care programs be adapted to reach all persons affected by HIV/AIDS, particularly those whose language, culture or immigrant status might limit their access to services, or leave them subject to oppressive and discriminatory situations. This is consistent with social work values that emphasize a transformational (or "emancipatory") approach, where unjust social structures are seen as responsible for inequality—and where social workers have an explicit commitment to social justice (Dominelli, 2002:4).

Although the epidemic is serious in the developed world, we must not forget that 95 percent of people with HIV live in the developing
world. Gender inequity, poverty, and unsafe sexual practices have led to spiraling HIV rates, particularly in the southern African countries.

While prevention of HIV infection is very important, lack of opportunities to receive treatment can undermine prevention messages as there may seem little point in knowing one’s HIV status when treatment is not available. ACCESS TO TREATMENT

Prevention and behavior change is crucial and as social workers we recognize how important education and awareness is in combating AIDS. Yet we also need to consider the issue of treatment. As Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa has noted: “You can’t avoid the issue of treatment anymore. There are 30 million people with HIV/AIDS (in Africa) and a minimum of six million who would qualify for treatment. What we’ve also discovered is that treatment not only keeps people alive, it restores hope” (Lewis, 2004).

However, today one of the major barriers to an effective HIV/AIDS response is the gulf that separates the rich and poor worlds in terms of access to live-prolonging HIV treatment. There are still those who say
"it can't be done," it is too expensive, or that there is a lack of infrastructure to monitor treatment—but it must be done. It is morally, ethically, socially and economically unsustainable to have the majority of those living with HIV/AIDS to have no access to life-sustaining treatment.

Equitable access to treatment is fundamental to social work, and as the international definition of social work emphasizes, the profession needs to be concerned with "the empowerment and liberation of people to enhance well-being .... Principles of human rights and social justice are fundamental to social work" (IFSW & IASSW, 2000).

For the first time this moral imperative is being realized through the policies of key organizations like the World Health Organization's 3 by 5 Initiative, which aims to treat half of those who need antiretroviral (ARV) treatment (i.e., 3 million people) by 2005—as well as offering new opportunities for strengthening HIV prevention efforts (WHO, 2003). It is gratifying to see that the Canadian Parliament, for example, has now endorsed a bill that will allow the export of generic drugs to developing countries, making Canada the first wealthy nation to pass such
legislation. This will amend the country’s patent laws to permit the government to order the override of patents to allow certain pharmaceutical manufacturers to produce and export generic drugs—including antiretroviral drugs—for use in developing countries.

The promise of increased access to antiretroviral treatment (ART) for people in need allows us to develop a comprehensive public health response to the epidemic that fully integrates prevention, care and treatment.

Evidence from the Caribbean, Africa and elsewhere indicates that introducing treatment in affected communities can reduce the fear, stigma and discrimination that surround HIV/AIDS, increase demand for and uptake of HIV testing and counseling, and reinforce prevention efforts. Improving access to treatment is needed to ensure that the beneficial preventive effects of ART—reducing stigma and increasing demand for testing and counseling—arc not lost.

Over the last six years, the introduction of ARVs in Europe and the USA has cut AIDS deaths by over 70%. In Brazil, the use of ARVs has cut AIDS mortality by 51% from 1996-1999. The excuse that in poor areas people don't take the drugs properly, endangering
themselves and

risking drug-resistant varieties of the virus appearing, doesn't bear out

in practice. In Brazil, 70% of patients take their medicines properly 80% of the time, the same as in the USA. Medecines Sans Frontiers' trial programmes in Uganda and Senegal have been very encouraging with rates of those taking medicines properly nearly the same as in the European Union (Greenhill, 2004).

Treatment is also a powerful incentive to get tested, providing a strong boost to prevention efforts (MSF, 2004). Costs have been pushed down to as little as US$140 per person per year for fixed-dose triple combination drug treatment, although this is still far too expensive for many.

The Global Fund to Fight AIDS, TB and Malaria was set up in response to the United Nations' Secretary General's call for the world to unite around fighting these epidemics. With Global Fund resources, more than 500,000 people are projected to receive antiretroviral treatment over five years. This represents a near tripling of coverage in poor countries (including a more than six-fold increase in Africa). All HIV
grants include prevention, much of which is focused on school-aged children and youth. This, if fully funded, could provide desperately needed money to buy the drugs, train the healthcare workers, build more clinics, and set up more prevention and care programmes. However, while UNAIDS has called for at least US$10.5 billion a year from the international community and US$15 billion by 2007, currently, governments spend under half this. While this may seem an enormous amount of money to ask, we may wish to bear in mind other seeming priorities. According to the Worldwatch Institute's 2004 State of the World report, providing reproductive health care for all women, ending hunger and malnutrition, universal literacy, global clean water, and immunizing every child in the world could all be achieved for less than people spend annually on luxury items like makeup, ice cream, and pet food. While the world as a whole spends US$4.7 billion on AIDS each year, the US spends almost twice this (US$8 billion) annually on cosmetics, while Europe spends nearly three times this amount (US$11 billion) on ice cream. Europe and
America spent nearly five times as much (US$17 billion) on pet food as they did on fighting global AIDS (US$3.6 billion) (Worldwatch Institute, 2004). Treating people for life-threatening illness accords with key social work values that emphasize that "every human being has a unique value, which justifies moral consideration for that person" and "each society, regardless of its form, should function to provide the maximum benefits for all its members" (IFSW, 1994:2). Making affordable drugs available is a moral imperative that will also reinforce prevention efforts. WHAT CAN SOCIAL WORKERS DO?

In a nutshell—a lot more. In the context of the HIV/AIDS epidemic, so social workers have been confronted with a vast range of new problems, from the psychosocial effects of infection and transmission of the virus to the generation (particularly within Africa) of large numbers of orphans requiring care. State-financed social work tends to be more prevalent in affluent, Western countries, but many social workers world-wide may be found in the non-formal sector, employed by nongovernmental organizations (NGOs), community, civil or religious organizations. Social work
interventions include attempts to prevent problems through tackling the
causes of social need, such as poverty, as well as the provision of care,
counseling and support to those affected. They are involved professionally in dealing with the factors that either reinforce or help to reduce the prevalence of HIV/AIDS (see Diagram I below). Social workers in many countries are therefore at the forefront of attempts to promote social development and to find sustainable ways of assisting families and communities.

Diagram 1. Factors that reinforce or help to reduce HIV/AIDS prevalence
Factors that reinforce HIV/AIDS

Factors that reduce HIV/AIDS

Gender inequity & male domination Gender awareness, sensitivity & sexual equality

Poverty & continuing impoverishment Mobilization of resources

Increasing urbanization & migration Integrated & supportive communities

Lack of information & epidemiological data Strategic information

Inadequate & isolated institutions Multi-sectoral approach & sharing of information

Isolated & marginal civil society Civil society engagement

Oppressed & disadYantaqed communities Empowered communities

Disconnected or authoritarian government Committed government & voluntary sector
often in conflict with Voluntary organizations involvement
Lack of political commitment Political leadership & advocacy
Reactive & fragmented approach Proactive & holistic approach
In their training and work experience social workers
develop the knowl
edge, skills and values needed to support people as they
cope with stresses,
changes and crises, including those triggered by illness, marginalization
and discrimination. Many other professions and individuals
are involved
with psychosocial care and emotional support, including
nurses, psychologists, doctors, community activists, volunteers and family
members. How
ever, the social work profession, by virtue of its holistic
perspective, is
capable of responding to the needs of vulnerable
populations, helping peo
ple gain more control over their lives-in partnership with them-and ad
ressing major political, social and economic issues.
SOCIAL WORK HIV/AIDS ACTION PLAN
Research carried out by the Southern Africa HIV/AIDS
Information
Dissemination Service (SAfAIDS) has shown the need for
updated in
formation on how social workers can deal with HIV/AIDS,
leading to
the production of an advocacy document on the role of the
social wel
fare sector (SAfAIDS, 1999; UNAIDS, IFSW & SAfAIDS, 2000).
Key
points in this action plan include:

1. creating an awareness of the negative effects of poverty on HIV/AIDS and lobbying for debt cancellation and other measures to ensure more resources are made available;

2. recognizing the crucial role played by the community—in particular women—in offering informal care and to reinforce this. An important aspect of this is helping to bring about gender equity;

3. building an effective coalition through networking and strategic alliances and to develop a clear understanding of the professional role of social workers, guided by policy statements of IFSW;

4. tackling stigma and discrimination and promoting acceptance of people living with HIV and AIDS (PLWHAs).

Consequently in dealing with HIV/AIDS, the social work profession needs to be more involved in these areas of concern as follows.

Tackling the Issue of Poverty

Poverty is a major factor in the transmission of HIV infection, but the epidemic itself also contributes to poverty. Social workers are engaged in a variety of poverty-related projects to help people with HIV and AIDS, but they need to get more involved in the policy arena. Social work associations, through IFSW, with its consultative status as an international NGO at the Economic and Social Council of the United Nations, can support the efforts being made by the UN and international NGOs to persuade the rich countries to do more to fund
anti-AIDS programmes in the developing or poorer regions of the world. Social workers also need to promote concern and respect for people living with HIV and AIDS. Human dignity is at the heart of this social work.

Social workers are confronted with the issue of how to maintain and strengthen human rights principles and values as part of their contribution to eradicate the problem of HIV/AIDS. In this regard IFSW has a Policy Statement on HIV/AIDS that stresses the need for social workers to be committed to the principles of social justice and human rights-of direct relevance where there is need to ensure through proactive advocacy that all people affected by HIV/AIDS have proper food, housing, education and health care and be able to exercise their rights in this regard without hindrance. In fact "one consequence of the spread of HIV in the developing world is the adoption of the aim to establish a more just economic world order" (IFSW, 1990:2).

The Statement also strongly urges the governments of the developed coun tries to fund AIDS prevention and treatment in proportion to their GNP.

Example I: Tackling Poverty and HIV/AIDS in Zimbabwe

Poverty has long been a companion of AIDS. In Zimbabwe, which has been ravaged by the epidemic, many orphaned adolescents end up becoming heads of households. In turn,
many of the young women among them fall into relationships with older men—"sugar daddies" or "mdharas" in the local Shona language—who pay their school fees but demand sex in return. Studies show that in Africa, HIV infection is six times as high in girls aged 16 to 19 as in boys, partly because teenage girls are powerless to negotiate safe sex and that use of condoms is rare. "Big dharas don't like their sweets wrapped," one girl told researchers. Another girl, 15, said in a focus group assembled by the researchers, "If you refuse, you stay poor. If you take his money and refuse sex, he will rape you." Many of these men seek out high-school-age sex partners, both because of the prestige of having a trophy girlfriend, and because it is believed the girls do not have HIV. Up to a third of such men, though, may already carry the virus. The SHAZ project was initiated with social workers in Zimbabwe under a joint project funded by the US National Institutes of Health and entitled "Shaping the Health of Adolescents in Zimbabwe" and is an HIV/AIDS prevention programme that offers young girls in Harare economic security to try and prevent them from being forced into sexual liaisons that transmit HIV. Young women in the project receive education, vocational training, and information on reproductive health. Volunteer local businesswomen teach them traditional female businesses, such as making clothes and growing spices. These mentors fulfill the traditional role of the African "tete," or auntie, who is consulted on all major life decisions. Early indications are that this is a useful approach that has been praised by Peter Piot, Executive Director of UNAIDS, as "absolutely the right thing" (see Chase, 2004).

Social work roles in tackling poverty might include:

• lobbying in support of the Global Fund through IFSW and UN bodies;

• strengthening community-based coping strategies through supporting existing traditional community self-help mechanisms (such as savings clubs, women's groups and foster families);

• identifying sources of financial and material assistance and encouraging community fundraising;

• working in close partnership with PLWHAs, building links between non-governmental organizations (NGOs), community-based organizations (CBOs), the government and donor agencies,
Tackling Gender Inequity, Power Issues and the Roles of Men and Women

Men have considerable power in sex. They are seldom criticized for having multiple sexual partners—and are expected to take the lead in sexual matters and to have their sexual demands met. This is particularly a problem in Africa where men's abuse of this power is a primary factor behind the HIV/AIDS epidemic. According to one survey 43 percent of Zimbabwean women have suffered physical violence from their husbands or regular partners, and 25 percent have been forced to have sex—marital rape. However not all men behave arrogantly towards women; many respect their partners and demonstrate respect in their sexual and other behavior (SAfAIDS, PANOS & UNAIDS, 2001).

The 2004 World AIDS Day focused on Women, Girls, HIV and AIDS.

Poverty and poor public services have combined with AIDS to turn the care burden for women into a crisis with far-reaching social, health and economic consequences. Women and girls pay an opportunity cost when undertaking unpaid care work for HIV and AIDS-related illnesses since
their ability to participate in income-generation, education, skills-building and caring for their families diminish. Research has shown that up to 90 percent of care due to illness is provided in the home, with women bearing the bulk of this caring. AIDS intensifies the feminization of poverty, particularly in hard-hit countries, and disempowers women. A study in the village of Kagabiro in Tanzania, for instance, demonstrated that when a household included someone with AIDS, approximately 43 percent of household labor was spent on AIDS-related matters and most of this was provided by women (Bollinger et al., 1999).

Gender issues have a critical impact on HIV and AIDS. UNAIDS has launched a Global Coalition on Women and AIDS, bringing together leading women and men committed to improving the lives of women and girls worldwide (UNAIDS, 2004). It is not sufficient to give assertiveness skills to young women who may have little or no power to negotiate safe sex. It is crucial also to tackle young men’s attitudes about sex and masculinity. This is particularly relevant in Africa, where cultural factors remain one of the key obstacles to HIV/AIDS prevention.
strategies.

Example 2: Building Supportive Informal Networks

Social work trainers at the University of Natal in South Africa have been using principles of developmental social work to implement a project initiated in response to the need for psychosocial services when women are informed about the HIV status of their children and, in the process, their own HIV status. Based at a large teaching and referral hospital in Durban, where 35-50% of children admitted with persistent nutritional deficiencies and diarrhea have symptomatic HIV/AIDS, there was no structured psychosocial assistance or post-test counseling for HIV/AIDS positive mothers before this project started in 1996. A developmental and empowerment-based process focused on the felt needs of group members, consciousness-raising, reflection in action, education and skills training. Women were involved in peer support groups, given training in basic counseling skills and involved in workshops with NAPWA (National Association of People Living with AIDS) on living positively with AIDS. This emphasized acceptance of one’s HIV status, making decisions about disclosure, responsible living and the adoption of safer sex practices, preparation for death and dying, morality and spirituality, nutrition, hygiene and the avoidance of the use of dmg’s and alcohol. The project also served as a fieldwork training unit for social work students who provided useful services to family members and to sexual partners on disclosure issues and assistance in respect of problems such as physical abuse of women, rejection and accommodation needs. The project included an interdisciplinary approach with the strategies positively endorsed by nurses, doctors and pediatricians (see Sewpaul, 2000). Social work roles in tackling gender inequity might include:

- helping reframe ideas about masculinity, helping men take responsibility for their own lives and to share responsibility with their partners for each other and their children;

- working closely with PLWHAs and together countering negative "macho" ideas in favor of positive attitudes to do with care and responsibility;

- ensuring that projects and programmes have a deliberate focus on gender from the initial concept stage, and that gender concerns are not just "added on" later as an afterthought;
• ensuring that gender considerations also include a gay focus (in situations where heterosexual transmission is the norm).

Building an Effective Coalition

Through a Multi-Sectoral Approach

Social work organizations need to develop clear operational guidelines on working with HIV/AIDS and identify the contribution that the social service sector can make. In July 2000 at the AIDS Symposium in Montreal, the Canadian Association of Social Workers (CASW), with others, developed a manifesto and plan of action for the profession with regards to HIV/AIDS. This advocated for social workers to enter into respectful professional partnerships with people living with HIV/AIDS, with due regard to basic social work values such as self-determination, dignity and worth of the individual; for different sectors to work together to tackle HIV/AIDS with the social services sector providing a lead role in this, and developing collaborative partnerships using a multi-sectoral approach.

Developing a multi-sectoral approach means that social workers need to find ways to reach the key individuals and groups that most af
fect the dynamics of the epidemic in their respective communities and

ensure that HIV/AIDS programmes are efficient, appropriate and sus
tainable, and reach the largest number of people possible with the
available resources.

As pointed out by the International HIV/AIDS Alliance (2001), key
aspects of developing this multi-sectoral approach and scaling-up social
work interventions will mean:

- reaching a higher percentage of the population, new target populations and new geographical areas;
- reaching different sectors (such as the government, health workers and the military);
- reducing stigma and increasing community acceptance of people living with HIV and AIDS;
- increasing community participation and the range of services provided;
- increasing capacity building, training and the financial and organizational sustainability of the voluntary organizations, NGOs and CBOs that social workers support;
- reducing new HIV infections and maintaining the impact of interventions.

Example 3: Coalition Building-The Para55 Organization A multi-professional body of Commonwealth Associations including the Commonwealth Organization for Social Work (COSW) have been actively encouraging Heads of Government to make statements on the catastrophic impact of HIV/AIDS in the Commonwealth and advising them on the measures they need to take to counter the epidemic. This lobbying effort was achieved through a statement in paragraph 55 on HIV/AIDS in the Durban Communiqué, adopted by the Commonwealth Heads of Government Meeting (CHOGM) in November 1999, which stated that Heads of Government “express grave concern over the devastating social and
economic impact of HIV/AIDS, particularly in sub-Saharan Africa." The Commonwealth professional associations-medical, pharmaceutical, lawyers, teachers, media workers, social workers, and others-recognizing that Commonwealth countries have 60 percent of the world’s HIV/AIDS infectivity as compared with only 30 percent of the world’s population, set up the group, which they called the Para55 Group, to work together to implement the terms of the paragraph and to extract the maximum assistance from Heads of Government and other key policy makers to reinforce their own efforts to fight the pandemic. The Group designed its own website (www.para55.org) to facilitate the exchange of information on the key issues involved in fighting the pandemic which have included preventive measures, mother-to-child transmission, the role of traditional healers, and the impact HIV/AIDS is having on the economic and social development of Commonwealth developing countries. The group has been involved in initiatives including the hosting of conferences, workshops and contributing towards the draft of the Declaration of Commitment by Heads of UN Member States, and at the UN General Assembly Special Session on HIV/AIDS (UNGASS) held in New York in June 2001. Through these activities the members of the Para55 Group hope to draw the attention of Commonwealth Heads of Government to the importance that commonwealth associations and other organizations attach to the implementation of Para55 and also to the reason why a multi-sectoral approach is imperative (see Haslegrave, 2001; Para55 Group, 2002).

Social work roles in developing a multi-sectoral approach might include:

- developing an awareness of how HIV/AIDS is a cross-cutting development issue (like gender and human rights) that affects everything;

- encouraging meaningful partnership between PLWHAs, communities, governments, donor agencies, international and local NGOs, the private sector and others in order to address the problems of HIV/AIDS;

- linking people with local support services such as drop-in centers, mobile clinics, shelters and hospices;

- working alongside PLWHAs and their self-help organizations and networks and assisting where appropriate, and if requested.
Tackling Stigma and Discrimination

The impact of HIV/AIDS is made worse by the stigma associated with the disease. While more HIV-positive people have been open about their condition, stigma still exists and prevents adequate care and prevention reaching those who need it.

At the heart of the stigma of AIDS lies shame—the perception that those with the virus have done something wrong for which they and their families should be ashamed. Discrimination entails a person acting on a pre-existing sentiment or stigma, which results in someone being treated unfairly. Stigma and discrimination therefore form a continuum of harmful thoughts and behaviors that are based on prejudice.

A major role for social workers concerns tackling stigma and discrimination. Richter (2001) argues that fear, ignorance and an inability to accept any deviance from the 'norm' (i.e., moralizing) constitute the main reasons for prejudice or stigma against people living with HIV/AIDS. She puts forward four origins of stigma against people living with HIV/AIDS:

I. moral attitudes and systems of belief around sex; thus
AIDS is seen as a punishment for immoral behavior that one should dissociate oneself from:

2. ignorance and a lack of knowledge leading to fear and irrational behavior;

3. self-interest, including a desire to create a chasm between healthy and 'un-healthy' people so as to reduce the possibility of personal vulnerability to HIV; and

4. media images of blame with a dichotomy between those who are "innocent" (for example, children gaining HIV through vertical transmission from mother to child) and those "guilty" (for example, those becoming positive through sexual intercourse).

Children affected by HIV/AIDS are even more vulnerable than adults as they face the possibility of stigma relating to their own status, as well as stigma flowing from their parent or caregiver's status. This stigma continues even after the death of their caregiver, when they may be rejected or treated with scorn by the extended family and the community. As one boy in South Africa explained "... people treat us badly, even the nurses themselves. They don't treat us like people who know about this sickness. The way they treat you is like they say you deserve it. They make it a point that you are shamed by your illness" (Clacherty & Associates, 2001:40).

Example 4: Tackling Stigma-The Stepping Stones Approach in Uganda Sexual health issues are deeply rooted in people's fears, prejudices, phobias and taboos. Most of us, wherever we live, find it difficult to talk about matters related to sex, gender and death. To help communities
address these difficult issues, the Strategies for Hope Series—a project of the British NGO ActionAid—produced the Stepping Stones training package in 1995. Developed in collaboration with the Norwegian Redd Barna-Uganda and ActionAidUganda, Stepping Stones focuses on communication and relationship skills, gender issues, HIV and AIDS. The package consists of a manual, accompanied by a video filmed in southwest Uganda where the manual was field-tested. The aim of Stepping Stones is to enable women and men to describe and analyze their relationships and other experiences and to develop solutions to the sexual health problems and risks which they face in the course of their daily lives. The materials were designed primarily for use with non-literate communities in sub-Saharan Africa, but have been found to be useful in many other geographical and cultural settings. Stepping Stones’ principles are based on the recognition that the best behavior change strategies are those developed by the members of a community themselves, and that the process of self-analysis leads to greater self-awareness and self-respect, enabling people to practice more assertive behavior. The approach has reduced stigma against people with HIV/AIDS and made people more willing to look after the sick. Other positive consequences have been changes in sexual behavior and helping empower people to protect their own sexual health (see Kaleeba et al., 2000).

Social work roles in tackling stigma and discrimination might include:

- providing access to voluntary counseling and testing, with follow-up counseling and social support;

- training and supporting PLWHAs, local volunteers and community members on HIV/AIDS coping strategies;

- working in partnership with PLWHAs to develop programmes that encourage openness, disclosure and share experiences of living with the virus;

- identifying, strengthening and supporting existing positive PWA and community responses to the epidemic.

CONCLUSION

HIV/AIDS continues to remain a global emergency and is spreading to many parts of the world previously unaffected. The scale
of the epidemic requires the combined efforts of all concerned international agencies, governments, voluntary organizations, community groups, people living with the virus and others to make an impact. Social workers need to become involved with efforts to reduce the effects of the epidemic particularly regarding prevention and treatment programs. The increased use of antiretroviral treatment in parts of the world where this is more accessible has dramatically scaled back death rates from AIDS and initiatives in this direction need to be supported. Equitable access to treatment is fundamental and creates a moral imperative for the social work profession towards promoting human rights and social justice. Social workers can also contribute in many different ways and at different levels by helping build a momentum towards tackling poverty, reducing gender oppression, developing strategic alliances with other concerned parties, and tackling stigma and discrimination. Specifically, social workers can lobby for increased resources to tackle HIV/AIDS, develop advocacy initiatives through their professional associations and the
IFSW, help build support structures in partnership with those affected by HIV and AIDS and assist community responses to the epidemic.

At the Montreal 2000 International Social Work Conference, Stephen Lewis in his keynote address gave the following invocation "... while con

licts, pandemics and escalating poverty are happening, the world is look

ing for your voice." Social work voices are being heard and there have been


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Society, New York: W.W. Norton & Co., Inc. doi: 10.1300/10 10v44n0 1_06 An Investigation of the Practice of Unsafe Sex Yet Repeated HIV Testing Naama Patinkin, BSc, BSW Ben Werner, MD Israel Yust, MD Yaron Yagil, MSW Margalit Drory, MSW Michael Burke, MD SUMMARY. Rationale: A purportedly heterogeneous group of people, who come to take tests at the Human Immunodeficiency Virus (HIV) Test

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ing Clinic, includes young males and females who lead a normative lifestyle with no unique characteristics, Within this population, we have observed one distinct subgroup of predominantly male individuals, who return from time to time to take the HIV tests. They tend to partake in many occasional sexual encounters with numerous partners, and despite their obvious knowledge of the risks involved, they attest to not using condoms during sexual intercourse. The aim of this preliminary study was to investigate the patterns of their risky behavior in conjunction with their test taking conduct. Methods: Ten self-referred volunteering subjects were recruited. Exclusion criteria: HIV-positive, drug and/or alcohol abusers, mentally ill, men who have sex with men (MSM) and minors. The study was carried out using semi-structured
interviews (40-90 min each). The interviews were recorded, transcribed and content analyzed. Findings: Data analysis showed several possible explanations for risky sexual behavior, such as applying of a variety of risk management mechanisms, refraining from impulse control behaviors, and self-destruction motives. The reasons for undergoing HIV testing were most frequently related to specific events, high-risk in nature, and not part of a routine behavioral practice. Conclusions: Our findings might suggest that within this population group, the prevailing primary preventive interventions would not satisfy the purpose of decreasing levels and frequency of risk-taking behaviors. In the opinion of the authors, there are two strategies that could be employed, simultaneously or separately. An indirect approach entails the increase and enhancement in utilizing widely spread media, e.g., feature films and television programs, to convey issues related to curbing risk-behavior. Direct emphasis should be put on secondary preventive measures, by encouraging frequent test-taking conduct, preferably accompanied by counseling, in order to decrease the risk of further transmitting the virus. doi: 10.1300/J010v44n01_07 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: doalelivery@haworthpress.com Website: http://www.HaworthPress.com © 2007 by The Haworth Press, Inc. All rights reserved.] KEYWORDS. HIV-testing, heterosexual, condom, risk, behavior RATIONALE

Clinical experience at the Human Immunodeficiency Virus (HIV) Test

Clinic at the Tel-Aviv Sourasky Medical Center has shown that people who request HIV tests can be classified into several main groups.

Most of these groups have already been well-documented and studied previously, such as homosexuals and injection drug users (IDU), since it appears they overtly demonstrate a risky lifestyle. Numerous studies have been conducted to learn about the risk behavior and motivation for testing of individuals belonging to these groups. Spielberg et al.
(2001) sought to identify factors influencing HIV-testing decisions among gay men and injection drug users. Riess et al. (2001) examined gender differences related to the reasons for testing for HIV by IOU. Hughes (2002) explored HIV-risk perceptions among inmates who were IOU. Donovan et al. (1994) reviewed a number of studies, carried out since the mid-eighties, in an attempt to identify the factors that are associated with continued risky sex in men who have sex with men (MSM). To the best of our knowledge only occasional reports have dealt with the sexual attitudes and practices of a sample of sexually active single heterosexual adults (Peart et al., 1996).

The group of people studied in the present work includes young males and females who lead a normative lifestyle with no unique characteristics. Only a few studies have been conducted among this group of subjects. Coyle et al. (1996) interviewed heterosexual respondents with low HIV-risk behavior regarding their experience related to their decision to be tested for HIV. Lupton et al. (1995) interviewed a sample of self-selected volunteers who had taken an HIV test in order
to introduce

a socio-cultural prospective to the reasons for seeking HIV testing.

Among the heterosexual HIV subjects attending our clinic, we ob

served a distinct subgroup of predominantly male individuals, who return

from time to time to take the HIV tests. They are frequently characterized

by having short-term conjugal relationships, and they tend to partake in

many occasional sexual encounters with a large number of partners. Al

though exposed to the risk of HIV infection, as well as other sexually

transmitted diseases, and despite their obvious knowledge of the risks in

tolved, they attest to not using condoms during intercourse. They invari

ably do not demand HIV tests results from prospective sexual partners

before engaging in sexual intercourse.

Whereas the earlier-mentioned groups have been extensively stud

ied, the latter group of subjects, to the extent of our knowledge, has not

yet been specifically addressed in previous studies. The aim of the cur

rent study was to conduct a preliminary investigation into the motives

and underlying reasons for requesting HIV testing in this subgroups' risky course of action in conjunction with their
test-taking behavior.

This study serves as a pilot for further in-depth investigations into this population. METHODS

Participants

This study focuses on a population of heterosexual individuals who had previously undergone HIV testing at least once and who subsequently sought HIV testing during the period when the study was conducted. The subjects had carried out numerous sexual encounters with occasional partners (at least three partners in the year prior to the study), and attested to their reluctance to practice safe sex, even though they were fully aware of the manner in which HIV may be contracted. Exclusion criteria included the HIV-positive individuals, drug and/or alcohol abusers, those with mental illness, MSM and minors.

Purposeful sampling, to select information-rich cases (Patton 1990 & 2002), was conducted on an occasional basis. Ten self-referred subjects were recruited at our HIV testing clinic. This preliminary inquiry was designed as a pilot study to determine whether a more in-depth investigation into this supposedly distinct subgroup is warranted. The authors
decided that in view of the extensive work involved in
analysis of data,

the pilot sample size will be limited to ten. All
participants signed an in
formed consent form after receiving an explanation
regarding the study

aims and methods.

Sociodemographic Characteristics of Interviewees

The group consisted of ten heterosexual males, eight of
them be
tween the ages of 24-35, one aged 49, and one aged 60. Eight
were bachelor,
elors, one was divorced, and one separated. Six
participants completed
undergraduate studies, two were currently students, and two
were
non-academic professionals.

Ethical Issues

In order to minimize the obligation to participate,
subjects were
asked to volunteer for the study only after receiving the
HIV test results.

At that time they were assured that they were not bound to
comply with
the request. Furthermore, the interview was scheduled by
telephone at a
later date.

The participants received an oral and written explanation
regarding
the aims and methods of the study, and were requested to
sign the in
formed consent form prior to the interview. All
participants were pre
sent with the option of receiving a report of the study's findings, only
one participant made this request.

Following the interview, participants were provided with the investi
gators' contact details, if they wished to apply for assistance or if they
had any questions or requests subsequent to their participation in the
study.

Participants' confidentiality was strictly protected throughout the en
tire study and its report. Following the interview, any potentially identi
fying information was omitted from the transcribed text so that even the
investigators engaged in analyzing the data were unable to identify the
subject. The final report divulged no identifying data.

Data Collection

The study was conducted from August 2003 through October 2003. It took the form of a naturalistic inquiry, which involved
semi-structured pre-planned face-to-face single session interviews
(40-90 min). The interviews were conducted in accordance with the
guidelines laid forth by Patton (1990) who suggested informal con
versational interviews comprised of "Questions [that] emerge ./i'om
the immediate context ... there is no predetermination of question top ics or wording" (p. 288). Participants were asked to disclose standard social-demographic data. Interviews were audio-recorded with the aid of a tape-recorder and later transcribed. All interviews were performed by a single investigator (NP). Since all interviews were carried out in Hebrew, special care was taken in translating the citations presented in a meticulous manner.

Data Analysis

Transcriptions were analyzed using a qualitative content analysis methodology. This entailed the extraction of citations from the text by the first investigator and an additional advisor specializing in qualitative analysis methods. These citations were then clustered into themes and sub-themes that reflected the principal motives outlined in the analyzed participants' texts. The saturation of theme clustering process was established when the unexpected abundance of risk management mechanisms emerged from the data. All citations were reviewed by all authors. FINDINGS

The two categories of behavior examined during the
interviews were:

(1) risk-taking behavior and (2) HIV-testing behavior.

Following content analysis, each behavioral group was

divided into

themes and sub-themes. Below are the citations made by the partici

pants, relating to each of the categories of behavior. The citations, for

the most part, speak for themselves.

Risk-Taking Behaviors

The category of risk-taking behavior (see Table I) relates to

reported risk-taking despite coherent knowledge of the risk. The participants ex

hibited a variety of psychic techniques employed to handle the encoun

ter with recognizing the existence of risk. TABLE 1.

Risk-taking behavior-Themes and sub-themes

Knowingly taking risks

Reasoning- 'I did it because ...'

Risk management mechanisms Sub-Theme Impulse control
Sensation-seeking Self-neglect Self-destruction Escapism
Social conventions Issues related to use of condoms Fading of effect 'The inevitable' Familiarity Retrospective check-up Remorse 'Immunity' Devaluation of risk factor
Doubt Denial and avoidance

Knowingly Taking Risks

All participants disclosed that the risks involved in unsafe sexual

conduct were known to them. Furthermore, they all were also knowl
edgeable with respect to occurrences of increased risk. "If you have sexual relations that you pay for, then you enter into some kind of risk group . . ." "If I have oral sex with a prostitute not using a condom and with an open wound on my penis . . ." "That I had sex with a transsexual, once in my life, out of curiosity, and this was the second time."

These are examples of such statements: sexual intercourse with a prostitute increases the risk, moreover when that is done without the use of a condom. The more extreme exposure is the sexual act carried out with a transsexual.

Reasoning-'I Did It Because . . .'

Reasoning refers to statements made concerning drives and/or motives leading to risky behavior. This theme can be further divided into sub-themes (as shown in Table I) that cover a wide range of logic-based justifications of the behavior described by the participants.

Impulse Control

The citations below attest to the existence of forces of impulse, which are not under control, that drive a person to perform the risky behavior.

Like the student that can’t help but disrupt the class—an uncontrollable urge to repeat the unwanted behavior or the decision that is not really well thought out but rather an act of impulse. "I could not get a grip on myself . . . just like a student unable to stop disturbing in class . . ." "... it is not the first
time, nor the second, nor the third, that I promise myself that it will not happen. " "In actuality everything is done on the premise (~fpleasure benefits versus risks. It is supposedly a calculated risk however in most cases the decision originates in your belly and not in your head. "

Sensation Seeking

Sensation seeking refers to behaviors exhibiting the need to partake

in excessively risky behaviors for the purpose of enhancing sensation. "I looked for something beyond-that is more interesting than life, more thrilling than life, more exciting than life, more diverse than life, more extreme than life, in order to escape from life ... "

Self-Neglect

This sub-theme refers to tendencies to engage in thoughts or attitudes

that portray neglect of one's own self and well being. "If I valued my own life then I wouldn't have risked my life."

Self-Destruction

The sub-theme of self-destruction refers to tendencies to engage in

behaviors inflicting self harm, both physical and mental. "During my life time I had periods when I did things which are definitely associated with self harm and the ruining of things that are good for me, not necessarily destroying my own body, but an attempt to demolish things that are good for me. " "I don't have the guts to commit suicide but I was looking for trouble. " "You are in a certain bad mental state that causes you to do it knowingly. "

As can be observed, self-harm is two-fold: it includes harming one

self to the extent of suicide and on the other hand consciously and non

consciously blocking what might be good for the person.

Escapism

Escapism describes a mode of behavior that seeks to avoid
dealing

with an issue. This can be achieved by t1eeing through
tavel or hedonis
tic life style or indulging in self pity, as appears in the
t sample citations
bellow. "IfI discover that the result is positive and not
egative I will go to a travel agency and immediately book
flight abroad and not care about anything. ... Like life
here for me is 'sh-t' and maybe good will come from this
predicament and I will go abroad again and things will look
different." " ... when I got into that thing [state of
depression] ... I had no girlfriend, I had nothing, I
didn't care about anything I didn't even care to take the
test ... it didn't interest me ... "

Social Conventions

This sub-theme refers to social conventions which allow
risk taking
behaviors to exist in a manner which distances the need to
take personal
responsibility. "I didn't use any contraceptives because
here [in Israel] it is different since the girls are
well-kept." "I say, everyone says that 'when I return to
Israel I will do the test' as if abroad it is not necessary.
" "If a person is so fanatic about condoms then the partner
starts asking herself all sorts of questions ... because this
is considered to be some kind ('t deviation from the norm . .."

The citations present a few examples of social conventions.
The deci
sion not to use a condom is based on the assumption that
the prevalence
of HIV in Israel is low, a fact that does not eliminate the
possibility of
contracting HIV but only serves as a social convention
'shield.' Taking
the test for HIV upon returning home after a stay abroad is
an act of
clearing the slate towards the future, and is considered a common practice. And finally, displaying too much concern may arouse suspicion and may cast doubt on the relationship.

Issues Related to Use ("fCondom"

Some of the participants conveyed issues of physical and mechanical difficulties related with the condom use, such as intimacy, performance,

and stimuli as presented in the citations below. "When you feel the women physically as well, then mentally it is more pleasurable. It is something non-instrumental." "I do have an erection but it can very easily be that I will lose it if I start messing around with the rubber." "As it is, it takes me a long time but I have no difficulty in prolonging intercourse... However, if I use a condom I can hardly feel anything."

Risk Management Mechanisms

An impressive range of intra-psychic attempts to resolve or deal with the risk taking behavior they conducted and reported about, was extracted from the participants' discourse. This theme of risk management can also be described in terms of coping with cognitive dissonance. This theme is divided into sub-themes as shown in Table 1.

Fading of Effect

This sub-theme pertains to a belief that in time the effect of the risky encounter, perceived as traumatic, will fade away. Below are two examples that depict the mechanism in operation, implying the
passing of

time as the element responsible for the fading of the impact. "I think that also with people in car accidents . .. if the trauma is handled properly . .. there will be a return to what we call routine . .. " "I don't know, there is something . .. that reduces any self-accounting, so that the trauma is diminished and somehow one returns to a kind of routine that is characterized by repeated mistakes . .. "

The 'Inevitable'

This sub-theme brings forth a deterministic stance—there is no use since things will happen anyway. As proclaimed by the citations below,

in the long run, the 'inevitable,' i.e., making do without a condom, will happen. "Within one or two weeks, even without taking the HIV test, we take cdf the condom . .. " "It is clear in my mind that by the second or third time, don't know when it will happen, it will be without [a condom]."

Familiarity

The citations clustered under this sub-theme refer to the misapprehension that if you are socially familiar with a potential sexual partner it is safe, and therefore justified, to have unprotected sex. "She is not someone I just met today, and that today I have sex with her . .. so that, at the very least, I have some idea about the person I'm with, and according to that, one will decide to take the risk." "One sleeps with girls, one doesn't care—and he thinks that she must be okay because she is from his workplace or from his college."

Retrospective Check Up

Here is an attempt to behave supposedly in a more prudent manner,

by checking the background of the partner with mutual acquaintances.
As in the previous sub-theme the justification is founded on social familiarity, somewhat more distant, with the partner. "I tried to inquire with the girls the extent of the danger I was in... and then, when I could, I tried to inquire with their girlfriends if they thought there was a risk involved."

Remorse

Here is an example of dealing with guilt in the aftermath of the unsafe action, constituting another mechanism of risk management. "I can't recall a case that I didn't stop and say to myself 'Wow! What a stupid thing to do. This is foolishness. '

'Immunity'

This sub-theme warrants special consideration. The stance formulated as "To me, it will not happen" is extensively in use in Israel and is articulated in numerous risk involving situations, such as reckless driving, military service and dangerous sports. Below are two citations, which most noticeably portray this theme. "To say to myself: 'to me it won't happen'" "Always there is the inner belief that 'okay I won't contract AIDS, ' that I won't be involved in a car accident and another a million and a half things that can happen."

Devaluation ("fRisk Factor"

This risk management mechanism is most clearly described in the citation below. "... there are many other risks that we are exposed to during our life time, and some of us are not even aware ("them at all. That is apart from AIDS there are other diseases that we can catch and they also are bad."

Doubt
This mechanism refers to the manner of casting doubt on events, any and all events, categorizing the risk of contracting HTV as one more example. "You can't be 100% sure ... just as I can't be sure that you won't take this tape and play it to your friends."

Denial and Avoidance

Denial and avoidance are among the most common defense mechanisms and are applied here as well, as can be seen in the citations below: "The truth is that I don't think about AIDS ... that is I do think, but I discard the thought pretty quickly ... " "There is a problem but you ignore it or don't talk about it. " "There have been situations in which I got into bed with girls ... whether we took tests altogether ... this a matter that is completely ignored."

Test-Taking Behaviors

The category of Test-taking behaviors relates to the participants' reported reasons for undertaking the HIV test at the time they had been recruited for this study, as well as their customary test-taking behavior.

Table 2 describes the major themes divided into sub-themes.

Concern for Oneself

Concern for oneself reflects the need to check following recent or past sexually risky behavior. This can occur either following a specific risky event or the accumulation of such events or as a routine checkup.

Following are citations attesting to all three sub-themes.

Following a Risky Event "I take the tests after conducting
reckless, carefree sex, without the use of contraceptives. " 
"... there have been days that I slept with two or three 
girls a day. " "... the condom tore ... I was sure that 
we were both goners ... within two days I ran to take the 
test. " "What brought me [to take the test] was non-use ("I 
contraceptives. " TABLE 2. Test-taking behavior-Themes and 
sub-themes

Theme
Concern for oneself
Concern for others
Intra-psychic considerations Sub-Theme Following a risky 
event Accumulation effect Periodic testing Other's request 
Concern for a special other Fear of harming others 
Conscientiousness Guilt A clean slate
Accumulation Effect "When I feel stressed about the number 
of risky events that have accumulated, the time has come to 
take a test ... " "I took the test several times; always 
it followed periods that were sort of wild from a sexual 
point of view. "
Periodic Testing "I do the test on a regular basis. " "... 
just as I back-up my computer once a month, I do the test . 
.." 
Concern for Others
In contrast to the previous theme, this theme pertains to 
ones' concern for others. The test for HIV will be taken following a 
specific request, or concern for the wellbeing of the sexual partner.
Other's Request "... and if someone [female] says let's go 
take an AIDS test, okay we take an AIDS test ... "
Concern for a Special Other "Because I finally found someone 
that I really like. " "I came because I have a new 
girlfriend ... and because she is important to me. "
Fear of harming Others "Yes, but it's not good, since in the 
meantime, I might cause harm to other people, ... " "... 
that if heaven forbid, tfu "fu tfil [also at the same time 
knocking on the table [wood]] I will infect someone . .. "
Illtra-Psychic Considerations

Intra-psychic considerations refer to reasons that do not pertain directly to the wellbeing of others or oneself, but rather to profound thoughts and a moralistic stance. In this category there are three subthemes.

Conscientiousness "I will not be able to bear it at all—not that I have infected and not that I have been infected."
"What do you mean? I behaved stupidly and I want to know if I have many years to live or slightly less years or that something unexpected will happen and it doesn't matter; in any event I am going to die."

Guilt "... my reasoning is that I want to know if I'm paying for my mistake now or not. It is important."

A clean slate "Now it is a chance to clean the slate."

DISCUSSION

All subjects participating in the exploratory study demonstrated no lack of knowledge pertaining to the ways of contracting AIDS and the means to prevent it. Nor were they unaware of the time lapse required before the test, performed after a risky event, can render satisfactory results. This information was gathered indirectly during the interview.

Test-taking practices exhibited by the participants are, largely, checkups following a risky event, as has been reported by Watanabe et al. (2004-).

They were either self-initiated or followed a request from another person.
The intra-psychic considerations theme would seem to fall in line with the risk management mechanisms identified in risk-taking behavior discussed below.

It appears that all sub-themes in Reasoning-'I did it because ...' are related to acts governed by drive or urge, serving as an explanation of the action described by the subject, however no evidence of coping was apparent.

Issues related to use of condoms, which we have included within the theme of Reasoning-'I did it because ... " have been reported by Crosby et al. (2003, and 2004). Complaints voiced by the participants in our study did not relate to issues of breakage or slippage, as studied by de Visser et al. (2003), nor to inaccessibility to condoms. In other words it can be deduced that not using a condom was intentional.

Several studies have emphasized sexual sensation-seeking as a significant factor in explaining risky behavioral patterns. Kalichman and Rompa (1995) introduced the sexual sensation-seeking and sexual compulsivity scales (SSSS), which have been applied principally to MSM.

In the present study, this was an infrequent occurrence,
and risk management was the prominent behavioral characteristic.

The group tested demonstrates a variety of cognitive mechanisms of risk management. Initial results suggest that the aim of these mechanisms is to resolve the conflict arising from the awareness of the risk involved in unsafe sex, yet the continual performance of unprotected intercourse.

These mechanisms are to be compared to strategies used in conditions of cognitive dissonance. Festinger's hypotheses deploy ways to reduce the dissonance: by selective exposure, by post decision dissonance that creates a need for reassurance and by minimal justification for action that induces a shift in attitude (Festinger and Carlsmith, 1959).

In our study, we have found examples that support these proposed categories as well as additional strategies. These intra-psychic operations manifest the coping capabilities of the participating subjects. The abundance of risk management mechanisms apparent in the participants texts' allude to the possibility that they choose to hold this stance of questioning, deliberating about the actions they had taken. Subjecting oneself to HIV testing would provide them
with the same opportunity. This may suggest a possible explanation to
their behavior and could hence present a point of entry for intervention
aimed at modifying the risky behavior. Such interventions can even be
administered during post-HIV-test counseling let alone more extensive
programs.

The limitations of this research are its small sample size and that it
was carried out in a small country, where socio-political influences may
skew the approach in risk-handling. Further, the number of people liv
ing with HIV/AIDS in Israel is low relative to most Western countries.

According to the reports from the Israeli Ministry of Health, up until
June 2003 fewer than 4,000 people were diagnosed as HIV + out of a
population of 6 million. An additional limitation is that all subjects, who
fit the profile sought for this study, were male. In a recent report by
Gaither and Sellbom (2003), men when questioned regarding risky be
havior, scored significantly higher than women. Notwithstanding, the
study does highlight an important subgroup of subjects that appears to
have been largely neglected as a potential source of disseminating HIV
infection.

These preliminary results suggest that, when addressing knowledge
able male adults, some existing preventive educational programs should
be reconsidered. In view of the abundance of risk management mecha
nisms, the authors feel that preventive educational programs should aim
at disrupting the 'calming' effect of these mechanisms. One idea that
could be implemented is the utilization of widely spread media, highly
accessible to this population, such as feature films and television pro
grams, to alter their perception of risk taking behavior.

In our study, several of the participants referred to the lack of discus
sion and inhibition to have discussions, between sexual partners, related
to condom use and HIV test-taking. Depicting scenarios containing
overt verbal communication as such could be viewed as a 'screen test.'

Concomitantly, direct emphasis should be put on secondary preventive
measures, by encouraging frequent test-taking not only by the subject
but also by the prospective sexual partner in order to decrease the risk of
spreading HIV transmission. Provision of post-HIV-test counseling


SECTION 3: AGING: Promoting the Psychosocial Health of the Elderly—The Role of Social Workers


De Leo, Diego. (March 2004). Gender Issues in Elderly Suicide: A Trans-Cultural Perspective. Keynote speech at the Asia-Pacific Regional


Zhang, Yuanzhcn (2002). Survey and reflections on the state of care for the rural elderly in the undeveloped central region. Chinese Sociology and Anthropology. 34 (2), 13-23. doi: 10.1300/101 0v44n0I_00 Promoting Older People's VoicesThe Contribution of Social Work to Inter-Disciplinary Research Jackie Powell, MA SUMMARY. UK government policies over the last decade or more have focussed on giving older people more voice in the design, delivery and assessment of services. Mirroring these trends, there has been a shift towards increased involvement of older people in the research process. Drawing on three research studies, this paper examines the contribution of social work to an inter-disciplinary research agenda designed to promote increased involvement of older people in issues of service quality in primarily health settings. Challenges and opportunities are discussed. Each of the studies illustrates the importance
of promoting research practice congruent with social work's commitment to partnership and empowering forms of practice. This, it is argued, requires the challenging of ageist assumptions, the use of a range of research methods and the valuing of different forms of knowledge.

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Involving service users in decisions about both their own needs and

wider issues of service development is seen as important, if not essen
tial, to the process of establishing person-centred
services. Such involvement is also regarded as a valuable way of facilitating people's sense of engagement as active rather than passive recipients of care.

User participation in service development, implementation and evaluation is growing in many areas, although the involvement of older people in such initiatives has been seen as slow relative to other user groups (Nusberg, 1995). Too often, it has been argued, older people have been assumed too frail or in need of others to represent their views, rather than have their voices sought on their experiences of services and their daily lives more generally (Barnes, 1997).

Within the United Kingdom, government policies over the last decade or more have focussed on giving older people and their carers more opportunities to influence the design, delivery and assessment of services. This trend can be seen as part of wider agenda to improve the overall quality of services and standards of care. For example, the National Health Service and Community Care Act (Department of Health, 1990) requires consultation with local communities in drawing up community care plans as well as consultation with individuals about
their needs for care. More recent policy documents have given fresh impetus to these ini-
tiatives (Department of Health, 2000a and 2000b). The National Service
Framework (NSF) for Older People (DOH, 2001), in particular, explic-
itly addresses issues of discrimination and participation through its em-
phasis on representation of older people in organisations across health
and social care settings, and the appointment of 'older people's champi-
ons' to ensure access to services based on needs rather than age. Within
this context, there are now a growing number of initiatives and different
ways in which older people are being involved not only as service users
but also as citizens in debating many issues that affect their daily lives
(Carter and Beresford, 2000; Thornton, 2000).
Mirroring these trends, there has been a shift towards increased in-
volve ment of older people in the research process. In part, this reflects
recent government policies that require consultation with service users
in the evaluation of services and, for example, older people's involve-
ment in the setting and monitoring of standards within the framework of
local 'Better Care, Higher Standards' charters (National
At the same time there has been a growth of social research methodologies that have sought to make greater use of an expanding range of qualitative methods which seek to engage research respondents in a more participatory process. In particular, the interest in research into individual lives has spawned a range of methods, including life stories, personal narratives, interpretive biography (Hatch and Wiesnewsky, 1995), many of which have foregrounded people's own definitions and experiences of their needs and preferred ways of dealing with these. For example, the use of such approaches has underlined the heterogeneity and diversity of older people's experiences and the ways in which ageing impacts differentially on different groups, in terms of class and gender (Arber and Ginn, 1995) and race (Blackmore and Boneham, 1994).

The use of narrative approaches that encourage both conversation and 'story telling' as part of the research process are key to understanding the nature of older people's lives and the place of formal services with their day to day experiences (Clifford, 1994). Whilst not
unique to social work research, such methods can be seen as distinctive or character
istic of research that is committed to listening to and making explicit the
voice or lived experience of those involved in the research process.

Whilst these trends in both practice and research are encouraging, a
number of critics have argued that progress has been slow, in part due to
the continuing influence of medicalised and paternalistic approaches to
practice (Thompson and Thompson, 2001), and the increasing domi
nance of managerial concerns within the research agenda (Barnes and
Walker, 1996). Moreover, traditional ways of framing older people's
needs primarily in terms of increasing dependency reinforce, rather than
challenge, ageist assumptions underlying both professional practice and
research with older people. Drawing on three UK research studies under
taken primarily in the health context during the past decade, this paper ex
amines the trends and challenges involved in the development of an
inter-disciplinary research agenda designed to promote the voices of
older people in issues of service quality in health and social care settings.
Each of the studies involved the use of qualitative methods to elicit older people's views and experiences, and in two examples a 'mixed method' approach was adopted. Each example also includes some observations on the composition and dynamics of the interdisciplinary research team.

**CHALLENGING AGEIST ASSUMPTIONS**

The first example is a study undertaken in the early 1990s that involved an interdisciplinary research team with backgrounds in medicine, nursing and social work. This was a joint initiative set up between the University of Southampton's departments of geriatric medicine and social work studies to promote greater involvement of older people in issues of service quality within the elderly care unit based in a large general hospital. It involved a small scale qualitative study designed to elicit older people's views of care in an acute hospital setting. It sought to give prominence to older people's perceptions of service quality and, more specifically, to have their voices heard within the audit cycle (Powell et al., 1994a).

From the outset, there was agreement from all team members that there was a need to understand older people's definitions of service...
quality and that this could only be achieved through listening to their views and experiences of their care. After considerable discussion, the notion of a conventional survey of patients' views was discarded. It was agreed that older people's views would be better explored using a qualitative approach to interviewing respondents that would enable them to share their views in a more interactive and conversational style. It was strongly argued that such an approach was particularly relevant when seeking the views of older people where many were identifiably frail and/or had some degree of sensory impairment (Powell et al., 1994b).

From the outset, the study was seen as contributing to a continuous audit cycle and the setting of standards within that process. In this respect, it formed one part of an overall quality strategy for elderly care services within the hospital and, in particular, addressed what was at that time an emerging consumerist agenda within health services more generally (Department of Health, 1991). As a way of engaging with these primarily managerial interests in issues of service quality, a focus group with nurse managers and medical staff associated with the elderly care
unit was set
up to elicit their concerns about the provision of
inpatient care and dis
charge planning. The various issues identified from this
setting were then
used as the basis for a topic focused interview schedule
(rather than struc
tured questionnaire). This 'tool' also provided a way of
engaging with the
managerial and professional agendas whilst retaining a
degree of flexibili
ity in exploring older people's concerns, perceptions and
experiences.
Each research interview became a site for the exploration
of both manag
ers and professionals' concerns alongside those of the older
people being
interviewed. The interview schedule provided sufficient
structure to ad
dress issues important to those providing care whilst
providing the oppor
tunity for older people to 'tell their stories' and share
their concerns in
ways that were meaningful to them. Although conceived as
valuable
findings in themselves, the results from this study were
used to imple
ment a number of changes in practice within the elderly
care unit. They
were also used to identify dimensions for standard setting
that ultimately
formed part of the audit cycle of standard setting,
monitoring and review.
Whilst this study took place a decade ago, it still highlights a number
of issues pertinent to undertaking interdisciplinary
research involving
older people. The success of this study in terms of
listening to older peo
ple's views on issues of service quality and incorporating
these views
into a standard setting cycle rested on the team's shared
commitment to
challenging ageist assumptions regarding the involve
ment
of older peo
ple in the research process (Thornton and Tozer, 1995). The
choice of
research methods that engaged with the interests of all
those involved,
including those sponsoring the study was also important. Much de
pended on the team's agreement to adopt a qualitative
approach (com
bining two methods of qualitative data collection) rather
than a more
traditional survey of older people's views using a
standardised ques
tionnaire. The expertise of the research interviewer in
relating to older
people, and the negotiating skills of some members of the
research team
in managing group dynamics and differences of view also
played an
important part in facilitating both the process and outcome
of the study. GOAL NEGOTIATION IN DAY CARE SETTINGSMIXED
METHODS

The second example of interdisciplinary research presented
here is a more complex study in terms of topic and methodology (Rohelis et al., 1998). The overall study was set up to examine the effectiveness of three models of day care for older people. Within this overall frame work, the study had three more specific aims: to identify the characteristics of the elderly population receiving different types of day care and develop criteria for attendance, to determine whether achievement of a negotiated goal was the most appropriate outcome measure for elderly people attending day care centres or hospitals, and to determine which of the three models of day care studied was the most cost effective. The research team comprised colleagues from health, social care and management backgrounds, all of whom had worked together on previous projects, although not in this particular combination. What constitutes the effectiveness of a service is notoriously difficult to define and in this study an acknowledgement of a diversity of perspectives on what might constitute 'success' was taken as a matter of investigation. In the context of an increasing preoccupation with accounting for costs, the need for measurable outcomes and attention to a diversity
group of inter
ests (managers, frontline practitioners and service users), this interdisci
plinary study sought to explore these various dimensions within the
overall study. The 'mixed methods' approach reflected this complexity
as it involved the collection of data from a variety of sources. A sample
of newly referred older people was identified in each of the three day
care settings and a range of quantifiable data relating to their medical
and social problems was extracted from their case records. Each of the
fifty patients from the three settings was interviewed using a number of
standard assessment instruments designed to collect data on functional
status. Additional qualitative data on the process and outcome of goal
negotiation were gathered via in-depth interviews with forty-five day
care attenders (fifteen from each setting), plus focus groups with mem
 bers of each of the three day care teams. Costs data were also collected
for each setting. Together these diverse sources of data addressed dif
 ferent dimensions of effectiveness across the three settings.

The qualitative study led by the social work researcher was designed
to address an aspect of professional practice, namely the
process of goal
negotiation with older people in the context of three day
care settings
(Powell et al., 2000). It stood alone as an investigation
into the differing
perspectives held by professionals and older people on the
processes in
olved in both goal setting and achievement. As part of the
wider study,
it contributed to the exploration of 'negotiated goal
achievement' as an
appropriate outcome measure for older people attending day
care provi
sion. It also formed a part of the cost-effectiveness
study, which involv
ing the setting of professionals and older people views
alongside
various costs associated with service provision (Powell and
Roberts,
2002).

The findings from the qualitative study revealed some
differences of
perception between those providing day care and the older
people receiv
ing this service. These were most marked in the more
traditionally organ
ised day hospital where a problem-oriented model of
intervention was in
use. Whereas older people’s needs were framed in terms of
dependency
and functional deterioration by staff, older people
themselves emphasised
their need for social interaction and support. In contrast to those staff members located in the day hospital setting, the staff team providing a more innovative form of outreach day care were explicit in their desire to develop a more person-focused approach through active engagement with older people in the process of goal negotiation. The 'fit' between these staff members and older people using the service was somewhat closer. Setting these various accounts of practice alongside each other illustrate the ways in which combining qualitative research methods can provide diverse insights into the relationships between individual service users and professionals. These findings also suggested ways in which older people could be more actively involved in identifying and negotiating goals across the three settings, thereby making a modest contribution to promoting more participatory and empowering ways of working with older people in a relatively neglected area of service provision.

Meetings of the research team throughout the time of the project provided opportunities for discussion of the overall research design and the different aspects of its implementation. The flow of information be
between the several dimensions of the study became particularly useful in the interpretation of the various data and in developing an understanding of both process and outcome issues. Each team member, despite their particular focus and differing commitments, was able to acknowledge the value of bringing together different sorts and sources of data to better explore the topic of common interest. In part, this was possible because each team member had a defined area of responsibility within the project that was given equal acknowledgement and respect. More over, the agreed research design was regarded as a mixture of qualitative and quantitative methods, which would combine to yield insights that would contribute to the improvement of day care services for older people. For the social work researcher this improvement in service provision was framed as promoting opportunities for older people to define effectiveness in terms of their goals for day care, alongside those of service providers and managers. IMPLEMENTING AN INTEGRATED CARE PATHWAY A POLICY DRIVEN AGENDA The final example chosen has much in common with the previous study in terms of a complex research design. It was undertaken at end of
the decade between 1999 and 2001. The overall aim of the study was to examine the effectiveness of implementing a care pathway for the treatment of femoral neck fractures in older people (Roberts et al., 2004).

More specifically, the study was an investigation into whether a care pathway in this context can reduce length of hospital stay while maintaining the quality of clinical care. The development of integrated care pathways (RCps) within multi-disciplinary clinical practice forms part of the UK modernisation agenda where the promotion of service quality is closely associated with the efficient use of limited resources across health and social care services (Department of Health, 2001). Given this changing policy and organisational context, a research design which addressed both aspects of this service initiative, namely costs and quality, was central to the funding of the project. The research team comprised a range of professional disciplines (medicine, nursing, social work), a health policy analyst and, given the complexity of the quantitative data to be collected and analysed, a medical statistician.

While adopting a mixed method approach, this study was the most tra
ditional in terms of the design of the three examples considered here. The qualitative dimension of the overall study was located within a prospective controlled before and after study which involved large samples of older people admitted to an acute hospital setting in the twelve months prior to and twelve months following the implementation of an integrated care pathway. Data on case mix (demographic details and pre-fracture function), process (operative details and reasons for any delay) and outcomes were abstracted from clinical records and the hospital patient administrative systems. Additional data were obtained from other professional records, e.g., occupational therapy and physiotherapy files. The primary outcome was length of stay on the orthopaedic ward within the acute hospital setting.

The qualitative study mirrored the overall research design in its 'before and after' dimension and drew on the two large scale samples for its two samples each comprising fifty older people. A semi-structured interview specifically designed to explore key dimensions of their hospital experience was carried out with each older person post-discharge. The primary
purpose of these interviews with older people was to elicit their own ac
counts of their experiences of their hospital care whilst ensuring that atten
tion was given to obtaining any specific views on delays during their stay
on the hospital orthopaedic unit. Focus groups with members of the
multi-disciplinary team were carried out both prior to and after the imple
mentation of the ICP. The qualitative data generated from these two meth
ods provided valuable insights into the process of implementation and the
perceptions of both professionals and service users on key aspects of inpa
tient care. Given the policy driven nature of this study, it could be argued
that the qualitative dimension provided a 'bottom up' or frontline perspec
tive on this process of organisational change.

The findings from the quantitative data indicated a significant in
crease in mean length of hospital stay associated with the introduction
of the ICP for the management of femoral fracture in older people. In
addition, improved clinical outcomes—a significant improvement in am
bulation on discharge and a trend towards reduction in admission to
long term care—were also recorded. The overall conclusion from these
findings was that care pathways for this group of older people can be a useful tool for raising standards but may require additional resources given the increased costs associated with both implementation and length of hospital stay.

The qualitative study and, in particular older people's accounts of their hospital stay provided a somewhat different picture. This added another dimension to understanding changes in the organisation and delivery of inpatient care to older people who have sustained a femoral neck fracture. The interview data from the two samples of older people offered no evidence of differences of views across the two groups. While there were differences in older people's accounts of their experiences within each sample, comparison across the two samples highlighted continuities of concern. Unsurprisingly, the need for information sharing particularly regarding pre-operative delays, changes in treatment procedures and discharge planning was a common theme across both sample groups. At the same time, the data revealed a diversity of personal accounts, not least in older people's information needs and how they wished to have these recognised and responded to.
The data also underlined a recurring theme from service users' accounts, namely the importance of sympathetic supportive care that addresses both emotional well-being and physical health needs.

Together these different types of data addressed different aspects of the process and outcome of implementing a care pathway. While they can be seen as complementary and mutually informative, the combining of these different types of data presented a number of challenges to the research team. As suggested earlier these two dimensions of the study can be regarded as top down (policy-driven) and bottom up (perspectives of frontline providers and recipients of care), and therefore relatively unproblematic in their integration. However, when these contrasting accounts were set alongside each other and presented to members of the interdisciplinary team, they generated considerable discussion and debate.

Tensions emerged within the team which reflected differences of view and underlying assumptions about the nature and purpose of the research study and, in particular, what constituted legitimate knowledge in this context. What emerged were divergent frames of reference for the valu
ing of different forms of knowledge. These ranged from an explicit hierarchy of knowledge privileging ‘hard’ data to a view that understandings derived from qualitative data should be given equal prominence along side quantitative data in the study. What lay at the heart of these debates was how data generated from individual accounts could be set alongside representative data other than as illustrative or anecdotal material. These issues remained largely unresolved in the context of this study, although managed constructively on the basis of respect for different research traditions within the disciplines and professionals represented within the team. Common areas of interest and agreement were emphasised along side these acknowledged differences. AN INTERACTIVE INTERDISCIPLINARY RESEARCH APPROACH

There are a number of common features to be drawn from a consideration of these three interdisciplinary studies, albeit briefly described. In a modest way, the commitment to involving older people in each of the studies represented a challenge to ageist assumptions underlying the exclusion of older people’s participation in research. However, within this broad commitment, there were differences of perception
about the nature of older people's involvement and the extent to which their voices should be heard and accorded status. Older people were not involved in negotiating the specific topics, all of which reflected professional and organisational interests. Older peoples' views were managed within the research process and whilst it might be argued that the social work researcher acted as their champion, she was, nevertheless, mediating their individual accounts.

The extent to which each of these studies promoted the involvement of older people's voices in the research process rested on the use of qualitative methods. In each study, semi-structured interviews facilitated a degree of interaction between researcher and respondents and provided opportunities for older people to recount their experiences in a flexible and meaningful way. Using a mixed method approach involving both qualitative and quantitative methods in two of the studies offered the potential for a more complex analysis and understanding of specific aspects of professional practice and organisational arrangements based on a diversity of perceptions held by the various interested
Such an approach provided both opportunities and challenges in this interdisciplinary context. Whilst there were opportunities for developing a more multi-dimensional analysis of data and potential for a more complex understanding of the chosen topic, the possibilities for conflict over the valuing of different forms of knowledge appeared inherent in the process. A sensitive balancing of interests and underlying power relations within the research team was a necessity and undoubtedly required a shared commitment to interdisciplinary working.

The common features that have been identified across these three research studies have also been described as characteristic of an interactive research approach. For example, Anne (2000) has argued that interactivity in an interdisciplinary context requires both collaboration between disciplines and partnerships with service users and citizens. A similar point has been made by Higham (2001) in her examination of social work's contribution to interdisciplinary research. She outlines the development of interactive social work research approach as one which includes: the influence of social work values (namely
empowerment and working in partnership) on topic choice and design and social work's mediating role with other disciplines. (Higham, 2001; p. 198)

The three studies identified here illustrate ways in which social work can contribute to developing a more interactive interdisciplinary research agenda. Each study sought to promote the involvement of older people in the research process. The social work member of the research team also actively promoted the use of qualitative methods as a more interactive approach to eliciting older people's accounts and argued strongly for the valuing of these perceptions as legitimate forms of knowledge. Thus, each study was shaped to varying degrees by social work's commitment to partnership and empowering forms of practice.

In the concluding part of this paper, the social work contribution to interdisciplinary research is examined further. THE CONTRIBUTION OF SOCIAL WORK

One distinctive (but not exclusive) contribution of social work in the interdisciplinary research context is a commitment to developing anti-oppressive strategies to combat ageism. The prevalence of ageism in the construction of assessment with older people is well documented (Hugman, 1994) and social work has made a substantial
contribution to
developing a theoretical framework for practice consistent with anti-ageist aims and principles (Hughes, 1995). The relevance of this work to both social work practice and research has been explored by Clifford (2000) in his exploration of a critical/autobiographical framework for exploring older people's needs. Thus, the challenging of ageist assumptions within the interdisciplinary context builds on practitioner experience and the experience of practice built on promoting partnerships with older people (Biehal, 1993; Thompson and Thompson, 2001).

Overall, each of the studies can be seen as exhibiting some success in promoting older people's voices in the research process. At the same time, there is scope for extending the boundaries of older people's involvement in interdisciplinary research and increasing their participation.

In each of the studies presented here, a conventional qualitative research method, namely semi-structured interviews, was used. The researchers who undertook these interviews were skilled in their ability to listen to and communicate with older people. Considerable efforts were made not to exclude people on the basis of poor communication skills.
or acknowledged memory loss. Nevertheless, research with older people does raise issues regarding those seen as 'hard to reach' groups such as people with dementia and older people from ethnic minority groups.

There is now a growing literature on innovative ways of working with older people previously excluded on the grounds of their mental frailty. For example, Mills (2003) makes use of counselling skills in enabling older people with dementia to share their experiences of health and social care services, and Cook (2003) has successfully used video work to increase older people’s involvement. Work carried out by Wilkinson et al. (2003) has also contributed to increasing participation of people with dementia from Asian communities, thereby enlarging our understanding of the lives and experiences of older people previous marginalised from mainstream research.

Seeking innovative ways on engaging with older people is clearly important given the now well documented evidence of ageist assumptions in both research and professional practice. As Bowes and Dar (2000) argue in their research with minority ethnic older
people, there is need to work in ways which do not replicate the exclusionary processes present in some areas of service provision. A review of initiatives which sought to involve older people in community care planning and evaluating services indicated the key role played by the voluntary sector in representing older people’s interests (Thornton and Tozer, 1996). Working in partnership with such organisations can be one way of promoting older people’s involvement in research. While the practicalities of pursuing such initiatives are demanding (Barnes and Bennett, 1998), there is undoubtedly scope for further progress in this area (Thornton, 2000).

Social workers intervene in complex social situations where there is a need to acknowledge and explore differences of view and experience. Mediating conflicting account and negotiating areas of shared agreement form a key component of the social worker’s role. Much practitioner orientated research has revealed the complexity of social work practice through the privileging of qualitative approaches where differences of view have been examined (Stanley, 1999). There is consider
able scope for the use of qualitative methods in the development of mixed methods research designs within the interdisciplinary context.

Social work has developed both an understanding of and the ability to work with diversity and differences of interest in both practice and research settings. Moreover, social work's interest in linking personal accounts to wider social structures forms the basis for developing a framework that incorporates these different dimensions of health and social care needs and provision (Williams and Papay, 1999).

Related to this multi-dimensional analysis of individual accounts within the wider dynamics of social and economic change is an understanding of the multi-faceted nature of knowledge, albeit located in an historical context. The recognition of methodological diversity has conceptual and theoretical implications. The use of a wider repertoire of methods which explicitly explore differences of perspective and experience generates different ways of knowing. The valuing of different forms of knowledge is an important component of interdisciplinary work, and interactivity within the research team is key to developing alternative
frames of reference as the basis for developing new conceptualisations of older people as service recipients. In a context where evidence-based practice continues to dominate the agenda and the need for measurable outcomes is evermore pressing, there is a role for the social work researcher to challenge more traditional notions of evidence in health and social care research and seek alternative conceptions of what constitutes legitimate evidence for policy and practice.

As with interdisciplinary work in practice, there is an assumption that interdisciplinary research is to be promoted. The bringing together of differing perspectives and skills has the potential for creating a more critically thoughtful perspective to the process. However, as these studies have revealed, this is not easily achieved. Creating a forum where all members of the research team can engage in discussion and debate, mediate differences of view and negotiate areas of shared agreement requires both skills and commitment from all parties. Managing the power relations inherent in any group involves both awareness of others and self-awareness, While much has been written about the role of re
Flexibility in the research process has focused on the relationship and power imbalance between researcher and respondent. Such analyses are pertinent to the interactions of the research team.

The implications for the social work researcher working in an interdisciplinary setting are complex. (S)he may bring knowledge, values and skills legitimately claimed as characterising social work to the development of an interactive model of working. Skills in negotiation and facilitation are important in working with professional colleagues within the research team as much as with those more conventionally seen as part of the research process.

In this context, service providers and older people using their services. Locating oneself in the complexity of power relations within the team requires constant attention to one's own engagement in the research process, not least one's personal and professional values in an interdisciplinary setting. A sense of professional identity based on distinctive characteristics (as outlined above) is important, alongside the valuing of alternative contributions and a shared recognition of overlapping interests and expertise.

The focus of this paper has been on the contribution of social work to interdisciplinary research and in particular, ways in which
older people's voices can be heard in the research process. While the research studies drawn on here are UK examples, they do have wider relevance. Recent changes in the British policy framework and the associated restructuring of health and welfare provision have parallels elsewhere across most in industrialised Western countries. While attention needs to be given to differences in national context, it is evident that these more global changes are reconfiguring relationships between service providers and recipients in the 'Westernised world.' There are opportunities here for rethinking research relations and forging partnerships that promote the diverse voices of older people. In advancing this agenda in an interdisciplinary approach, Arber, S. and Ginn, J. (1995) Connecting Gender and Ageing: A Sociological Approach, Buckingham, Open University Press.


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SECTION 4: PRACTICE: Do Culturally Sensitive Services for Chinese In-Patients Make a Difference?


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Does Difference Matter? Diversity and Human Rights in a Hospital Workplace

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Summary. The urban hospital workplace is a dynamic environment that mirrors the cultural and social diversity of the modern city. This paper explores the literature relating to diversity in the workplace and then describes an urban Canadian teaching hospital's comprehensive approach to the promotion of an equitable and inclusive diverse environment. With this goal, four years ago the hospital established an office of Diversity and Human Rights staffed by a social worker. The office pro

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The hospital workplace tends to be a microcosm of its environmental context. Prejudice and discrimination in the broader community will, without intervention, replicate themselves in organizational culture and
staff interactions. Racial, ethnic, religious, gender, sexual orientation, age, status and ability-based discrimination can be seen in complaints filed with human rights agencies. In Toronto, one of the most multicultural cities in the world, the cultural mosaic is dense (Statistics Canada, 2001). Forty-four percent of the city's population is born outside of Canada and most new immigration comes from Asia. This paper will explore some of the literature relating to diversity initiatives in the workplace and will describe a comprehensive approach to a diversity program in Toronto's Mount Sinai Hospital. LITERATURE REVIEW

Characteristics of Diversity

Diversity can be succinctly defined as noticeable heterogeneity (WordNet 2.0). In a social context, the term diversity refers to the presence in a population of a variety of attributes such as age, gender, ethnicity, race, religion, language, culture, sexual orientation, physical, psychological and mental ability, socio-economic background and other exceptionalities. In the workplace, diverse identity groups might also include differences in status, role, educational and technical background, skill level and tenure.
According to Holvino (2004), the concept of diversity is based upon
those effects that come to members of stigmatized groups, and are related
to group-level differences that provide advantage to some and disadva
tage to others.

Organizational Diversity Research

Looking at diversity through a social work lens, one might first see
the social values perspective (Gibelman, 2003; Gourdine, 2004; Mor
Barak, Findler & Wind, 2003; Srivastava, 200 I). However, most of the
literature on the topic comes from a variety of business-related disci
plines such as management, business psychology, industrial relations
and economics, all of which may have different parameters for measur
ing the outcomes of diversity. From most perspectives, however, there
is evidence that optimizing diversity in the workplace is not without its
challenges (Debebe, 2004; Dreachslin, Jimpson & Sprainer, 2001;
Dreachslin, Weech-Moldonado & Dansky, 2004; Gummer, 2000;
Holvino, 2004; Kochan et al., 2003; Martins, Milliken, Wiesenfeld &
Salgado, 2003; Mor Barak, 2000a, 2000b; Osborne, 2000;
Pelled, Eisenhardt & Xin, 1999; Ragins, Cornwell, & Miller, 2003; Sheriidan,
This conclusion is no surprise to social workers, who routinely work with the complexities of diverse groups and communities. Sheridan (2004) notes that employees of different identities often avoid confrontation for fear of being accused of racism, sexism or homophobia. Holvino (2004) states that diversity in teams may simultaneously produce more conflict and employee turnover as well as more creativity and innovation. Similarly, Milliken and Martins (1996) report: One of the most striking and important findings of research on diversity is that groups that are diverse have lower levels of member satisfaction and higher rates of turnover than more homogeneous groups. This is true across a wide range of types of diversity including age, gender, racial/ethnic background, and tenure. (p. 420)

Management literature has not only documented conflicting outcomes of diversity, but also conflicting outcomes of initiatives to address inequity. Data from the British Workplace Employee Relations survey of 1,620 settings, analyzed by Perotin and Robinson (2000), indicate that the most active equal opportunity or diversity management programs can have an initial adverse effect on production, especially if the proportion of workers from diverse groups is small.
Overall, however, they found that measures designed to correct discriminatory practices have a positive effect on productivity, and that this effect increases with the larger the proportion of women and workers from other marginalized groups in the organization. Interesting to social work, they also found that the joint existence of employee participation schemes and equal opportunity programs was generally associated with a productivity advantage over and above the separate effects of the two types of policy. The positive complementarity between organizational practices that support both diversity and participation related to their joint impact on discriminated groups.

Other research also indicates that organizational culture and group norms can moderate the negative experience of racially diverse workers. Thomas and Ely (2001) studied three work settings with different approaches to diversity management and developed theory about the conditions under which racial and cultural diversity enhances or detracts from work group functioning. Their theoretical models are access and legitimacy, discrimination and fairness, and integration.
and learn

integration-and-learning perspective, cul

tural diversity is a potentially valuable resource, not only to gain entry

into previously inaccessible markets, but also to encourage group mem

bers to value differences as opportunities for learning. Hobman, Bordia

and Gallois (2003) corroborate this finding. They found that demo

graphically dissimilar members were found to be more involved in

groups that enjoyed working with professionally and visibly diverse

members, and they also underscore the importance of creating a climate

that welcomes diversity: "Groups with high openness to diversity facili

tate communication that is more open, fair and explorative, and involve

dissimilar individuals in team process, thereby effectively using the

diversity available in the team" (p. 320).

One of the most important studies to test the "business case" for di

versity was conducted for the BOLD Initiative (Business Opportunities

for Leadership Diversity). In a five-year field research project, a consor

tium of top American academics in the field of diversity, the Diversity

Research Network, studied the relationships between race
and gender
diversity and business performance in four large U.S. finns (Kochan et al., 2003). They measured a range of outcomes, including
team performance appraisals, group bonuses, group processes, business
growth and
employee satisfaction, and found "virtually no evidence to
support the
simple assertion that diversity is inevitably either good
or bad for business" (p. 17). However, they do assert that diversity is a
reality in labour
and customer markets, and that in order to be successful, organizations
need to develop co-operative supportive cultures that make
a long-term
commitment to diversity. Such organizations will view
diversity as an
opportunity for mutual learning about the best ways to
accomplish work
goals.
There appears to be a growing consensus that the main focus of debate
on diversity, equal opportunities and productivity should shift from indi
vidual employee characteristics to features of the work environment
(Perotin & Robinson, 2000). Martins et al. (2003) note that diversity may
be greatest at lower levels of the organization but almost non-existent in top
management positions. The under-representation of people of
management positions is undisputed (Agocs, 2002; Dreachslin, Jimpson & Sprainer, 2001; Dreachslin, Weech-Maldonado, Dansky, 2004; Oliver, 2004). Rutledge (2001) states that the key ingredient to the implementation of a diversity plan and culturally competent policies is the "absolute commitment and support of the organization's governing bodies and executive management" (p. 313). Moreover, Mor Barak (2000a) states that since workers are affected by their interpretation of organizational culture, "it is important for management to push beyond affirmative action programs and to create a work environment that is inclusive and that values the diversity of its workforce" (p. 64).

Healthcare Sector and Diversity

Anderson, Scrimshaw, Fullilove et al. (2003) note that "the ultimate goal of interventions to increase the delivery of culturally competent healthcare is to make the healthcare system more responsive to the needs of all clients ... and close the gaps in health status across diverse populations" (p. 72). However, without effective diversity management strategies, racial and ethnic differences can compromise team functioning and communications.
tion, leading to dysfunction in the delivery of care (Dreachslin, Hunt & Sprainer, 2000). Health workers of colour not only repmi overtly racist comments from patients, families and colleagues, they may also be subject to covert or systemic racism (Das Gupta, 2003). In a study that looked at di versity management practices in 203 Pennsylvania hospitals, researchers found little indication of positive activity. Results were consistent with ear lier research that indicated that U.S. hospitals responded to American equal opportuni ty legislation with compliance, but did not tend to be proactive in diversity management (Weech-Maldonado, Dreachslin, Dansky, DeSousa & Gatto, 2002). Commenting on this study, Ciccocioppo (2002) states: "In ternal champions who understand the critical need for change lead success ful organizational change efforts, The fact that there is little activity in this area indicates that executives personally do not understand the value of di versity" (p. 125). From a pragmatic perspective, one can argue that these results are surprising. Demographics demand an effective diversity and hu man rights perspective in the healthcare sector (Barney, 2002; Mor Barak, 2000a), and given the serious shortages of skilled staff in
healthcare

(American College of Healthcare Executives, 2002), the issue of work force diversity is inescapable (Weech-Maldonado et al., 2002; White, 2002).

Moreover, a diverse workforce can provide a more comprehensive range of abilities, more broadly-based decision-making and the capacity to provide better service to diverse populations (Shea-Lewis, 2002).

Diversity Management Programs in Organizations

Diversity training is one route to addressing gaps in the practice and management of diversity in the workplace. Dreachslin, Hunt and Sprainer (2000) found that team communication improves when leadership is skilled in diversity management. Rather than focusing on individual traits (the trait mode), Konrad (2003) argues that the emphasis should be on identity groups, because group-level interventions create awareness of differential treatment as well as opportunities for collective action within organizations.

Similarly, with regard to diversity programs, Jackson, Joshi and Erhardt (2003) point out that many organizations target individual attitudes and behavior but give little weight to "the powerful social dynamics that arise within natural work unit" (p. 822). Kochan and his colleagues (2003) agree: Training programs that improve the
skills of managers and team members may be particularly useful, but training alone is not likely to be sufficient. Organizations must also implement management and human resource policies and practices that inculcate cultures of mutual learning and cooperation. (p. 19)

Practice Implications for Social Work

The profession of social work, with its emphasis on generic interpersonal, group, community and social action skills, positions social workers to move into novel roles in healthcare organizations (Nelson, 2004; Sulman, Savage & Way, 2001). Consistent with social work's value base, one of these areas is workplace diversity (Mor Barak, 2000a, 2000b).

Moreover, social workers' systems intervention skills can deal with organizational structures and policies that foster inequity (Mor Barak, 2000a).

Mor Barak (2000a) also emphasizes the concepts of inclusion and exclusion, and social work's expertise in advancing the person-environment fit. He states that exclusion from organizational information networks and from important decision-making processes is one of the most significant problems facing today's diverse workforces. The organizational actions that he recommends include a strong mentoring process for diverse employees, and workshops to teach inclusive behaviours. Both Mor
Barak (2000a) and Somcrs and Birnbaum (2001) recommend focus groups for new employees and members of diverse groups to hear needs and complaints and to understand the complex behaviours related to diversity management. These are all roles that social workers can develop.

The Diversity Research Network advises that "while there is no reason to believe diversity will naturally translate into better or worse results, diversity is both a labor-market imperative and societal expectation and value" (Kochan et al., 2003, p. 18). The Network also suggests that organizations need training in group process skills to help managers facilitate constructive conflict and effective communication. In these statements, concepts from a business management perspective resonate clearly with social work knowledge and values and act as a platform for intervention.

The following portion of the paper describes a diversity and human rights management program with a social work perspective in an urban North American hospital.

A HOSPITAL'S DIVERSITY AND HUMAN RIGHTS PROGRAM

The Ontario Human Rights Code (2000) is a provincial law that gives protected groups identified under the Code equal rights and opportunities
without discrimination in specific areas such as employment, housing

and services. However, as noted in the Pennsylvania hospital study

(Weech-Maldonado et al., 2002), compliance with legislation alone does

not necessarily further the progress of diversity. Therefore, when a

healthcare organization wants to provide an environment that is respect

ful and free of discrimination and harassment, what steps can it take?

Mount Sinai Hospital, a 472 bed acute-care teaching hospital located in
downtown Toronto, created the Diversity and Human Rights (D&HR)

Office staffed by a social worker in September, 2000. That same year, it

also created a broadly-based diversity and human rights committee which

now has representation from unions, key departments, members of reli-
gious and ethnic minorities and people with disabilities. The Diversity

and Human Rights program at the hospital would be inadequate if it were

simply a training initiative; therefore, the D&HR office manages four pri-
mary areas: complaints management, education and training, policy re-
view and development, and equitable access to services.

Complaints Management
A key function of the D&HR office is direct mediation of diversity and human rights issues. The office has addressed approximately 60-100 human rights and harassment complaints per year since it was established. An indicator of the success of the approach is that most complaints (~90%) are resolved through informal processes such as mediation and facilitated discussion. Another indicator of success is that the office is viewed as a resource for all levels of the organization, and it provides advice and support to managers on conflict resolution and human rights issues. On the one hand, as education raises the consciousness of staff, it is expected that complaints will diminish. Conversely, education gives permission to staff to voice concerns to the D&HR office that might otherwise have remained hidden. It is therefore likely that the numbers of complaints will remain at the current level for some time.

Education and Training

Experiential, full day diversity and human rights workshops are a requirement for all employees, and given the number of staff and the turnover in a large healthcare setting, the process is an
ongoing one. Since
the program began, all hospital managers, supervisors and
union represenatives have received training. As physicians have key
roles interacting with patients and hospital employees, they are also
participating in training. Specialized training geared to the needs and
interests of physicians has been developed in a separate training program
that is co-facilitated by a physician who specializes in cultural competency.
Education is delivered in other formats as well. A critical component
of complaints follow-up is organizational development and training. To
address this need, the D&HR office designed specific retreats and work
shops on topics such as fostering a positive work environment, informal
mediation and conflict resolution, defusing hostility, meeting facilitation,
and dealing with conflict in the workplace. Another mandatory feature of
the program is six hours of bias-free hiring workshops for all personnel
involved in hiring processes. Moreover, since orientation of new staff is
an important opportunity for education about workplace policies on dis
 crimination and harassment, the D&HR office participates in those ses
Sions.
The office also organizes celebrations and educational events that provide an opportunity to raise awareness on human rights issues including: Aboriginal Day, Black History Month, Lunar New Year, Ac cess to Healthcare for People with Disabilities, Homelessness and Healthcare, December 6th Events (raising awareness about violence against women), and the International Day for the Elimination of Rac ism. The office also holds meetings of the hospital's gay, lesbian, bisexual and transgender caucus. Communication is another vital function.

To raise the profile of human rights and diversity issues in the organization, the D&HR office maintains an email list of employees with a strong interest in human rights issues and sends out regular updates on case law, forums and workshops. This effort gets a boost from the colourful D&HR website which highlights current articles, case law and upcoming events that support the values and activities that confirm diversity in the hospital.

Policy Review and Development

The Diversity and Human Rights committee, which is chaired by the
D&HR Advisor, developed an assessment tool, created a comprehensive D&HR policy and plan, and has undertaken a review and development of workplace policies. Using a consultant, the D&HR office arranged interviews and focus groups with key informants to determine diversity and human rights needs in the organization. The office reflects the interests of the broader diversity community through active participation in the Ontario Diversity Health Practitioners Network.

Equitable Access to Services

Effective communication is the foundation of effective health care delivery. The language interpretation subcommittee of the D&HR committee developed a proposal for a comprehensive language interpretation and translation program which has led to the expansion of interpretation services. In addition, the subcommittee is developing a proposal for patients and employees who have a hearing impairment, including fire alarm notification, text telephones (TTYs) and amplifiers.

Next Steps: A Focus Group Study of Diversity and Human Rights in the Work Environment

The D&HR committee, which functions as an oversight body for di
versity and human rights in the organization, identified a need for an ongoing quality assurance process to monitor the effectiveness of D&HR initiatives and to explore whether there were additional opportunities for improvement. The committee, with the support of the hospital, worked with a social work research consultant to design a qualitative focus group study to explore the perspectives of hospital staff. The study reflects the committee's special interest in the perceptions of members of identity groups identified under the Ontario Human Rights Code (2000) who might be more likely to experience diversity-related problems in the workplace (Agocs, 1997; Agocs & Burr, 1996; Agocs, BUIT & Somerset, 1992). It also looks to identify recurring themes, hot spots and best practices in order to avert crises and to aid in future planning. The following is a brief outline of the study, which is currently ongoing.

Study Development and Methodology

For the development of the discussion guide and detailed study plans, the D&HR committee struck a subcommittee consisting of 3 social workers, a clinical nurse specialist and the hospital's
Patient Relations

Facilitator. The subcommittee made a point of bringing each section of work back to the D&HR committee's monthly meetings for their approval. One of the important decisions taken was to move the study beyond the realm of quality assurance and to submit it for ethics review to the hospital's Research Ethics Board.

The research project is an exploratory, non-experimental qualitative study that is interviewing approximately 120 staff members in focus groups of 4-8 participants each. The purpose of the study is to determine staff members' perceptions of their workplace environments with respect to diversity and human rights issues. The number of focus groups has been determined by the number of major identity clusters in the hospital (generally outlined in the Ontario Human Rights Code and specifically identified in the setting by the D&HR committee), and has been augmented by several general open-membership groups to reflect a broad range of hospital staff. The roster of groups is as follows: people of colour (x2); gender (x2); ethnicity/religion (x2); persons with disability (x2); sexual orientation (x2); status/role, such as
Recruitment to identity groups and general groups is through advertisement within the hospital and is open to any full or part-time permanent staff member. The majority of staff members participate in self-selected identity focus groups, while the remainder participate in general staff groups.

Each group has two facilitators: one of the principal investigators and a member of the Diversity and Human Rights Committee who has been trained to co-facilitate the focus group. The committee co-facilitator is, whenever feasible, a member of the current identity group being assessed.

All group discussions use the same guide.

Current Progress of Focus Group Study

Approximately two thirds of the groups have been completed and they have been lively, with participants eager to share their stories. The narratives themselves are offering rich and unanticipated learning. After completion of the groups, the data will be analyzed and presented first to the Diversity and Human Rights Committee and the administration.
tion of the hospital. Although the different identity
groups report a vari
ey of issues that will require detailed analysis, one
universal theme has
emerged: the importance of the hospital's formal diversity
and human
rights initiatives. From participants' responses, it seems
clear that posi
tive change in the organization has followed the hospital's
decision to
create these programs: The organization is trying to put
processes in place to be more transparent ... and more
accommodating to all the differences we have around. I
think since the Diversity and Human Rights has begun in
this hospital, there was a lot of changes made with respect
to a lot of stuff that was happening previous to that, that
isn't happening right now. Not just complaints, it's also
the training. People are aware ... more careful in what
that say and what they do. Even with some of the guys, if
you hang out with them outside, they're very careful.
Because these are the guys who could say all kinds of
stuff, And if you accepted it, that means you think that
it's ok, Now I may accept it but if I have someone next to
me, hanging with them, they may not accept it So they are
very fully aware what to say amongst anyone, regardless of
who they are. So yes it is visible, you can see the changes
since Human Rights and Diversity came along, It's not an
office that's tucked away somewhere, its there all the
time, I know I'm very aware of it. Everyday I see something
and I think, 'thank goodness we have the office of Diversity
and Human Rights.'

From the perspective of the D&HR committee, the findings
from this
study will provide insights about the nature of diversity
and human
rights issues in the hospital and the effectiveness of its
current policies and
practices. The results will also offer improved
opportunities throughout the
organization to ensure a positive, respectful work
environment. After an internal discussion within the organization, the investigators plan to distribute the findings more widely. CONCLUSION

The literature on diversity and human rights in the workplace validates social work’s daily struggles and triumphs with diverse populations. The complexity of the issues requires dedicated, long-term support from health care organizations in order to promote equity and to unlock the benefits of diversity in the workplace. The benefits accrue not only to our co-workers, but also to the communities that we serve. In a heterogeneous community, effective and compassionate care can only be delivered through the development of a consistent and universal cultural competence that welcomes all constituencies. The mission of the office of Diversity and Human rights at the hospital will continue to be the promotion of respect, dignity and eq


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Best Practice Case Management for Improved Medical Adherence Betsy Vourlekis, PhD Kathleen Ell, DSW SUMMARY. Less than optimal treatment adherence for many health conditions impedes clinical progress, leading to increased morbidity, mortality and health care costs, particularly for low-income and racial and ethnic minority patients. When properly understood as a complex phenomenon involving patient, provider, and health system interacting factors, adherence improvement is a natural target for social work's
multi-system model of case management. We present five key elements for a generic "best practice" case management blueprint applicable to a range of medical settings. The theory and evidence base for the elements are discussed and illustrated with SAFe, a tested social work case management program to improve adherence following abnormal cancer screens. doi: 10.1300/1010v44n03_03 Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: docdelivery@haworthpress.com Website: http://www.HaworthPress.com © 2007 by The Haworth Press, Inc. All rights reserved.

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Optimal health improvement strategies for many diseases and health problems often require longer-term adherence to recommended regimens, including medication compliance, regular periodic screening, diet control, and follow-up on referrals. Yet the World Health Organization estimates that even in developed countries only 50% of patients adhere to treatment recommendations (WHO, 2003). Inadequate and non-existent health care resources are an important contributing factor, but many other barriers influence patient adherence thereby impacting on clinical progress and, ultimately, morbidity, mortality and health care costs. Low-income racial and ethnic minority persons are particularly at high risk for poorer health outcomes (Institute of Medicine, 2003). Treatment adherence is a complex phenomenon resulting from the interplay of a number of potential barriers operating in the patient, provider and wider health care system. Patient blaming is a common response of health care professionals that overlooks the intricate field of influences on patient behavior. Experts recognize that successful ap
proaches to improved adherence across a range of diseases must accu
rately assess barriers on a case by case basis and target multiple systems
with more than one intervention (WHO, 2003). Properly understood,
the problem of non or less than optimal adherence is a natural target for
social work's multi-system spanning model of case management with
its comprehensive focus. Linked to the important outcome of medical
adherence, social work case management for carefully targeted high
risk populations is an important value-added component to health care.
Increasingly, case management approaches are being developed
and tested to promote preventive, diagnostic and treatment follow-up
adherence for a range of medical conditions including asthma, cancer,
HIV/AIDS, coronary disease, diabetes, and depression (Evans et al.,
1999; Freeman et al., 1995; Gilbody et al., 2003; Hunkeler et al., 2000;
Karter et al., 2004; Lamee et al., 2003; Lipkus et al., 2000; Magnus
et al., 2001; Malta et al., 2003; Philis-Tsimikas and Walker, 2000;
Pugh et al., 2001; Riegel et al., 2002; Webber and Reilly, 1997.) How
ever, existing approaches to case management are highly variable and
may address some barriers such as patient education or system snafus, but not both and ignore others. Although professional standards (NASW, 1992) exist and CDC has promulgated guidelines for AIDS and breast and cervical screening programs (CDC, 1999), these are general statements of process rather than specified intervention models with evidence-based components. In addition to the imprecision and variability surrounding implementation of case management, cost concerns and limited reimbursement for case management also constrain administrators' views.

Consequently a viable social work case management model for today's health care environment will need to offer a comprehensive evidence-based and cost-sensitive approach. In this paper we present a suggested generic "best practice" case management approach to improve adherence for medical conditions, and illustrate its key components in a specific case management program. The approach is based on (1) a conceptual and theoretical framework for understanding barriers to optimal health care; (2) links between the framework and specific case.
management components and activities; and (3) evidence supporting the utility and effectiveness of the key case management components. THE PROBLEM OF ADHERENCE

Effective case management requires a comprehensive understanding of the problem of non-adherence. The World Health Organization's recent inclusive review of adherence research in nine chronic disease conditions sets forth a five-dimensional explanatory model and summarizes factors found to be significant for each dimension (WHO, 2003). Adherence is affected by the interaction among social and economic factors, particularly minority status and poverty, health system and health care provider-team factors, condition/illness-related factors, therapy or treatment-related factors, and patient-related factors such as level of knowledge, health beliefs and attitudes, and hopelessness (WHO, 2003). To this model we would add the overarching influence of cultural factors, operating at patient, health care provider, and larger health system levels to shape perceptions, attitudes, communications, and resource allocation in ways that impede optimal adherence outcomes.

Barriers to Adherence

Research documents this complex set of person-environment
factors
and interactions that contribute to medical non-adherence (e.g., Clark, 2003; Jacobson et al., 1990; Johnson et al., 2003; see WHO, 2003 for a comprehensive treatment of this research). Individual barriers include lack of knowledge, health beliefs and attitudes, limited problem-solving skills, depression and other mental disorders, including substance abuse.

Social and economic barriers can be absence of social support, pressing economic and family distractions, and a lack of practical resources such as transportation and childcare. There are multiple potential barriers in the health system and clinical care process, including inadequate or inaccessible resources, poor communication, lengthy waits, lost or incomplete records, and poorly organized and coordinated delivery systems.

Also contributing to non-adherence are health condition factors specific to the particular illness or health problem such as degree of disability, symptom severity, and the presence of co-existing disorders, as well as therapy or treatment related factors such as side-effects and complexity and duration of the regimen (WHO, 2003). Cultural influences potentially.
tially operate on any of the above factors. Many efforts to improve patient adherence address just one or two potential barriers or fail to identify individual differences in circumstances, with disappointing results.

Theory-Driven Intervention

The strength of social work case management is its ecologically valid multiple interacting systems (life-space) intervention field. However, the case manager needs a better-specified blueprint for specific intervention strategies within this complex field of influencing factors. We formulate a theoretically derived model of health actions and decisions that incorporates the multiple factors influencing adherence and links them to key case management strategies. The model combines elements from the Health Belief Model (Becker, 1974), Transtheoretical Model (Prochaska & DiClemente, 1994), and Socio-cultural Explanatory Theory (Ashing-Giwa, 1999). Health behavior and outcomes are viewed as the result of a decisional-interaction process (involving the patient with a specific illness/condition, the provider, the recommended treatment, therapy regimen, and the health care system) that includes predisposing
(knowledge, attitudes, coping skills, resources), reinforcing (social support, cues to action, adequate communication), and enabling (resource acquisition, reduction of practical obstacles, system responsiveness)
influences in the "health condition" life space.

Regardless of the illness or disease, case management to improve adherence consist of capability to provide bundles of activities/techniques designed to affect predisposing, reinforcing and enabling influences on a patient's behavior that are to be used differentially on a case by case basis, depending on individualized comprehensive assessment. For example, case management includes interventions aimed at enhancing a patient's self management skills—such as a self-prompt system-practice in forming and asking questions of the provider, exploration and education concerning perceptions and understanding of the health problem and the resources available to cope with the health threat, and clinical counseling to reduce psychological distress. All of these possible activities target predisposing influences. Another set of potential activities strengthens reinforcing influences; for example, facilitating communication of information between
health care workers and patient, providing reminders through supportive
reinforcing informational messages, or intervention with family and other
network members. A third set of activities addresses enabling influences
and includes patient referral for psycho-social resources, assistance in
problem-solving with competing priority difficulties, assistance with clinic
and and care process obstacles and complexities, and locating and establishing
linkages to needed resources for the entire clinic.
Recognition of the cultural influences operating is critical in all three areas.
For example, culturally derived perceptions of the meaning of illness and its
treatment are an important component of patient "understanding" which "education" alone
will not necessarily influence. Likewise, indifference or rudeness in a clinic
setting may interact with a patient's culturally derived suspiciousness or
skepticism about the provider system. Culturally mediated beliefs, prac
health care system may contribute to a variety of poor "fits" in the health
care decisional process. Figure I illustrates the relationships among case
management activities, adherence barriers and patient outcomes based on
concepts of the health decision model. A CASE MANAGEMENT BLUEPRINT
Research on adherence and the theoretically driven intervention model outlined above suggest there are five essential features of a case management intervention blueprint to improve medical adherence. An effective approach must (I) be integrated carefully into the clinical care process; (2) be culturally competent; (3) be individualized and interpersonal; (4) intervene in multiple systems; and (5) provide feedback to the care system for quality improvement. Each element is discussed below and illustrated from SAFe, a specific social work case management program designed to improve patient adherence to diagnostic follow-up following abnormal breast and cervical cancer screens.

FIGURE 1. Linking Theoretical and Case Management Components

#1: Health care outcomes are the result of an interactional decisional health care process involving the patient (in his/her unique circumstances) the health care providers and the health care system.

#2: Case Management implements interventions to influence patient behavior and to im
prove the fit (e.g., timing, cultural acceptability, communication, resource acquisition) between the patient and services provided.

#3: The decisions the patient makes are presumed to be influenced by predisposing factors (knowledge, attitudes, perceptions, psychological stress, competing life priorities), reinforcing factors (social support, effective communication, cues to action), and enabling factors (resource acquisition, reduction of practical obstacles, system responsiveness) that can be assessed as the presence or absence of an array of barriers.

Case management interventions influence all three factor domains.

#4: Based on Sociocultural Explanatory Theory, case management addresses cultural and social-contextual factors aimed at influencing the clinical care process. Case management is based on an understanding of the cultural beliefs, practices, and preferences of patients and their families so that a better "fit" can be attained between the knowledgeable and respected in the implementation of case management.

SAFe Case Management

SAFe (Screening Adherence Follow-up) was developed and tested over a five-year period in multiple sites with a target population of medically underserved, minority women at higher risk of non-adherence (Ell, Vourlekis, Muderspach et al., 2002; Ell, Padgett,
SAFe aims to improve women's adherence, empower women to increase health competence over the long run, provide culturally responsive services, enhance clinic access to community resources, and improve continuity and efficiency of care.

SAFe is interpersonal time-limited case management provided by a case manager (BSW or human-service trained/experienced) and clinical social worker (MSW) team. SAFe combined strategies of proven efficacy into a comprehensive approach, providing patient education and supportive emotional counseling (Lerman, Hanjani, Caputo et al., 1992), systems navigation (Freeman, Muth, & Kerner, 1995), "bridging" help between patients and providers, as well as customary case management activities of resource acquisition, monitoring care, and patient advocacy.

The case manager provides most of the service; the clinical social worker sees a small percentage of women with mental disorders and/or severe psychosocial circumstances and supervises the case manager. Women receive services at the appropriate level for a period of six months to one year or until recommended diagnostic follow-up is completed.
SAFe improved patient adherence significantly over site baseline
rates, non-enrollee rates, and control group rates, with rates of adherence improving from 6% to 25%. In the SAFe randomized control trial,
women receiving SAFe case management achieved equal or higher rates of both adherence and timely adherence across all severity classification categories for both mammography and PAP when compared to women in the control group. Adherence rates were similar across ethnic groups, and improvements achieved across urban and rural community based screening clinics, urban diagnostic and treatment medical centers, and geographic regions (Ell, Vourlekis, & Padgett, 2003).

FIVE KEY ELEMENTS FOR EFFECTIVE CASE MANAGEMENT

Integration of Services

Effective case management requires a designated case manager(s) that is carefully integrated into the health care setting and its routine clinical processes. Focused on both patient and health care system/provider barriers, case managers must have timely access to charts, schedules, and patients and be readily accessible to clinical staff. Since case
management activities are tied to reducing adherence barriers, they are
coordinated with the actual timing and procedures of clinical care pro
cesses to the greatest degree possible.

In SAFe, while all low-income women with abnormal screens were eligi
gible for case management, there were substantial difficulties locating
and reaching women after they had been informed of their results. Further
integration of case management (and the case manager) with the clinical
care processes so that case management initial assessment and interven
tion occurred along with notifying a woman of her results would have im
proved efficiency and decreased the problem of failure to locate women.

For cost-efficiency, case management needs to be a targeted service
(based on known risk populations) and/or provided only after assessment
reveals probable barriers or a trigger event, such as a missed appointment,
occurs. Whatever the approach, service criteria and screening processes
need to be transparent to all clinic staff and integrated with existing medi
cal appointment routines to the maximum.

Cultural Competence

Effective case management requires trained culturally
competent case managers (Brach and Fraser, 2000). Recruiting bi-lingual ancl/or bi-cultural case managers and clinicians for the population served may be a high priority. In addition, case managers need training to understand stand and respect the multiple influences of cultural beliefs, practices, where specific advocacy may be required for equal access to resources.

SAFe recruited personnel in keeping with site demographics. Overall the SAFe clientele to date has been 72% Hispanic, 10% African Ameri can, 6% White, 5% Chinese (accounting for most of the clientele at one site) and the remaining 7% "other." Only 25% of patients were American born. All of SAFe's materials were translated into Spanish and Chinese, and services were offered in these languages if a woman preferred. Initial case manager training included extensive discussion of cultural beliefs and practices with respect to cancer and health care, systematic identifi cation of the social contextual realities of different minority groups served by the clinics (e.g., illegal aliens in California; length of time in the country; family structures and expectations). Ethnically targeted re
sources were identified to the extent possible (i.e., cancer information in Spanish; Spanish-speaking hot line). On-going supervision and discussion of culturally mediated attitudes and behaviors was provided. For example, as evidence accumulated linking almost all cervical cancer to the sexually transmitted virus HPV, case managers had to augment their educational interventions to include both explanations and explorations of sexual practices and beliefs within a cultural framework.

Individualized Services

Case management should be individualized, interactive and patient-centered, addressing the specific health circumstances of the patient and only the barriers and needs actually identified. It is not a "one size fits all" intervention. Systematic comprehensive assessment of each patient (covering the range of known potential barriers to adherence) should guide a case management plan and activities in accord with general service protocols for different levels of service intensity.

Not all patients need the same type of help or the same amount of help.

Cost-conscious case management needs to make differential use of personnel depending on patient need and focus on immediate barriers to
adherence. Interaction may be face-to-face or on the telephone.

SAFe developed an initial scripted assessment and intervention that is provided to all women eligible for case management. Embedded in the script (which takes 20-30 minutes) are evidence-based questions about the range of potential barriers to adherence together with queries and educational responses specific to the woman's own circumstances.

For example, if the woman is scheduled for a needle biopsy, she is asked if she understands what this is and then provided with a simple explanation. Educational messages about abnormalities versus having cancer are reinforced several times. When women identify barriers such as transportation and childcare, case managers first ask women if they have or can now think of possible solutions. Mental health screening is done with a standard instrument, the Patient Health Questionnaire, a version of PRIME-MD (Spitzer et al., 1999). Using a woman's responses to all of the assessment questions, the case manager generates a risk profile and the woman is assigned to one of three levels of service using a clinical decision-making algorithm derived from the
evidence about risks contributing to non-adherence. Thus the care plan is directly generated from the initial contact.

To date SAFe has served 1,331 women across all study sites. Slightly less than half (45%) received minimal assistance from the case manager (initial assessment plus educational supportive counseling and a reminder call later), 36% Level II (Level I plus systems navigation and/or resource referrals) and 19% level III (Level I or II plus MSW short-term clinical intervention). Data from SAFe shows that women assigned to different service levels actually do receive progressively more contacts as needs intensify, and that adherence rates are equally good for women regardless of level of service (Vourlekis, Ell, & Padgett, 2005). Women’s circumstances sometimes change during the period of case management service, necessitating a reassignment of service level as additional service is indicated.

Multi-System Interventions

Case management protocols and service plans should be designed to address any potential contributing factor to the adherence problem, based on
systematic consideration of predisposing, reinforcing, and enabling influences on patient behavior. Considering first the patient-system, specific interventions aim to reduce patient predisposing factors. These interventions include patient-tailored information/education, emotional support to reduce psychological distress, empowerment strategies to increase patient competence in problem solving and health self-management, and exploration of perceptions about availability of adequate resources to cope with the demands of the health threat.

Routine interventions aimed at enhancing reinforcing factors should consider a range of systems such as mobilizing greater social support, patient reminders about appointments and requirements through supportive reinforcing informational messages, and facilitating communication ("bridging intervention") between a patient and health care provider to improve mutual understanding thereby reinforcing medical directives.

Enabling interventions should target barriers in the wider social system such as lack of transportation or child care, clinic scheduling that interferes with a patient's work, uncoordinated care, or
Empowerment strategies should involve the patient in problem solving to the extent possible to increase self-care competency.

SAFe's scripted initial assessment and intervention assures that all potential adherence-influencing factors are examined to begin with and provides specific educational information concerning a woman's specific health circumstances. Data from SAFe shows the most frequently identified barrier is that a woman does not understand the screening result and/or the recommended follow up (predisposing factor). Thus educational counseling and emotional support are provided to all women in this initial contact.

Separate scripts for the initial case management contact were written for mammography and gynecology patients. Use of scripted health education information is important for case managers who, while trained in the content of the health information, are not specialized health educators. It is critical that the health information be specific to the woman's
circumstances, stated simply, and absolutely accurate. The script, while

time consuming to develop initially, provided consistency and clarity in

the educational message.

To illustrate, a woman with an abnormal PAP smear would hear the

following sequence of information: "Do you know what a PAP test is

for?" After the woman answers (even if somewhat correctly) the case

manager says "(That's right) A PAP test or PAP smear is a simple, pain

less test used to find female cancers of the cervix or uterus. The cervix is

the lower narrow end of the uterus or womb (The womb is where the

baby develops). A few cells are removed from the cervix and studied

under the microscope to see if there are any abnormal changes in the

cells." Following some additional questions about whether the woman

has been asked to have a follow-up exam and in the event she has the

case manager says "There are different reasons that women may have

for not being able to keep scheduled appointments or to follow other

recommendations. I'm going to name some of these and I'd like you to

tell me if each one may be true for you." The woman is then asked about
her understanding of what she is to come back for. She is then asked

about her understanding of the different possible follow-up exams. Af

ter she answers, and, as above, even if partly correct, the case manager

provides the following information: "If results of your PAP smear

showed that you need another exam, then it is necessary to do a more

complete exam of your cervix. One possible exam is to repeat the PAP

smear. Another exam is a colposcopy, which is like a regular female

exam, except the doctor uses a magnifying device to look at your cervix.

A colposcopy can find problems, like abnormal changes in cells in your

cervix at a very early stage, before there is a chance for you to get cervi

cal cancer. If there is a problem, early treatment can completely prevent
cancer of the cervix."

Farther along in the interview the case manager probes about fear of

cancer as follows: "Some women say that they are afraid that if they

have the exam, they might find out they have a serious problem. Do you

have any worries like this?" If the woman indicates yes the case man

ger replies, "A PAP test result that requires you to have a further exam
usually does not mean you have cancer. In fact, very few of the fol
low-up exams show cancer. Most show abnormal cells in the cervix that
will later become cancer if they are not treated. But if you find and treat
the problem early, you can completely prevent cancer of the cervix. The
best way to find the problem early is to get this follow-up exam. Even if
the exam does show cancer, there is an excellent chance of a total cure,
if it's found early enough. If you do go for your follow-up exam, and
find out that there is not a serious problem, then you'll be able to stop
worrying. Even if there is a problem, in almost all cases, it can be easily
cured."

The case manager asks specifically about a woman's previous expe
riences with the clinic and its personnel. Perhaps a woman reports that
her health providers do not answer her questions satisfactorily. When
her expectations are negative and her sense of self-efficacy to deal with
difficulties low, the case manager uses empowerment techniques such
as validating the importance of her concerns, suggesting practice in
writing the questions down ahead of time, and even coaching and re
hearsing how to ask. The case manager will educate at any point of con
tact to dispel a woman's mistaken ideas about her medical condition or
the treatments needed. For example, a woman who is clinically de
pressed but believes "that is just the way life is" is helped to understand
that this is a medical condition that can be treated and she can feel better.
She is offered a choice of referral for medication or brief "tal king" ther
apy with the MSW and in some instances will choose or is encouraged
to use both.
SAFe recognizes the importance in many cultures of a family view of
health and illness, as well as the belief in the primacy of the family unit
rather than the individual. Therefore addressing the reinforcement in
fluence of family members may be needed. Women with cervical ab
ormalities particularly fear negative family reactions to diagnosis and
treatment. Helping women voice their fears, re-framing their situation
(“your family needs you; will they be better off if you become truly ill
and incapacitated, whatever the cause?”), and, in some cases, speak
ing/meeting directly with family members to enlist help and support are
a part of case management. Finding ways to improve patient-provider communication and understanding enhances trust and openness, which in turn shape and reinforce medical directives. Locating and/or providing translation services is frequently needed, and developing a resource base for sporadic translation service to a multi-ethnic clientele is challenging.

SAFe case managers work in overburdened, understaffed and underfunded clinical settings with absolute resource shortages. Digging up usable resources and then working with patients to access them requires dedication to creative problem solving. Since in most cases enabling factors rest in the environment, not the patient (although effort and persistence is required of the patient), it is here that many models and practitioners of case management fall down. This can result in overly focusing on predisposing factors in the patient and, when problems remain, blaming the patient. Or the case manager becomes discouraged and defeatist, identifying with the powerlessness of the client. SAFe uses peer consultation and discussion with other colleagues to identify, develop
and link with resources and to strategize best access
tactics for over
loaded services. In general, medical and nursing colleagues
understand
that there are formidable resource difficulties and are
deeply respectful
and appreciative of SAFe case managers' tenacious efforts. Supervisory
and administrative clinic staff constantly reinforce and acknowledge the
importance of and skill required in dealing with environmental barriers.

Quality Improvement
There is a continual tension in case management between the case
specific focus of the work and the frequent reality of broken, iii-de
signed care processes and systematic service delivery problems that cut
across many or all patients. Individual case managers cannot be ex
pected to solve larger system failures and inadequacies that may con
tribute to problems in adherence. However, a case management pro
gram is a quality improvement addition to a health care setting when
straightforward processes to monitor its information and activities arc
built in, providing useful information to managers about system and
resource problems.
SAFe uses two case management process quality indicators—(1) timely identification and contact with eligible women and (2) identification of health system barriers—to examine case manager service records routinely for systemic problems that are then brought to the attention of administrators and policy-makers who have responsibility for improvement. This does not guarantee improvement will occur, but data and visibility concerning problems is often a strong motivator for change. For example, as SAFe began in one large urban medical center the case managers found that many women they called, who had abnormal results noted in their charts, had not, in fact, been informed of this. SAFe protocol required the case manager to discontinue the interview and to inform the clinic of the non-notification, resulting in problems with timely contact. After investigating, it was learned that the notification process consisted of a single part-time clerk. Another person had left many months before and the position had not been filled. The flaw in the clinic process was a serious one, and bringing it to light resulted in a rapid response and improvement. Another case management program, similar to SAFe,
includes monitoring of provider adherence to the clinic's own standard of care guidelines as it tracks patient adherence to prescribed procedures and appointments. It is not the case manager's responsibility to interfere with medical provider practices, but data from the case management program provides to administrators quality improvement information on provider behavior (Engelstad et al., 2002; Engelstad et al., 2001).

CONCLUSION

The model of case management discussed and illustrated here is a complex practice modality appropriate for a carefully targeted population of patients known to be at high risk for non-adherence. For settings serving a high risk population, the outlined five key elements of effective case management can be adapted to a variety of diseases and health conditions and the clinical settings that address them. Although the general categories of adherence barriers are similar across health problem and patient populations, careful analysis of the condition-specific research base concerning known adherence barriers will lead to modification or augmentation of the assessment tool and identification of the specific differences in the present...
tation of factors. For example, medication compliance for persons with HIV makes substantial organizational demands on a patient, whereas medication compliance for persons with schizophrenia may be influenced more by the patient's concern about stigma. Appropriately scripted health information salient to the specific health problem and range of likely treatment/therapy possibilities would need to be written. And the most effective and feasible approaches to successful integration of case management with existing clinical processes would vary by setting.

The SAFe model of case management brings a critically necessary social work perspective to the problem of adherence. Widely recognized as a problem involving both patients and systems, adherence improvement requires the ability to fully understand and address difficulties in system-patient interactions and to craft interventions that can target either or both. When successfully targeted only to those who are at higher risk, and provided only to the degree dictated by a patient's unique circumstances, social work case management is an affordable and uniquely multi-system intervention. NOTE

To learn more about SAFe and for adaptable resources to
support case management for improved adherence, a fully specified tool kit for SAFe Case Management, including the Service Manual, Training Manual, scripts, and data collection instruments is avail


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Improvement of Return Rates in a Neonatal Hearing Screening Program: The Contribution of Social Work Maria de Fatima de Campos Franço, PhD Juliana Cristina Fernandes, MSW Maria Cecília Marconi Pinheiro Lima, PhD Tereza Ribeiro de Freitas Rossi, PhD

SUMMARY. This paper aims to describe the implementation of a Neonatal Hearing Screening Program in a school hospital, focusing on the return rates among infants who failed the first screening. The population who goes to the school hospital for health services comes mainly from
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E-mail address: docdchvcry@haworthprcss.com]. Available online at http://swhe.haworthpress.com © 2007 by The Haworth Press, Inc. All rights reserved. doi: 10.1300/J010v44n03_04 179 economically underprivileged groups. Even though our previous return rates were comparable to those reported elsewhere, we felt it was important to improve the methodology of the screening process in order to try and obtain better results. Our hypothesis was that scarce knowledge on early hearing loss detection and on the benefits of early intervention could be reasons for mothers to give less importance to the second screening. So, a strategy was developed around the idea of providing very detailed information to the mothers about the screening process since preliminary data, gathered with a different group of in-patients, had shown that mothers possessed little knowledge about neonatal hearing screening and the consequences of hearing loss for children’s development. The no-return rates decreased considerably (from 39.8% to 25.8%). The findings of this research showed both the need of an adequate way of imparting information to the mothers of newborns about hearing screening in economically underprivileged populations, and the role of social work in this process. Without adequate knowledge on hearing screening and the consequences of hearing loss, a high percentage of newborns may not take advantage of free universal hearing screening programs. doi: 10.1300/J010v44n03_041Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2007 by The Haworth Press, Inc. All rights reserved.; KEYWORDS. Neonatal hearing screening, social work, parents, information

INTRODUCTION

Hearing impairment is a non-visible sensorial problem, making it difficult to detect and perceive sounds. Prevalence rates of hearing impairment are estimated at 3:1,000 live births and 2 to 4:100 from intensive care units (American Academy of Pediatrics, 1999; Comite Brasileiro
sobre Perdas Auditivas na Infância, 2001). But these numbers may vary, depending on the group or method applied (Finitzo et al., 1998; Mehl & Thomson, 1998; Uchêa et al., 2003); therefore reducing negative effects through early identification, habilitation and amplification is crucial (Vohr & Maxon, 1996).

The difficulties caused by hearing impairment can cause problems, especially in relation to language acquisition and language development. Studies about language, speech and emotional development of deaf or hearing impaired children done by Yoshinaga-Itano (2003), for instance, indicated that language development is positively and fundamentally affected by the age in which the hearing loss is detected, as well as by the age in which the intervention starts. According to another study by Yoshinaga-Itano et al. (1998), when intervention occurs before the age of six months, linguistic and social performances of children with hearing loss is significantly better than those of children who started the intervention process later. So, detecting hearing losses in the first six months of life is crucial to the child's development. This argu
ment is reinforced by Luterman (1999), who reminds us that early inter-
vention has shown a decrease on the damages for the child, and a
decrease in the stress for the family.

So, the earlier hearing loss is detected, the more efficient the proce-
dures adopted can be, and the greater the prospects of the child in his/her
linguistic development and academic performance. That is the reason
why hearing impairment detection and early intervention programs
have been increasingly encouraged.

In the United States, the Joint Committee on Infant Hearing (JCIH,
1994) has recommended Universal Neonatal Hearing Screening
through Auditory Brainstem Response (ABR) and Otoacoustic
Emissions (OAE) before the infant is three months of age, and the start of inter-
tervention by six months of age. Nowadays, early hearing detection and
intervention programs for identification of infants with hearing loss are
common all around the world. In some places, hearing screening is con-
sidered a matter of public health (Vohr, 2000).

However, newborn hearing screening programs in developing coun-
tries are unattainable for several different reasons. Poverty, ignorance and
fatal diseases are often regarded as major barriers to the development of
services for conditions such as hearing disorders. Also, the costs associ
ated with newborn screening and follow-up services are generally re
garded to be beyond the capacity of many developing countries.
technology is excessively costly, and material and human resources are
limited. So, hearing impairment is of low priority for health systems in
the developing world and routine or systematic screening for childhood
hearing impairment is rarely reported (Madriz, 2001; Olusanya et al.,
2004).

In Brazil, the diagnosis of children’s hearing impairment is carried
out late, at around three years of age (Silva et al., 1995; Nakamura et al.,
2000). Gonçalves (1990) found out that in Campinas—where the school
hospital targeted in the present study is located—the average age of diag
nosis for deafness was two and a half years,
A survey of 101 hearing impaired children enrolled in assistance pro
gams (between 1992 and 1999) at Cepre 1 showed that 61.4% of them
were diagnosed after their 18th month of life and, for
42.4% among those,
intervention was begun only after their 30th month of life (Françozo & Barbalho, 2000). In the last five years, the mean age of diagnosis of deaf children referred to Cepre was 10.63 months (Higuchi & Françozo, 2005). In another survey with 834 families living in different areas in Brazil and enrolled in a Correspondence Course for Parents of Deaf Children (developed after the one held at the John Tracy Clinic), the data has shown that 54.3% of them only suspected their child had some kind of hearing impairment when the child was between 24 and 36 months old; 19.4% suspected only after the child was three years old (Lima & Françozo, 1999).

There are different reasons to explain late diagnosis of hearing loss in Brazil. Frequently, parents are not responsive to early signs of hearing loss. It is also not unusual to have parents postponing the pursuit for as sessment until the child is over two years old; there are often family sto ries of a relative (a grandparent, a great-great uncle, and so on) who started talking only at three or four years of age, and this is seen as a good reason for postponing the examination; thus, the family only looks
for help when language acquisition is severely delayed. To compound the grim picture, many parents do not know their child is entitled to early diagnosis and intervention, or how to get them. In the case of poor families, besides lack of information about resources for audio-logical assessments, other difficulties are also reasons to postpone the search for exams: lack of free public health services, cultural prejudices about hearing impairment and, most of all, hardships of life resulting from poverty tend to turn hearing impairment into a lesser issue. Finally, reasons stemming from mental life are equally important and, by and large, have a strong influence on late diagnosis. Psychological mechanisms such as fear, denial, guilt, and so on, make it difficult for parents to face the hearing impairment of their child, or even its sheer possibility (Luterman, 1999; 1987).

This situation has drawn the attention of policy makers, and, in some Brazilian cities, legislation has been passed in which hearing screening for newborns is deemed mandatory. This kind of policy helps to shorten the time between the family’s suspicion and diagnosis and intervention. Neo
natal hearing screening in Brazil, nowadays, is performed in 237 places (either public or private), in 22 of the 27 Brazilian states (GATANU, 2005).

In Campinas, there is city regulation (Camara Municipal de Campinas, 2000) that requires maternity hospitals to screen newborns up to their 60th day of life.

NEONATAL HEARING SCREENING PROJECT AT UNICAMP

Since 2002, CEPRE and CAISM2 have carried out a project called Detection of Hearing Loss in Neonates (Lima et al., 2002), which consists of screening for early detection of any hearing loss. The screening encompasses all infants born at the maternity. The infants presenting high risk for deafness or those who had to stay at Intensive Therapy Unit are not included in the Project, and are directed to a special service. Hearing screening is performed using the transient evoked otoacoustic emission (Ecocheck). The infants are tested 24 hours after birth and before hospital discharge. Social workers talk to the mothers before the infant is tested.

The explanation about the test is given for a small group of 4 to 6 mothers, staying in the same maternity's room. On average, 200 monthly screenings are carried out at the maternity. Audiologists, speech
therapists and social workers are part of the project's professional team.

The results of the screening are recorded in the health card of every newborn that is tested. Those who either failed the screening or are not able to undergo the test are scheduled for the second stage screening within a month, at CEPRE, as outpatients.

When the mother brings the infant for retest, she is interviewed by a social worker, who checks for doubts or questions she may have about the assessment. If the infant fails the second stage screening, he is referred to be assessed through an automated auditory brainstem response technique (AABR), at the university's hospital. Once parents get the results of the AABR, they notify the professional team and, if hearing loss is detected, the infant is referred to the appropriated service. In cases of moderate, severe or profound hearing loss, the child can start intervention right away, at CEPRE.

The Users of the Service

Most of the newborns that go through hearing screening at CAISM come from families of underprivileged neighborhoods. Recent investigations with this population group (Franço et al., 2003a;
Franco et al., 2003b) showed that:

- Half of the parents have gone through less than 8 years of schooling. Around 16% of them have finished high school; just a very few have gone to university.

- Almost half of the women (46.6%) are housewives; 13% of them work in low positions in industry or commerce. Very few women are in the skilled labor or liberal profession force; 8.4% work as home maids, 18.3% are unemployed and 6.9% are students.

- The men are basically unskilled, working in industry or commerce (51%), and 32.1% are self-employed; almost 5% are unemployed and the remainder are employed in construction work.

- Most of the families (59.5%) live in Campinas (many of them in distant periphery areas), and the others live in small towns around the city.

- The family income varies from very low to medium low-more than 40% of the families have a family income up to two 'minimum wages' which amounts to less than two hundred dollars a month; only 9.1% of the families have a monthly income above nine times the 'minimum wage.'

- The mother is the one responsible for bringing the infant for the second stage screening. She usually comes with the baby by herself (29.8% of them are accompanied by the husband, a grandmother, another relative or a friend).

- Among those infants who return for second screening, almost half (48.1%) are first child.

In short, we can say that the family is nuclear, the parents are young, and they are in the first stage of the family life cycle.

The First Results

In the initial five months of the project, 812 newborns were screened prior to hospital discharge; 19.2% (156) of them either failed the screen.
ing or were not able to undergo the test; the mothers were informed
about the results and scheduled to bring the infant for the second screen.

No-return rate was 39.8% (94 infants).

In the literature, the figures reported for parents not returning for Stage 2 screening can be as high as 29% (Barbosa et al., 2001), 31.5%
(Finitzo et al., 1990), 25% (Isaacson, 2000), 48% (Prieve et al., 2000)
and 33.3% (Simonek & Valladares, 2001). Even though our return rate was within the range of those reported elsewhere, we felt there was room for improving the methodology of the screening process in order to have better results.

The reasons for parents not returning with their infants for the second stage screening are numerous and interconnected, as we have pointed to above: difficulties in having access to public services (lack of money, problems with transportation and so on), fear of discovering that the baby is hearing impaired, and lack of knowledge about the effect of a hearing loss as far as children's development is concerned. But, in addi
tion, Young et al. (2001) list weak communication of the professional team with parents themselves as one of the procedural
reasons explain

ing high no-return rates. We thus decided to alter the communication

pattern at a seemingly crucial juncture, that is, we decided to have the

audiologists change the way they inform the mothers about the results

of the test. Instead of simply explaining the possibility of there being

vernix in the ears when the screening was performed (which would con

sequently interfere in the results), they also explained about the risks of

a hearing loss—thus emphasizing the importance of returning.

After this change, a new survey was conducted in order to identify

the number of infants' returning for the second screening. For the fol

lowing six months, data were collected and the results showed that

1,120 newborns were screened before hospital discharge; 292 (26.1 %)

either failed or were not able to undergo the test and were referred for

the Stage 2 screening. Fifty percent (146) of them returned. In the case

of those who didn't, the professional team contacted the parents, by

means of a letter or a telephone call, and explained to them the need for

retest. Of those, 27.3% brought their infants to re-screen. On the whole,

106 infants took the second stage screening, and,
consequently, the no-return rate was 36.3% (Rossi et al., 2003). Again, our return rate was high, despite changing the way the results were informed, i.e., despite emphasizing the risks of hearing loss. So it was clear to us the need to again refine the procedures aiming to improve the return rates. Since changing the way the test results were informed did not significantly reduce the no-return rate, we decided to investigate the knowledge mothers have about neonatal hearing screening. Our hypothesis was that scarce knowledge on early hearing loss detection and the benefits of early intervention could be reasons for mothers to give less importance to the second screening.

A total of 138 mothers who had their infants during the month of July, 2003, were interviewed. A questionnaire was used to gather personal data (age, schooling and place of living) as well as data about their knowledge of neonatal hearing screening. The great majority (82.6%) of mothers answered that they knew nothing about hearing screening. Of those who knew something, 58.3% got the information at the mater
nity, and the other ones gained some knowledge by talking to friends or through the media. Only 6.5% of the subjects were acquainted with the legal dispositions about the neonatal hearing screening in the city. We also found that lack of knowledge was not related to age, schooling or place of living (Françozo et al., 20ma).

Thus, our results indicate that, indeed, scarce knowledge about hearing loss is characteristic of our population group. We accordingly hypothesized that this may be one of the factors leading to high no-return rates.

The New Approach

The new strategy, with a new group of newborns and their mothers, was developed around the idea of giving very detailed information to the mothers about the screening process. This strategy was to replace the old one, in which social worker's explanation of the test was given for small groups of mothers. The explanation was clear but short, unless anyone raised doubts or questions.

However, it's known that right after giving birth, women may be fragile and experience different and, sometimes, confusing feelings. As
a consequence, information given at this juncture may not be fully as
simulated. But, since the hearing screening has to be done before hospi
tal discharge, the mothers have to be informed about the test. Trying to
cope with this situation, our goal was to approach mothers individually,
trying to maintain a pleasant atmosphere during the conversation so
they could feel at ease to talk, ask questions and so on. Besides, social
workers attempted to use very clear vocabulary to talk not only about
the screening and its specific legislation, but also about the effects of
hearing loss in a child’s development. In this project, which lasted a
month, social workers talked to mothers before the newborn went to
hearing screening.

A group of 127 mothers who had their babies screened were inter
viewed. Among those babies, 27.5% either failed the screening or were
not able to undergo the test, so the speech therapists informed the moth
ers of this and made a new appointment for the second stage screening.

Of these, 74.2% (26) returned for the retest. Our no return rate, thus,
dropped to 25.8%-an improvement, when compared to the first screen
When they brought the infant for retest, the mothers were again inter
viewed by a social worker, who tried to find out what they had assimilated about the hearing screening process. The social worker used open questions to guide the interview. Most mothers were able to identify, in a simple way, the need for neonatal hearing screening. 'To know if the child listens well' or 'To know if the baby has any hearing problem' were the frequent answers to the questions raised by the interviewer.

Some mothers even expressed their position about the importance of the test, for 'if something "wrong" is found, the treatment can start soon.'

Further, a few mothers asked about the possibility of bringing other babies (neighbors, relatives) to undergo screening—such infants were born in maternities where free hearing screening was still not offered. Altogether, the interviews seem to indicate that the mothers did assimilate the information given to them while in the maternity.

SOCIAL WORK AND NEWBORN HEARING SCREENING PROGRAMS

There is scarce literature related to newborn hearing screening within social work, not only in Brazil (due, among other reasons, to the very re
cent introduction of such procedure in the country) but also worldwide.

Universal newborn hearing screening and its attendant requirement for effective multi-professional intervention, however, has pushed forward the agenda for social services for deaf children and their families (Young et al., 2004).

An important and lone contribution comes from Young's research on newborn hearing screening in relation to social and educational services (Young et al., 2004; Young et al., 2005), especially its impact on early intervention services in England. It focuses, along with other things, on how teachers of the deaf perceive the role and practice of social work. In the majority of cases, the contribution of social services is seen in narrow terms: the provision of equipment and benefits, advice, or response to severe need/crisis such as child protection. Nevertheless, where social work with deaf children is specifically resourced and the specialist deaf child social worker is knowledgeable, it is possible to build a distinct role for social work involvement with families as part of the multi-professional team.

Our own experience also showed that the presence of a
social worker

in neonatal hearing screening team can broaden the range of the procedure, by dealing with parents in different moments of the screening. The process of using individual interviews to inform mothers about newborn hearing screening program produced good results as far as return rates are concerned. It also showed the need of adequate ways of imparting information to the mother of newborns about hearing screening in economically underprivileged populations. Without this, a high percentage of newborns may not take advantage of free universal hearing screening programs.

Newborn hearing screening provides an opportunity for social workers to have a significant impact when working with families in medical setting—it is a new and challenging field for social workers. NOTES

1. CEPRE (Center for Studies and Research in Rehabilitation) offers educational and rehabilitation services for deaf or visual impaired people and is part of the university’s Medical School.

2. CAISM is the Center for Integral Attention to Woman’s Health (which includes a


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Physicians' Ability to Influence
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SUMMARY. Diabetes is aggravated by a sedentary lifestyle, obesity and smoking. Based on a theoretical model relating attitudes and behavior, this study examined the association between physicians' self-efficacy in counseling diabetic patients on life style behaviors and their counseling practices. Data were gathered from a representative sample of 743 primary care physicians in Israel's two largest health plans. The main findings were that only a small percentage of physicians felt capable of influencing their patients' life-style behaviors. Self-efficacy had an independent effect on the likelihood of counseling diabetic patients on life style behaviors, controlling for other background variables. We conclude that there is a need for enhancing physicians' life-style counseling skills, and that social workers could expand their role by training physicians to counsel effectively. This could both improve the care of diabetic patients, and strengthen the status of the social work profession.
profession in the healthcare system. doi: 10.1300/10

INTRODUCTION

Diabetes is aggravated by a sedentary lifestyle, obesity and smoking.

Life-style education and modification can both prevent diabetes and affect the control of diabetes. Good health education is essential for helping a person with diabetes mellitus avoid obesity, smoking, and an unhealthy diet (Anthony et al., 2004; Claudit, 2004; Palmer et al., 2004; Kriska, 2004).

Studies have shown that physician counseling about life-style behaviors is effective in reducing cardio-vascular risk for patients with diabetes and other diet-related chronic diseases (Tabenkin, 2004). Therefore, counseling diabetes patients on changing their life-style behaviors is a crucial element of their treatment (Gaede, 2003; Chobanian et al., 2003), and indeed is a major component of clinical guidelines for treating diabetes patients (American Diabetes Association, 2003; Clalit Guidelines, 2002).

In Israel, the prevalence of diagnosed diabetes is...
estimated to be between 3% and 6% of the population, and primary care physicians play a central role in managing diabetic care (Goldfracht & Porath, 2000). Because of the relatively intensive care required by these patients, physicians assess that between 5% and 10% of their work is dedicated to these patients.

Since 1995, Israel's two largest health plans (which together insure over 80% of the population) have disseminated clinical guidelines for treating diabetes to their primary care physicians. The guidelines address the process of diagnosis and follow-up, indications for beginning medication and conducting periodic examinations and laboratory tests, how to explain the disease to patients, and how to provide life-style counseling.

There are many barriers to changing physician practice patterns, in general, and those related to adopting clinical guidelines, in particular (Cabana et al., 1999). Integrating preventive care and life-style counseling into daily physician practice is particularly complex (Crabtree et al., 1998). Indeed, studies have shown that physicians infrequently counsel
their patients on life-style behaviors; this has been corroborated by the low rates of patients who report having received counseling on these issues (Glasgow et al., 2001; Stange et al., 1998; Stange et al., 2000; Stafford, 2000; Galuska, 1999).

Several studies have investigated the barriers specific to life-style counseling, chief among which were found to be lack of time to educate or counsel patients, lack of the necessary counseling skills, and lack of reimbursement for this activity (Petrella & Wright, 2000).

Other barriers were poor adherence of patients, physicians' perception that health promotion was primarily the responsibility of nurses, and a lack of proper training in life-style counseling (Gould et al., 1995).

Physicians' perception of their efficacy for inducing life-style change among their patients, were found to be central for the implementation of preventive practice (Steptoe et al., 1999; United States Preventive Task Force, 1996).

Based on a theoretical model relating attitudes and behavior (Cabana et al., 1999), this study focuses on the effect of a significant attitudinal
factor-perceived ability to influence the life-style behaviors of diabetic patients ("self-efficacy") for effectively counseling of diabetic patients which is expected to affect physicians' de facto counseling of these patients.

Therefore, the objective of this study was to examine primary care physicians' self efficacy in counseling diabetic patients on lifestyle behaviors and the association between self efficacy and self-reported counseling practices for these patients.

In this paper we argue that social workers, who are trained to apply behavioral and psychosocial principles—"behavioral medicine"—(Graves & Miller, 2003; Wodarski et al., 1991), could contribute to improving both physicians' self efficacy and counseling practices.

LITERATURE REVIEW: LIFE-STYLE BEHAVIORS AND DIABETES

Overweight, inappropriate diet, lack of physical activity and smoking, increase the risk of cardiovascular morbidity and mortality in general and among diabetic patients in particular. (Bray et al., 2003; Solberg, 2004; Tabenkin, 2004; Pate et al., 1995; Rao et al., 2001).

The adoption of a healthy life-style by diabetic patients, including achieving optimum weight and exercising regularly, is a
A healthy life-style has a dominant effect on the control of blood glucose, blood pressure, and cholesterol levels and, in concert with medication, can be used to reduce the risk of complications (Chobanian, 2003; UKPDS, 1998). However, only a few studies have been conducted to assess the rate of life-style counseling to diabetic patients by primary care physicians (Stafford, 2000).

Effective counseling on life style changes improves diabetes control (Jones et al., 2003). Studies have found that lack of information about diabetes, and a lack of the skills required for self-care, lead patients to behave in an unhealthy manner. This underscores the need to effectively counsel patients about their condition and its treatment, and to this end, physicians must be thoroughly trained according to the bio-psychosocial model, so as to be able to provide patient-centered care (Gallant, 2003; Prueksaritanond, 2004).

Studies have shown that inducing diabetic patients to adopt appropriate life-style behaviors is difficult (Hall, 2003; Anderson, 2003). Dia
betics apparently find it particularly difficult to make life-style changes,
as they are extensive, and therefore very disruptive to the patient’s pre
vious life-style. Moreover, diabetic patients may feel stigmatized by the
illness, by its symptoms, such as hyperand hypo-glycaemia, and by the
management of the condition (the need to give themselves injections,
and to maintain a different diet). These feelings may make it especially
difficult for them to comply with recommended life-style changes
(Broom & Whittaker, 2004; De Coster, 2001). Therefore, counseling
diabetic patients about changing their life-style behaviors is a major
challenge to medical staff. Social workers are trained to apply behav
ioral methods and to address psychosocial needs. Therefore, they could
take part in counseling and assist in tailoring treatment plans to
individual needs, increasing the probability of adherence (Wodarski et
al., 1991). METHODOLOGY
The Study Population and Sample
The study population included all community-based primary care
physicians who were employed by Israel’s two largest health plans
(Clalit Health Services and Maccabi Healthcare Services), which provide care for over 80% of the population. A representative sample of 997 physicians was then drawn from this population, after stratifying for health plan affiliation, specialty, and terms of employment (salaried versus independent physicians). A total of 52 physicians did not meet the inclusion criteria (i.e., did not practice general medicine, had retired or died, had been fired, or were not currently working due to a medical condition). Of the remaining 945 physicians, 743 completed the questionnaire, giving a response rate of 78%. Reasons for non-response were refusal (18%), or that the questionnaires got lost in the mail, the interviewers were unable to establish contact, or they physician could not communicate in Hebrew (2%). Each physician was assigned a weight based on his probability of being sampled.

Data Collection and Analysis

The study was conducted between October 2002 and March 2003. The physicians were asked to respond to a structured pre-tested questionnaire sent to them by mail. To enhance compliance, we used a computer-based monitoring system with telephone reminders to the
physicians in the sample who did not return the questionnaire. To ensure the physicians' anonymity, once a questionnaire was returned and coded, it was not possible to identify the physician who had completed it.

To measure self-efficacy in counseling diabetic patients on life-style changes, physicians were asked to rate their ability to influence diabetic patients to stop smoking, begin exercising, and change their eating habits (three separate questions). Answers were rated on a five-point scale: very good, good, moderate, limited, and very limited. An aggregate measure was built for "self-efficacy to influence life-style behaviors," composed of the average score for these three items. The measure was then divided into three categories: high self-efficacy (an average score of 3.5-5); moderate self-efficacy (an average score of 2.8-3.4); or low self-efficacy (an average score of 2.7 or less).

To measure life-style counseling practices, physicians were asked to what extent they discussed life-style behaviors (smoking, exercise, and diet) with their diabetic patients at least once a year. Their responses were rated on a four-point scale: with almost all patients; with most pa
patients (half or more) patients; with a few (less than half) patients; with almost none of the patients.

In order to examine the association between self-efficacy and self-reported counseling practices, both bivariate and multivariate analyses were conducted. Bivariate analysis was performed using overall chi-square tests. Multivariate analysis was performed using logistic regression, with the objective of identifying the independent effect of self-efficacy on self-reported counseling practices, controlling for six other independent variables that could affect counseling practices. For this analysis the dependent variable "counseling practices" was defined dichotomously, as counseling "almost all patients" (value) versus all other categories (i.e., counseling of some patients).

The data were analyzed using the Statistical Package for the Social Sciences (SPSS, SPSS Inc., Chicago, IL). FINDINGS

The characteristics of the physicians in the sample are presented in Table 1. Most of them were middle-aged (their average age was 50), almost half (43%) of them were women, about half of them had studied medicine in Eastern Europe or the former Soviet Union, about half
(46%) of them were family medicine specialists, and only 32% were generalists who had no specialty. About half of the physicians had worked in the community for over 17 years, while 22% had worked in the community for only six years or less. Most (58%) of them were salaried. About half of them saw more than 35 patients per day (the average was 44 patients per day), and reported that the average visit of a chronically ill patient lasted 14 minutes.

TABLE 1. Characteristics of Primary Care Physicians Who Responded to the Survey (in %, N = 743)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under age 44</td>
<td>186</td>
<td>25</td>
</tr>
<tr>
<td>45-55</td>
<td>371</td>
<td>50</td>
</tr>
<tr>
<td>56 or over</td>
<td>186</td>
<td>25</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>424</td>
<td>57</td>
</tr>
<tr>
<td>Women</td>
<td>319</td>
<td>43</td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>238</td>
<td>32</td>
</tr>
<tr>
<td>Family physician</td>
<td>342</td>
<td>46</td>
</tr>
<tr>
<td>Internist/other</td>
<td>163</td>
<td>22</td>
</tr>
</tbody>
</table>
Country of graduation from medical school

Israel 186 25
W. Europe or N. America 171 23
E. Europe or former Soviet Union 342 46
Other (Asia, Africa, S. America, Australia) 44 6

Seniority

1-6 years of work in the community 85 11
7-16 years of work in the community 257 35
17-26 years of work in the community 238 32
27 or more years of work in the community 163 22

Employment status

Salaried physician 431 58
Independent physician or both salaried and
Independent 312 42

Number of patients per day

25 or fewer 149 20
26-34 178 24
35 or more 416 56

Length of consultation with diabetic patients

10 minutes or less 238 32
11-20 minutes 468 63
20 minutes or more 37 5

Fifty-nine percent of the physicians perceived that most of their dia-

metic patients found it difficult to maintain the required life-style (Le'
diet, physical activity, and ceasing to smoke), Furthermore, only 13%
perceived that their diabetic patients complied with most of their
treatment orders.

Low rates of physicians reported having a good or very good ability
to influence their patients' life-style behaviors: 17% reported this re
garding the cessation of smoking, 27% reported it regarding exercise,
and 34% reported it regarding diet. Only 2%-4% rated their ability to in
fluence their patients in each of these life-style behaviors as very high
(Table 2).

The distribution of the aggregate measure of self-efficacy for influ
cencing life-style behaviors (based on the average score for the three
items cited above) was as follows: 23% of the physicians reported high
self-efficacy, 41% reported moderate self-efficacy, and 36% reported
low self-efficacy.

A correlation was found between the physicians' sense of self-effi
cacy, and the extent to which they reported actually counseling their di
abetic patients on life-style behaviors: 72.4 of those with low self
efficacy reported discussing life-style behaviors with
almost all of their patients, compared to 85.4% of those with high self-efficacy ($p < 0.001$, chi square test) (Table 3).

A multivariate analysis was conducted to assess the independent effect of self-efficacy on counseling practices, while controlling for six other independent variables related to physician background characteristics (gender, age), professional characteristics (specialty, country in which they studied medicine), and work-load (length of consultation, the number of patients seen per day). The measure "self-efficacy to influence life-style behaviors" was found to have an independent effect on discussing life-style changes ($OR = 1.8$, $p < 0.001$) (Table 4).

SUMMARY AND DISCUSSION

The main finding of this study was that higher self-efficacy is correlated with higher reported rates of counseling diabetic patients on life-style behaviors. Furthermore, the multivariate analysis revealed self-efficacy to have an independent effect on the likelihood of counseling, controlling for the effect of other independent variables such as age, gender, specialty and work load.

TABLE 2. Reported Ability to Influence Diabetic Patients' Life-Style Behavior
(in %, N = 743)

Area of Influence Very Good Moderate Limited Very Good Limited

Cessation of smoking 4 13 46 32 5
Exercise 2 25 50 22 1
Change eating habits (diet) 2 31 55 11 1

<table>
<thead>
<tr>
<th>TABLE 3. Counseling of Diabetic Patients on Life-Style Behaviors, by Self-Efficacy Measure (in %)</th>
<th>Counsels on Life-Style Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost All Patients</td>
<td>Counsels on Life-Style Behaviors</td>
</tr>
<tr>
<td>Total n = 743 79.8</td>
<td></td>
</tr>
<tr>
<td>High Self efficacy (average 3.5-5), n = 158 85.4</td>
<td></td>
</tr>
<tr>
<td>Moderate Self Efficacy (average 2.8-3.4), n = 302 83.8</td>
<td></td>
</tr>
<tr>
<td>Low Self Efficacy (average 2.7 or less) n = 283 72.4</td>
<td></td>
</tr>
<tr>
<td>Some Patients 20.2 14.6 16.2 26.6</td>
<td></td>
</tr>
</tbody>
</table>

This finding corroborates those of a previous study, which showed that physician attitudes toward health promotion, their perception of their skills, and their self-efficacy for promoting life-style changes that reduce cardiovascular risk were central to the implementation of preventive practice (Steptoe et al., 1999). It also corroborates the findings of a previous study that perceived success at counseling affects the likelihood of counseling on exercise (Sherman & Hershman, 1993).

We should note, however, that high rates of physicians reported coun
selling their diabetic patients on life-style behaviors, including those physi-
cicians with low self-efficacy. This discrepancy can be attributed to several
factors, the first of which may be over-reporting of counseling by physi-
cicians, due to social desirability (they know counseling is expected of them).
Indeed, evidence of this is provided by the findings of a survey of the pa-
tients of these physicians, only a low rate of whom reported being coun-
seled by their physician regarding life-style change. For example, only
19% of diabetic patient’s reported that their physician asked them about
smoking, 32% reported that their physician discussed exercise with them,
and 59% reported that physician discussed diet with them (Gross et al.,
2005).

TABLE 4. Counsels Almost All Diabetic Patients on Life-Style Changes, by
Self-Efficacy and Background Variables (Logistic Regression) B

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>coefficient</th>
<th>Odds Ratio (el)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High self-efficacy</td>
<td>0.59</td>
<td>1.80 (1.37-2.37)</td>
</tr>
<tr>
<td>Aae (56+)</td>
<td>-0.55</td>
<td>0.58 (0.37-0.89)</td>
</tr>
<tr>
<td>Gender (men)</td>
<td>-0.03</td>
<td>0.97 (0.63-1.46)</td>
</tr>
<tr>
<td>Specialty (internist)</td>
<td>0.13</td>
<td>1.14 (0.72-1.79)</td>
</tr>
</tbody>
</table>
| Country of graduation from medical school (Israel) | -0.40
Another explanation might be that, since counseling diabetic patients on life-style changes is crucial to treatment of these patients and is integral to all relevant clinical guidelines, physicians do in fact counsel patients, even though they don't feel capable of doing so effectively (i.e., report low self-efficacy). In that case, the patients' reports would be inaccurate. It might also be that the physician did discuss life-style change, but did so ineffectively, such that patients did not recall the discussion and therefore reported that they had never been counseled.

The Role of the Social Worker in Improving Primary Care Physicians' Counseling Skills

The finding of this study that only a small percentage of physicians feel capable of influencing their patients' life-style (that is, report low self-efficacy) is noteworthy. This finding corroborates previous studies that physicians report barriers to practicing preventive med
icine, such as a lack of knowledge and skills, and a lack of self-confidence (Corouz et al., 2000; Cabana et al., 1999).

Given the association discussed above between life-style counseling and self-efficacy, physicians' reports of low self-efficacy for counseling on life-style behaviors may indicate a need to improve their counseling skills, so that they'll feel better able to counsel patients and consequently will be more likely to do so, and to do so more effectively.

Confidence to counsel has been found in a previous study (Gould et al., 1995) to be greater among health professionals who feel they have been properly trained in behavioral counseling. This suggests that negative attitudes toward counseling may reflect a lack of familiarity with effective counseling methods. Other studies have found that insufficient confidence, knowledge, and skills (Huang et al., 2004) lead to a perceived lack of success in outcomes from counseling (Sherman & Hershman, 1993).

Effective counseling should take into account the diabetic patient's feelings about the disease, complications ensuing from the disease, and the patient's success in self-management of the disease (De...
Costar, 2003). Given the many issues that should be considered, it is obvious that physicians need training to effectively counsel their patients on life-style behaviors.

Social workers could play an important role in enhancing physicians' life-style counseling skills, since they are trained to use a comprehensive approach, which takes into account the bio-psychosocial context of the patient's way of life, and to acknowledge the emotional difficulties associated with changing behavior. This approach enhances the effectiveness of counseling (Wendt, 1990; De Coster, 2001), and may be conveyed to physicians. The use of such methods might help physicians build trust and improve communication with their diabetic patients.

To date, social workers in Israel have mainly worked directly with patients, although some are already teaching counseling skills to medical students and residents specializing in Family Medicine. There are not enough social workers employed by the health plans to work directly with all patients, and take on responsibility for life-style counseling. In Israel, the organization of primary care clinics is
such that the main care providers for diabetic patients are primary care physicians, who see them regularly every three-six months, and therefore are responsible for comprehensive care including counseling on life-style behaviors.

Expanding the role of social workers to include training practicing physicians in counseling techniques, may be the key to effective influence on the life-style behaviors of diabetic patients. Social workers could share their knowledge and effective counseling techniques with physicians, thereby improving their skills and, as a result, their self-efficacy in this difficult area. Social workers might accomplish this by initiating workshops to train physicians in counseling, or by preparing counseling manuals or videos demonstrating effective counseling techniques. Social workers could also be available for one-on-one consultations with physicians who encounter problems with a specific patient and wish to work on effective strategies for overcoming them.

However, in enhancing their role in the system, social workers would need to take the initiative, market their services to physicians, and con
vince them of their value as consultants. It appears there is a window of opportunity for social workers to do this, as the study findings indicate that physicians are aware that they have a problem, and this is the first stage in the willingness to receive help. Nevertheless, social workers will have to invest effort in implementing this idea, since some physicians may resist training by non-physicians. We believe that such an investment would be worthwhile, as expansion of the social worker's role could both improve the care of diabetic patients, and strengthen the status of the social work profession in the health care system. NOTE

I. However, there are no published data on the exact time allocated to treating these patients in Israel. A large observational study conducted in the United States reported that American Diabetes Association. (2003). Clinical practice recommendations 2003. Diabetes Care, 26(suppl I), S1-156.


Clalit Health Services (2002). Guidelines for the treatment of diabetes type 2 in the community. Internal publication. Tel-Aviv. (Hebrew)


diabetes stages of change


Prueksaritanond, S., Tubtimtes, S., Asavanich, K., & Tiewtranon, V. (2004). Type-II


Perceptions of Online Support for Hospitalized Children and Adolescents

David B. Nicholas, PhD, CSW Jane Darch, BA, BEd, CCLS Ted McNeill, PhD, RSW Leanne Brister, BA, CCLS Kimberly O’Leary, MSW Deborah Berlin, BSW, MSW, RSW Donna Koller, PhD

SUMMARY. This study identifies perceived outcomes following hospitalized children’s participation in a pediatric online support network. Nineteen participants were interviewed, including child and adolescent patients who had used the network while in hospital, their parent/family caregiver, and a familiar health care provider. This triadic sampling approach provided a range of stakeholder perceptions. Results convey a wide spectrum of benefits and challenges.
in accessing and utilizing an online support network for hospitalized children. Participa

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docdclivcry (0) haworthprcss.com]. Available online at http://swhc.haworthpress.com © 2007 by The Haworth Press, Inc. All rights reserved. doi: 10. 1300/J010v44n03_06 205 tion in the network was identified as a means of fostering pediatric patient enjoyment, education, connection with peers, and coping. Information, social connection and distraction served as catalysts fostering positive outcomes for children. Identified barriers to network participation included inaccessibility and limited availability of computers, issues with technology, and discomfort with
Online support networks are increasingly being introduced as a therapeutic resource for hospitalized children. This study examined the experiences and impacts of participation in an online pediatric network, entitled STARBRIGHT World® (Bush, Huchital, & Simonian, 2002).

STARBRIGHT World (SBW) provides online resources for ill children including games, activities, education, and interaction with peers. Evaluation comprised qualitative interviews with pediatric patients, their parents and health care providers in which perceived impacts of this online intervention were examined.

BACKGROUND

Current generations of children and adolescents are well-versed in computer-based communication and online capacities. Accessibility and convenience of online technology advance the potential for its use as a therapeutic tool in groupwork (Galinsky et al., 1997; Nicholas, 2003). Attributes of accessibility and convenience are
crucial for hospitalized children as their condition and hospitalization may preclude access to conventional supports. The significance of being able to access social supports is particularly salient in the context of hospitalized, chronically ill children. Studies comparing levels of social interaction between chronically ill children and their healthy peers report that ill children experience significantly more isolation than other children (Krulik & Florian, 1995).

Recent studies on computer use, addressing various childhood illness populations, report a desirable impact on variables of loneliness, worry, anxiety and willingness to return to hospital for followup treatment (Battles & Wiener, 2002); and knowledge, peer support and coping (Hazzard, Celkano, Collins, & Markov, 2002). A positive impact on child pain intensity, pain aversiveness and anxiety is also demonstrated (Holden, Bearison, Rode, Kapiloff, & Rosenberg, 2000). Based on four clinical cases of children with cancer, Brokstein, Cohen and Walco (2002) report that a network support fostered therapeutic relationships with psychosocial-based health care providers, and outcomes
suggested that participating children dealt with issues "relevant to their conditions in a manner consistent with their own coping styles" (p. 42). Finally, online network support provides a source of distraction for hospitalized children. Various forms of distraction are extensively supported in psychosocial literature in pediatrics. Studies have found distraction techniques associated with improved coping for children undergoing medical procedures (Vessey, Carlson, & McGill, 1994).

Despite reported benefits of online interventions, little attention has been given to the perceptions of pediatric patients who engage in online support. Moreover, the processes of online participation have received minimal study. To address these gaps, this study examined perceptions and experiences of children who used an online pediatric support network; identified processes of online participation; explored types of network use; and described perceived outcomes for pediatric patients and their families. THE INTERVENTION

An online intervention, entitled STARBRIGHT World (SBW), was introduced to participants. This online system comprised a broadband
interactive network for ill children, and offered graphically-appealing online information, entertaining activities, and opportunities for peer networking. Specific features of the network included text-based chat rooms, videoconferencing, and postings of questions and answers on a bulletin board. Throughout North America, children could participate in online peer dialogue with patients in over 95 children's hospitals. A search engine provided children the potential to search for peers based on age, geographic location, medical condition and interests. Hosted chats on specialized topics (i.e., cancer, cystic fibrosis, coping) were also provided. Beyond information on the site, more than 1,000 Websites were linked, all of which had been pre-screened and firewalled against access to the Internet. METHODOLOGY Ethnographic interviews were conducted with three stakeholder groups most familiar with the processes and outcomes of children's online participation. These groups comprised: (1) pediatric patients who had used the network during hospitalization, (2) their parent (family caregiver) and if possible, (3) a health care provider familiar with the particular child's expe
rience of using the network. The 'long interview' approach was utilized, based on a semi-structured interview guide outlining open-ended questions and probes (McCracken, 1988). Interviews were audiotaped, transcribed verbatim and subjected to theme generation, assisted by qualitative data analysis computer software (Nvivo, see Richards, 1999). Data were viewed by an experienced qualitative researcher and inter-rater reliability was demonstrated through an independent review of a sample of the data by a second data analyst. Saturation of themes emerged following redundancy and exhaustion of new themes in the data. Trustworthiness of emerging themes was further demonstrated by established standards of thick description, referential adequacy, peer debriefing, member checking and negative case analysis (Lincoln & Guba, 1985). Health care record reviews and network utilization data provided descriptive case detail and ensured sampling variation. Scientific and ethical review and approval were obtained prior to study commencement. THE SAMPLE A total of nine hospitalized children and adolescents at a pediatric hospital in eastern Canada participated in interviews. These patients had
been provided network orientation and training, and all had used the
network a minimum of three times. In six cases, parents
(and in one
case, an accompanying adult family member) and three health
care providers were also subsequently interviewed about the
impact of the network.

Work. The sample of children (N = 9) was adequate according to 'long
interview' methods in which McCracken (1998) argues that
saturation
of themes can emerge with 8 interviews. Interviewed
children and adolescents ranged in age from 4 to 17 years with a mean age
of 11.3 years.

Seven participants were male, two female. They lived in
varying regions of eastern Canada, and resided in a range of urban (n
= 7) and rural
(n = 2) locations; in some cases, a substantial distance
from the treating
hospital. Children and adolescents had a wide range of conditions 2 (see
Table 1) and two children were followed in a
transplantation program.

Length of time in hospital within the past year ranged from
4 days to 90
days, with a mean of 31.8 days (see Table 1). RESULTS

Participants generally viewed SBW as a resource fostering
constructive psychosocial adaptation to patient's illness and
hospitalization. Inter
view findings are multifold and convey processes of how young patients became engaged in online network participation, the nature of their involvement, and perceived impacts. Each of these areas is addressed below.

Reasons for Engaging in the Online Network

All children became engaged in SBW following an invitation from a pediatric health care professional. Health care professionals introduced a child to the network after considering the child’s potential interest and suitability for computer use, language literacy, and eye-hand coordination.

Knowledge about a child’s former experience and enjoyment using computers further prompted health care providers to advocate network participation. Beyond individual factors, health care providers described network participation as a means to foster supportive group interaction among multiple children on a hospital unit. A health care provider stated, “I’m fortunate enough to have an enclosed area where I have generally more than one teen on (the network) at a time. So I end up introducing them to each other.”

Children’s decision to participate in SBW was influenced by a variety of factors. Identified influences included: feeling
well enough to participate, interest in the computer, observing other patients engaging in online activity, a desire to learn, and health care staff encouragement.

Some children specifically became interested in network utilization as a result of the prospect of accessing games that were perceived as "fun." TABLE 1. Demographic Characteristics of the Sample Population

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Primary Condition</th>
<th>Days in Hospital Last Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>M</td>
<td>4</td>
<td>Acute myeloblastic leukemia</td>
<td>14</td>
</tr>
<tr>
<td>Participant 2</td>
<td>F</td>
<td>8</td>
<td>Dermatomyositis</td>
<td>13</td>
</tr>
<tr>
<td>Participant 3</td>
<td>M</td>
<td>8</td>
<td>Hirschsprung disease</td>
<td>66</td>
</tr>
<tr>
<td>Participant 4</td>
<td>M</td>
<td>9</td>
<td>Lymphangiomata</td>
<td>4</td>
</tr>
<tr>
<td>Participant 5</td>
<td>F</td>
<td>11</td>
<td>Cystic fibrosis</td>
<td>16</td>
</tr>
<tr>
<td>Participant 6</td>
<td>M</td>
<td>11</td>
<td>Acute lymphoblastic leukemia</td>
<td>15</td>
</tr>
<tr>
<td>Participant 7</td>
<td>M</td>
<td>11</td>
<td>Acute lymphoblastic leukemia</td>
<td>49</td>
</tr>
<tr>
<td>Participant 8</td>
<td>M</td>
<td>13</td>
<td>Acute lymphoblastic leukemia</td>
<td>19</td>
</tr>
<tr>
<td>Participant 9</td>
<td>M</td>
<td>17</td>
<td>Congenital heart disease</td>
<td>90</td>
</tr>
</tbody>
</table>

Clearly, social workers, child life specialists and other health care professionals play an important role in informing children and adolescents about the network. How the network is introduced appears to have a bearing on participants' potential interest. If health care providers effectively explore children's interest and engage them in potentially appropriate online support, these children are more likely to
participate.

Types of Network Utilization

Age, developmental stage and personal interests appeared to have an impact on how the network was used by participating children. Reflecting typical developmental processes, younger children favored individual-oriented activities whereas older children and adolescents more frequently engaged in dyadic or group-based activities. Children under 10 years of age tended to engage in solitary activities such as playing online games more frequently than interacting or chatting with peers.

For these younger children, the network was often seen as, in one parent's words, a "distraction tool and entertainment." Activities and games were described by younger children and their parents as the aim of online participation: He certainly likes the sports or action-oriented games, ... arts and crafts, ... (and) quizzes. I think it was initially the games, mostly the games that got him. He liked just playing with computer games, video games.

In contrast, older adolescents tended toward interactive activities such as video conferencing and chats. An adolescent illustrated this preference by stating, "I liked the video conferencing. It was nice to talk to people from different hospitals, and I liked the chat..."
lines.” Based on statements made by older children and adolescents, video conferencing and the chat room were seen as meaningful and integral activities augmenting their social connection with a peer group. Accordingly, social connection via this network permitted adolescents to engage with peers by moving beyond the confines of hospitalization and allowing communication with others in similar circumstances. An older child stated that friends who have not experienced illness "don't understand" what life is like for a child with a rare illness. In contrast, network communication with other ill youth permitted participants to both meaningfully convey their realities, and perceive themselves to be 'understood.' Given adolescents' frequent propensity for peer engagement, finding supportive interaction among peers appears potentially relevant for this adolescent population. Social workers and other health care professionals play a substantial role in introducing this notion, particularly as teens are initially strangers. Mediating and/or facilitating this encounter among teen peers, social workers can play an important role in engagement, initiating group work, finding common topical
ground or points of interest and ultimately in allowing teens privacy for peer dialogue. In summary, these findings reflect appropriate developmental responses thereby highlighting the ability of SBW to meet the needs of a range of pediatric patients.

Perceived Impacts

Participants conveyed benefits and limitations associated with online network utilization. Identified benefits included distraction, coping, so cial support, enhanced communication and education. Limitations were also conveyed, and included a finite (hence limited) number of available computers in the hospital, inaccessibility, challenges with technology, and discomfort with online interaction. These benefits and challenges are addressed below. BENEFITS

Distraction and Mutual Participation with Siblings

Participants described the online network as an enjoyable distraction.

According to one participant: "it just gives another option of things to do during the day (while in hospital). And I also enjoy talking to other people from different places." Another stated, "(the online network) has ... helped to make the time pass a little quickly."
Participants suggested that the online network tempered the arduous and painful experiences of hospitalization. Accordingly, children associated difficulty and sadness with hospitalization; however, online participation was seen to ease and distract participants from daily stresses.

Toward ameliorating the impact of illness and hospitalization, participants indicated that network involvement increased children's state of contentment while in hospital. For example, a young child was asked to speculate about his hospitalization had he not been provided with access to the network. He replied, "Mmm, wouldn't be that fun." Another child stated, "I probably would have found (hospitalization) a lot longer be cause I wouldn't have that option to do during the day." A parent stated, "He (my child) would be more bored, wouldn't you? It's a nice change from (a television-based video game) because he was kind of glued to that for a long time, until the Child Life Specialist said, 'well, you'll like this computer.' "

A health care provider commented that online network participation provided children with an opportunity to, "have fun in a normalized..."
way, by playing on a computer, doing things they would do at home."

Other benefits were described as providing, "opportunities for social

ization with other kids ... (as well as) distraction tools from the pain, the

illness or how they're feeling, or just to pass the time in the day if

they're staying in for a long time."

Online resources provided children with the opportunity to chat

about their illness and engage in discussion as much or little as they de

sired. In addition, the ability to also engage in a topic of interest unre

lated to illness was appreciated, especially given that the focus of

hospitalization primarily revolved around their own illness and treat

ment. Similar to this outcome of patient distraction, a health care pro

vider described the network as resource for a child, "to look forward to,

(and a) motivation to get out of (the hospital) room."

Another described

SBW as, "a good way to talk with the other kids." A mother indicated

that the network offered an alternative to active play for her ill son. She
described her son as, "a very active (child) ... Because he can't always

go out and play, I think to be able to do it vicariously through the
The computer has been really good for him."

The wide variety of available online activities promoted play among hospitalized children and their visiting siblings. A parent stated, "(the network) helped with his brothers when they came to visit. (The ill child) showed them so they were on it too. So they had fun together on it. Keeps them all busy down there when they come for a visit." Having an available and amenable array of activities for both her ill child and his siblings was seen to be a substantial contribution to maintaining sibling relationships as well as providing a helpful conduit to access support and mutually-engaging activity during family visits to the hospital.

Accordingly in the context of pediatric care, the network afforded an enhanced level of family centered care.

Personal Mastery and Coping

Beyond the reported value of patient distraction (Vessey et al., 1994), SBW was described as fostering mastery and coping. Perceived anonymity among computer users encouraged open communication, information exchange, and coping. A parent highlighted a perceived level of anonymity associated with online support by stating, "being on
the computer

sometimes (allows you to) talk more than you can when you sit down face to face ... (There is) ... anonymity about it." Despite knowing that others would read online comments, a sense of privacy appeared to yield heightened self-expression. Children incurred therapeutic benefits as exemplified by a parent's observation: "(The ill child) even played a few games where he shot at things. He used to tell that he was killing his cancer cells. In some ways I guess it's almost like therapy for him."

In another instance, computer-mediated interaction was seen as a means of promoting mastery and confidence, as illustrated below. I think it encouraged (the ill adolescent) ... to know that he had the ability to 'do.' I think it really boosted his confidence, knowing that he had something to offer other kids, and that someone saw that while he was on the computer. I think that it made him happy to think that he might be able to give to somebody. So I would say that it really gave him a boost in his confidence, which is a real important thing. I was just happy to see him interested in something, ... to take a positive spin on things.

Identified outcomes of mastery and coping appeared to coincide with increased self-esteem. Understanding how these important outcomes may be linked or causally-related, lie beyond the scope of this study and invite further examination in subsequent research.

In terms of family life, participation in the network...
sometimes fos
tered positive family dialogue and coping. One adolescent viewed the

network as a means of introducing something innovative, interesting or

fun to others in his family. Another stated, "the purpose for my family

would be (that) they (the family) would be happy because I'm enjoying

myself while I'm in the hospital." Accordingly, he felt that SBW of

ferred vicarious benefit to his family as they saw him engaging in and en

joying constructive activity. For both patients and their families then,

network participation appeared to render hospitalization less unpleasant

and promoted positive psychosocial adaptation.

Social Support

Given the developmental needs of older children and adolescents, it

was not surprising that they valued the online availability of peer inter

action and support. A patient described the network as, "giving you

somebody to talk to. And (somebody) that will have an idea of what

you're going through, and you may have an idea of what they're going

through with being in the hospital for lengths of time." Another older

child similarly commented, "... I wanted to hear what the other hospi
tals were like and it makes you feel like you're not the only one who is in the hospital and sick."

Some participants felt that the opportunity to talk with peers was a crucial feature of the network. Children enjoyed connecting with peers with a similar condition; an opportunity that, for some, was largely un

available (e.g., children with rare conditions; children in isolation). For others, it provided an impetus to go into a playroom and interact with other ill children within the same unit. In the following instance, the computer was in the playroom. This invited peer interaction: I think it’s one of the things that’s taken (the ill child) into the playroom even on the days he might otherwise (have) stayed in his room. It’s been a real "code" for him and he has met other little boys his age who are also involved (with the network).

A parent similarly felt that online utilization beneficially fostered constructive relationships with other patients, health care staff and volunteers: (Without the online network), he probably would have spent more time in his room glued to the TV. It has been a good opportunity for him to interact with some of the other kids on (the unit). Because other kids are in the playroom and want to play with him, he will. It has also given him the opportunity to play with other staff or volunteers. He’s so shy, but if they ask him what he’s doing or can they play with him or whatever, he’s quite welcoming to that.

Benefits of peer interaction were multi-faceted. Participants de
scribed outcomes of feeling understood, developing new friendships,
expressing their own ideas, and increasing personal mastery and a sense
of independence, as illustrated below. Talking to kids that have the same problems as you, things that your friends don't understand. It's nice to make friends ... I have a friend on the chat line and video conferencing. . . . you
get to talk to people that are in hospitals and they understand the time, like how long it seems or how short. And just getting ideas or talking about ideas of how they pass the time ... while you're in the hospital. (The online network) is a way for (the ill child) to be independent and talk to somebody besides someone who is providing health care: the nurses or the doctors, or me (parent). You know, it's a way for her to get in touch with someone of her age, a peer group—which she really needed.

As a result of SBW, relationships emerged or were strengthened,
from which patients derived meaningful support. In summary, this sup
port came from multiple sources including online peers, in-hospital
'playroom' peers, and family members. These various supports each
had been positively influenced, in varying ways, toward support facilitation by engagement with SBW.

Communication

Several participants felt that the level and quality of communication
among the child, family and health care professionals had been favorably affected by network involvement. A parent stated, "(through the online network the ill child) has gotten to know (a health care provider)
a lot better so he feels much freer, ... to go ask her for help. Yesterday,
asking her to come and talk to me a bit about (a specific medical proce
dure), he didn't think twice about it." In this case, prior network-based
communication promoted greater comfort and ease in subsequent
health-related dialogue between this family and their health care pro
vider. Accordingly, complex online interaction opened the door to
supportive relationships with health care providers.
For others, topics addressed on the network ignited greater health-re
lated dialogue among children, their parents and health care providers.
Beyond health issues, compelling non-illness topics also were pre
sented on the network. These increased the scope of familiar topics for
conversation with family and friends; a benefit appreciated by partici
pants. Specifically, relief from a sole focus on illness was observed as a
welcomed diversion.
Cumulatively then, the network offered personal benefits of in
creased control and mastery as well as a variety of issues to discuss, a
mutually rewarding environment for interaction, and a positive source
of relationship-building. Participants described beneficial outcomes of greater communication as peer, family and health care provider dialogue was facilitated.

Education

Online network participation was designed to increase health-related knowledge (e.g., condition-specific, general health issues) as well as provide non-health information (e.g., topics of regional interest). For example, a child described receiving help in handling injections/needles. An adolescent stated, "I enjoy learning about different medical conditions that people have. So it is kind of neat to hear what they have gone through." Beyond health care information, one parent identified the network as having a developmentally beneficial outcome. She stated that in, "a lot of the games, (her ill child) has to answer questions" which helps him, "learn numbers and recognize letters"; a key milestone for this child at his developmental level.

Other educational gains included exposure to persons from other regions and cultures. This interaction permitted a glimpse into diverse contexts and circumstances, and provided a connection to others with
whom participants otherwise would have had no opportunity to meet.

Knowledge was reportedly gained specifically by peer-facilitated learning among children on the network. A health care provider commented,

"(children) learn better through other kids ... It’s important at that age to be friendly (with peers) ... , so it’s a good way to talk with the other kids, ... kids maybe who (you) don’t know."

In summary, SBW was appreciated for its provision of education in terms of not only health information but also its non-illness content. For this reason, the network offered opportunities to learn about topics unrelated to health, thereby normalizing the children’s environment.

Taken together, recreational and child-friendly approaches of the network were seen to increase children’s knowledge and interest in a variety of topics while simultaneously providing peer support.

CHALLENGES

Beyond substantial benefits, participants also conveyed challenges associated with network participation. Specific challenges included limits in the number of available and accessible computers; intermittent difficulties using the technology itself; and, in a few cases, negative on
line interactions. These issues are discussed below.

Inaccessibility

Participants described periodic barriers to accessing and utilizing the network. A logistical barrier was the finite number of computers within the hospital and, hence, limited locations to access the network. One mother observed that the computer used by her child was located, "down in (the children's) lounge, and we didn't always get a chance to get down there ... when he was really sick." This pragmatic consideration was seen to limit network utilization. In response, a mother advocated widespread availability of the network to children in hospital. She further recommended access within all patient rooms: (The ill child) would say to me, "oh Mom, look at that beautiful playroom and I can't even go," And at one point there was (another child) across the hall from her and they wanted to talk so bad, but they couldn't because they both had different bugs ... If they had a computer, between them, they could have had a great time. So, I'm thinking down the road when computers are in every room, it will make kids' lives a lot more normal.

Several participants similarly emphasized the need to ensure ongoing availability of network support for children, and several offered recommendations for increased accessibility. For instance, a parent recommended, "especially if (children) are in isolation. , . put (the network)
on laptops and it (would) take a lot less space ... It would be more portable between rooms and we could take it to a lot more places." Another parent recommended, "it would have been nice for the child's class to have had an opportunity to talk to her especially (for) kids that are far away from their class for long periods."

Technology-Based Challenges

Several participants identified barriers to network utilization as a result of technology-based problems and/or personal challenges using the computer. For instance, a child had difficulty remembering his online password: "You would need a password to log in and I forgot mine...." A parent described system difficulties with the computer: "Sometimes (the ill child) gets a bit frustrated ... because (the computer) freezes." A few participants described instances when accessibility to others for videoconferencing had been prohibitive. For instance, participants described being unable to find a videoconferencing partner with whom to "meet" and communicate. When a partner was found, occasional software problems were noted in connecting
with that individual (e.g., difficulty deciphering the
computer-mediated voice, not receiving the video picture, delayed
response, connection loss). A parent described challenges in connecting:
"The
other thing is timing because by the time you get down
there (to the
playroom), and on (the computer), you don't always get the
people
on the other end." One respondent attributed this type of
issue to a
"time zone problem" in that synchronous connections such as
videoconferencing potentially crossed numerous time zones
including ease in arranging virtual face-to-face meetings
with peers. In
an instance in which the interviewer asked, "how does that
feel when
it (the computer) gets stuck?" a child responded, "I want
to be mad at
it." Similarly, a health care provider stated, "The biggest
(challenge)
is consistency with working the computer games. Often (a
window
with a picture of) a dog comes up and says that they're
unable to locate their site or for safety purposes it's been blocked. And a lot of
the time they go to put on a game and they can't get it to work. So that
gets frustrating ...."

Beyond difficulties with software function, computer
maintenance

and the prevention of vandalism were issues of concern to health care providers. Accordingly, an important health care provider consideration was the balance of optimizing accessibility to the network while simultaneously ensuring the security and maintenance of the computers.

Negative or Uncomfortable Online Interaction

While most children enjoyed online dialogue with peers, a few children described discomfort in forging relationships with unknown persons and discussing personal health details in online interaction. Although uncommon, instances of discomfort were described, as were instances of self-consciousness over seeing oneself (or being seen by others) on camera in the context of videoconferencing. In such cases, illness-related visible changes in appearance could exacerbate embarrassment.

A health care provider conveyed rare concern about children connecting with peers who were not previously known: It's hard. They (the children) get shy, you know, especially (when the child is) not familiar with the concept of a chat. And when they are (familiar), it's usually chatting with their friends ... Then you put them in a chat room, with a ton of people that they don't know, and all of a sudden they're faced with trying to make conversation with strangers. It's not so easy, especially when sometimes the (others) ... want to talk about their illness ...
A health care provider described an instance in which a participant learned upsetting information relating to another child's condition. The health care provider noted the difficulty this information presented for the recipient, and the challenge it created for the health care provider in considering how children's dialogue could be monitored and augmentative professional support, if needed, could be provided.

In summary, participants did not view these challenges as prohibitive and, in the context of the reported benefits, they viewed the network as an important psychosocial resource for pediatric patients and families.

Accordingly, all participants stated that online participation offered psychosocial support to hospitalized children. Support in this context encompassed distraction, education and peer contact; all of which appeared to cumulatively yield outcomes of increased control, mastery and coping. DISCUSSION

Despite identified challenges, the online network was perceived to offer substantial benefits to hospitalized children. These findings are supported elsewhere in literature on the STARBRIGHT World network (Baldwin,
2000; Rode et al., 1998) and other computer systems for use in pediatric set


transcends what could be viewed as just using a computer.

The network offered social connection, provided new opportunities

and learning, and increased exposure to peers who lived with similar
daily realities. The educational focus of the network-through activities,

interaction and information“allowed children to enter a 'larger world'

that transcended their daily hospital regimen. They were permitted dif

erent vantage points and tools for articulating, reconsidering and man

aging circumstances within their own lives, as exemplified by a child

who became emotionally more able to receive injections following

online information and interaction.

To this end, the network appeared to be an effective catalyst for pro

viding information, social connection and distraction. The network edu

cated and contributed to ongoing and important processes of self-care

and social support. Vicarious benefits included an increased peer net

work, sibling interaction, dialogue with health care team members, and
family-centered care.

Figure 1 depicts the transcendent role of the network in facilitating communication, information and distraction. In this model, the child's interaction with peers, family members and health care providers is supported and augmented by the online network. SBW provided a valued repository for heightened communication, knowledge, peer contact, personal control and mastery, and coping. CONCLUSION

Social workers, child life specialists and other health care professionals play an important role in enthusiastically introducing the network and exploring its affinity with children's interests and propensities. For older children and adolescents, social workers can effectively assist in encouraging initial peer interaction, particularly when online peers are previously unacquainted. Encouraging freedom to form meaningful peer relationships has the potential to foster supportive friendships, mutuality and social support among adolescent patients.

FIGURE 1. Processes and Outcomes of Network Support for Hospitalized Children

Offering effective and accessible child-centered resources constitute
important elements for pediatric health care delivery. This study con
tributes to the literature and offers additional evidence for online net
works as a promising resource for children and a tool promoting
family-centered care. In particular, the impact of the STARBRIGHT
World system appears to exceed general expectations of what a com
puter can do, particularly in the context of pediatric health care. Finally,
the replication of earlier findings in the literature strengthens the con
tribution that this type of online intervention potentially contributes to
important child health outcomes such as enhanced self-esteem and
reduced depression (Burgos, Robinson, & Lin, 2000).
Given its introduction to children at a time of health crisis and uncer
tainty, the potential contribution of an online support network appears
far-reaching, particularly in the context of future technological advance.
Despite identified barriers and areas for further network refinement as out
lined herein, the ongoing availability and accessibility of effective online
resources are warranted. Moreover, ongoing development of pediatric sup
port initiatives, integrating advanced technology and practice innovation,
constitute important and promising endeavors for social workers and other health care providers. Given the substantial workload demands, online networks appear promising as an augmenting source of psychosocial support. NOTES

I. Health care providers comprised Child Life Specialists employed in a pediatric hospital, and volunteers who were supervised by Child Life Specialists. Four interviews were held with these health care providers although one health care provider was interviewed on two occasions due to involvement with 2 child participants.

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Rode et al. (1998), The therapeutic use of technology: The Child Life program and Starbright world at Mount Sinai Medical Center in New York helping children cope with illness, American Journal of Nursing, 98, 3345,

Vessey, J" Carlson, K L., & McGill, J, (1994), Use of distraction with children during an acute pain experience, Nursing Research, 43, 369-381, doi: 10.1300/J044v43n03_06 Clinical Practice Standards and Ethical Issues Applied to a Virtual Group Intervention for Spousal Caregivers of People with Alzheimer's Julie Dergal Serafini, MSc, PhD Candidate Thecla Damianakis, MSW, PhD Elsa Marziali, PhD SUMMARY. Advances in technology have improved access to health and social services by offering more abundant and convenient choices for clients. In particular, the use of technology for delivering services to older adults and their families alters new possibilities for service delivery, by

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Marziali, PhD, is Director, Katz Center for Gerontological Social Work Research, Schipper Chair, Kunin-Lunenfeld Applied Research Unit, Baycrest, and Professor, De partments of Social Work and Psychiatry, University of Toronto.

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Group Intervention for Spousal Caregivers of People with A1"heimer's: Serafini, Julie Dergal, Thecla Damianakis, and Elsa Marziali. Co-published simultaneously in Social Work in Health Care (The Haworth Press, Inc.) Vol. 44, No. 3, 2007, pp. 225-243: and: Social Work, Health, and Medical Development: Compassion in Social Policy and Practice (cd: Scree Dunlont, and Myreille St-Onge) The Haworth Press, Inc., 2007, pp. 225-243. Single or multiple copies of this article are available for a fee," from The Haworth Document Delivery Service 11-800-HAWORTH, 9:00 a.m. 5:00 p.m. (EST). E-mail address: doedelivery@haworthpress.com, Available online at http://swhc.haworthpress.com © 2007 by The Haworth Press, Inc. All rights reserved. doi: 10.1300/J500v44n03_07 225 reaching people who are often isolated, and have difficulty accessing traditional services. Despite the continued advances in technology development and its integration into healthcare delivery, health care practitioners need to consider how to adapt and uphold clinical practice standards and address ethical issues in an e-health environment. Given the gap in the literature with respect to discussing these issues, this paper illustrates relevant issues in the context of developing and evaluating an
Internet-based intervention for spousal caregivers of persons with dementia. Based on a four year project, a psychotherapeutic group intervention was delivered via the Internet to three groups of spousal caregivers. This article identifies some of the key practice standards and ethical issues that arise when using computer technology to deliver a psychotherapeutic group intervention. The article will also provide examples of relevant issues related to maintaining practice standards and ethical procedures that need to be addressed during the application of a computer-based psychotherapeutic group intervention for spousal caregivers of people with dementia. doi: 10.1300/J014v44n07 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <dxdelivery@haworthpre.com> Website: <http://www.HaworthPress.com> © 2007 by The Haworth Press, Inc. All rights reserved.] KEYWORDS. E-health, group intervention, caregiving, older adults, dementia

INTRODUCTION

Advances in technology have improved access to health and social services by offering more convenient choices to people, who otherwise may experience barriers to using existing services. In particular, the use of technology for delivering services to older adults and their families offers new possibilities for service delivery by reaching people who are isolated and have difficulty accessing traditional services. Despite the continued advancements in technology and its integration into systems of healthcare delivery, technology-based services and interventions raise two unique challenges that have not been well addressed in the literature (Bauer, 2001). First, while delivering services using technology (e.g., the
Internet) may be advantageous for clients, practitioners need to consider how to adapt and maintain in an e-health environment clinical practice standards originally developed for face-to-face interactions.

Second, practitioners need to determine how ethical issues will be addressed when technology is used to provide services to clients. The purpose of this paper is to examine social work professional standards and ethics as applied to the delivery of clinical group interventions in an Internet-based environment. There are two objectives: Firstly, we identify specific clinical practice standards and ethical issues that arise when using computer technology to deliver a psychotherapeutic group intervention. Secondly, we provide examples of strategies used to establish and maintain clinical standards and ethics in the context of a computer-based psychotherapeutic group intervention for spousal caregivers of people with Alzheimer's disease. Our observations were generated from a project that focused on the development, implementation and evaluation of an internet-based group intervention for caregivers of persons with Alzheimer's Disease. The aim of the project was to emulate face
to-face psychosocial support group process in an Internet videoconferencing environment, (b) explore the feasibility of using technology for delivering a psychosocial intervention, and (c) obtain feedback regarding participants' perceptions of the benefits of participating in a virtual group.

A secondary aim was to determine whether older adults with no prior computer Internet experience could be trained to access technology for information, and psychosocial support (Marziali, Donahue, & Crossin, 2005). More details on the development of the group theoretical frame work, the objectives of intervention model and the outcomes can be found in published work (Marziali, Donahue, & Crossin, 2005; Marziali, 2004; Marziali, Damianakis, & Donahue, 2004).

WHY DELIVER CAREGIVER GROUPS VIA THE INTERNET?

There is currently an extensive body of literature on intervention studies with caregivers of people with dementia. A meta-analysis of the effectiveness of a variety of caregiver intervention studies showed small to moderate effects overall, with psychotherapeutic and psychoeducation interventions having the most consistent positive results in the short-term.
Sorensen, Pinquart et al., 2002). A subsequent meta-analysis that examined psycho-social interventions for dementia caregivers showed similar significant, but modest results (Brodaty, Green et al., 2003). There is a paucity of studies of on-line service programs for caregivers and reports of Internet, video-conferencing group interventions for dementia caregivers (Brennan, Moore, & Smyth, 1995).

Given the trend of increased use of technology for the delivery of health care services to people in their homes, it is important for social workers and other healthcare providers to examine professional standards and ethics when moving from delivering face-to-face group psychotherapy to providing this service via the Internet (Bauer, 2001).

Frequently caregivers are home bound due to the following: (a) caregivers provide care 24/7 and cannot leave the person with dementia unattended, and (b) caregivers are responsible for numerous other daily activities such as employment, managing a household, and addressing the needs of other family members. Consequently delivering services via the internet to caregivers within their homes makes services ac
The concept of e-health has been defined in varying ways including
"the rapid access to shared and remote expertise by means of telecommunica-
tions and information technologies, no matter where the patient or the
relevant information is located" and "the use of telecommunication tech-
nology to exchange health information which provides access to health
care across time, social, and cultural barriers" (Stanben-y, 2000). E-health
encompasses a broad range of possibilities ranging from diagnosis, treat-
ment, education, and research that influences how patient care is pro-
vided. E-health, which has become the preferred term in healthcare,
refers to "all forms of electronic healthcare communication via the
Internet, ranging from informational, educational, and commercial prod-
ucts offered by professionals, non-professionals, businesses or consum-
ers" (Dyer, 2001). One of the reservations regarding e-health is the lack
of guidelines, standards and regulations available to ensure that e-health
is practiced legally, ethically and meets high practice standards in a vari-
ety of settings (Stanberry, 2000). To date, most of the disseminated re
search is on the ethical and legal aspects of e-health. The literature that
does exist in this area has focused on the issues related to informed con
sent and the risks associated with privacy and confidentiality (Stanberry,
2000). There has been little attention paid to other important ethical is
sues that should be considered including: adherence to standards of pro
fessional practice and recognition of potential clinical risks when using
technology to deliver services (Stanberry, 2000). Lacking are studies that
specifically focus on whether professional practice standards are met in
an e-health environment.

Particularly problematic is the unregulated provision of counseling
and therapy services via the Internet. There are currently more than 250
private practice web sites, and e-clinics, representing more than 700
e-therapists, which are expected to exceed 5,000 by 2005 (Ainsworth,
2001; Dunaway, 2000; Grohol, 1999a, 1999b). Despite this rapid in
crease in e-providers of psychological health care services, there are no
practice or ethics standards that insure the delivery of high quality psy
chotherapy services. At present, any person or professional can develop
a Web-based practice, and judgement of the quality of the service is left
to the service users who are in most instances, unqualified to judge
whether the therapist meets professional practice standards.

Several health care disciplines have recognized that using
technology to deliver services presents unique challenges for ethical
consideration. For example, the social work profession has questioned whether
delivering e-therapy via the Internet, poses challenges that may not be reconcilable
with current social work regulation (Kanani & Regehr, 2003). Given the lack of clear guidelines, others have raised the issue of maintaining ethical
standards in practice (Marson & Brackin, 2000).

Specifically, Kanani and Regehr examined four key responsibilities that are essential to the therapeutic relationship: the duty to obtain informed consent; the duty to maintain confidentiality; the duty to warn third parties of harm; and the duty to maintain professional boundaries. In an examination of these principles, they conclude that "social work practice needs to be reexamined to determine what variations in practice requirements may be necessary for social workers engaged in on-line counseling to provide quality care" (Kanani &
Regehr, 2003, pg. 160). This comment is true not only for clinicians providing counseling online, but any online health or social service. Currently, the responsibility of certifying and regulating health professionals working in a technology-based therapeutic setting is ambiguous. With respect to professional misconduct and/or negligence when using technology to work with a client, there is neither a specific code of ethics that applies to the e-health care provider, nor is there a regulatory body that sanctions professional e-health practitioners. For example, health professionals are not currently required to verify their professional status while providing online services, and there is no method to review their qualifications, or to apply quality control (King & Poulus, 1999). Another issue that needs to be considered is the possibility that client may reside in a different legal jurisdiction than the health provider and thus different regulation would apply. Since practice standards have evolved for other modes of communication (other than face-to-face), such as the telephone, it is expected that the Internet client-provider relationship will be similarly governed by evolving ethical practice norms (Spielberg, 1998).
to address the challenge and develop guidelines for on-line clinical social work practice and encourage the development of new professional committee structures responsible for monitoring the application of professional practice standards for on-line services.

Other disciplines have begun to develop guidelines for insuring professional standards for the delivery of counseling services using technology (American Counseling Association 1999), and for on-line communications and consultations (E-risk Working Group for Healthcare 2001). In addition, the International Society for Mental Health On-line (ISMHO), a non-profit society that promotes the understanding and development of on-line communication information and technology for the mental health community, has released guidelines for on-line mental health services and practice standards (International Society for Mental Health Online 2000).

However, these guidelines have been criticized for being too global. In particular, scholars have noted that the APA guidelines do not specifically outline what constitutes acceptable ethical conduct of psychologists in an e-health environment (King & Poulos, 1999). More recently
two initiatives have advanced the development of e-health delivery standards. First, the International Medical Informatics Association (IMIA) released a Code of Ethics for Health Information Professionals in 2002, in at least 13 languages (IMIA, 2002). As well, a recent and important milestone in the telehealth field in Canada is the National Initiative for Telehealth Framework of Guidelines (National Initiative for Telehealth, 2003). These contributions begin to raise consciousness about the need for all health professionals to be aware of basic practice standards for service delivery using technology. However, these guidelines continue to be non-specific to any professional group, and lack detail in terms of meeting specific standards that apply to specific models of intervention.

Apart from guidelines developed to monitor on-line professional practice, the Health on the Net Foundation (HaN) has developed a code of conduct for health professionals operating medical and health Websites. This allows consumers to determine the credibility of the organization and the information posted on their Website. The HaN functions as an accreditation body that ensures that their members adhere
to specific

Website principles. HaN subscribers number 3,000 sites and include the

American Alzheimer Society, the American Cancer Society, the National

Institute of Mental Health, and the Mayo Health (Health on the Net Foun
dation 1997).

Despite the fact that some organizations have adopted guidelines and
codes of ethical standards for on-line health service delivery, there is no
regulatory body or monitoring system that holds organizations account
able for technology-based services, Given the multitude of existing
e-health 'practitioners' who may not practice legitimately, such as
'crackers,' 'virus writers,' and 'unlicensed or unqualified providers,'
among others, there needs to be a mechanism to establish accountability
among professionals (Dyer, 2001).

CLINICAL CONSIDERATIONS IN THE IMPLEMENTATION OF
TECHNOLOGY-BASED SERVICES

The delivery of mental health services on-line is appealing to clinicians
for several reasons (Childress 1998; Dunaway 2000). First, e-therapy al
lows people to access services when (a) geographic barriers preclude atten
dance at a clinic due to residing in rural areas, (b) physical or sensory
impairment preclude travel to a service centre, and (c) transportation and
time constraints preclude participation in face-to-face interventions. These
barriers to service access apply particularly to caregivers of persons with
long-term debilitating diseases such as dementia. Currently, caregivers are
increasingly acquiring computer skills, and accessing valuable information
via the Internet (Echt, Morrell, & Park, 1998; Alexy, 2000). Also studies
show that older adults' attitudes towards computers is modifiable (Jay &
Willis, 1992), but different training models may be needed to address the
learning needs of older adults with visual and physical impairments. IDENTIFYING ETHICAL ISSUES IN AN E-HEALTH ENVIRONMENT
Several ethical issues need to be considered when delivering Internet
services including, but not limited to informed consent, privacy, confi
dentiality, and the duty to protect. As outlined in their respective profes
dional codes of conducts, health care providers from different disciplines
are required to obtain informed consent prior to providing treatment or
services (e.g., NASW, 1999). Obtaining informed consent in an e-health
environment may present some unique challenges. First, the anonymity
associated with technology-based interventions makes it difficult for the
health provider to assess whether the client is of legal age and has the ca
pacity to consent (Childress, 1998). As well, it requires that the provider
disclose all known benefits and risks of the treatment being provided. In
most cases, there is no empirical evidence to support the efficacy and
risks of the prescribed on-line psychotherapeutic treatment (Bloom, 1998).

While codes of ethics are intended to protect the privacy of the client it
may be difficult to guarantee privacy in an Internet environment (Dyer,
2001). For example, caregivers who participate in an on-line group text
based intervention may be observed by other family members. Also, care
givers may share computers with family members and as a result, their files
and messages may be accessed by others (Childress, 1998). Unless encryp
tion is used, the maintenance of confidentiality from the server end when
delivering Internet-based services may result in breaches of confidentiality
at two points: during the transmission of data, and during the accessing of
information (Childress, 1998). Similarly, the client or health provider may
mistakenly send a message to the wrong person (Grohol, 1999b). Since to
tal security of the Internet cannot be guaranteed, confidential communica
tion may always be at risk (Kanani and Regehr 2003).

Security software, such as encryption or password protected Web
based messaging have been commonly used in the intervention litera
ture as safeguards to protect confidentiality and minimize the risks asso
ciated with on-line communication (Ainsworth, 2001; Dunaway, 2000;
Grohol, 1999b). It is important for clinicians to use tools such as fire
walls, passwords, and backup storage systems to support the security of
the information communicated on-line (Childress, 2000).

The duty to warn and protect third parties from harm is an important
ethical consideration in the delivery of health care services using tech
nology. The lack of face-to-face interaction limits the health provider’s
ability to assess the potential risks to clients. As well, due to the absence
of client 'body language' and the inability to verify the client's identity
and home address, it may be difficult for the health provider to respond
quickly and effectively to crises situations, as for example suspected
suicide attempts. Implementing a monitoring system that allows the
health care provider and the client to contact each other on a regular ba
sis is essential. While geographic distance may pose b
amers, obtaining c
ontact information prior to commencing treatment and offer
ning an emergency or on-call telephone number, will insure clients' safety in the event of a crisis (Childress, 1998; Grohol, 1999b). In summary, health care professionals need to reexamine variations in practice that are necessary to accommodate the delivery of services via the Internet while maintaining high standards of care.

ILLUSTRATION OF ETHICS AND PRACTICE STANDARDS APPLIED IN AN INTERNET-BASED INTERVENTION FOR DEMENTIA CAREGIVERS

Described is a caregiver intervention group that demonstrates the clinical and ethical challenges when transferring from a face-to-face group intervention to an on-line group intervention. The aim of the group intervention was to (a) build rapport among group members, model self-other reflective processes, and provide problem solving strategies, and (b) integrate the provision of information, with identify ing the emotional barriers to information processing and problem solv ing. Group sessions were unstructured to allow participants maximum
opportunity to share and learn from each other and to enhance their

knowledge and skills in managing the care of their relative (Marziali, Donahue, & Crossin, 2005).

Caregivers of spouses with moderate level dementia were recruited for participation in a psychotherapeutic group intervention. Eighteen care givers (six within each of three groups) participated. Each caregiver was visited in their homes by a clinical researcher who described the project, the potential risks and benefits, responded to questions and obtained signed consent. The transition from face-to-face to on-line video conferencing group interactions occurred in an iterative fashion. The first group of six caregivers met face-to-face for eight weeks and then were trained in a lab to use computers and access the password protected Web site that supported the video conferencing group meetings. Computers, video cameras, and audio head sets and high speed Internet connections were installed in the caregivers' homes. Following training in the use of the computer and negotiating the Web site, participants logged on from home for weekly group sessions of one hour duration. The second group
met face-to-face for four weeks, were then trained in a lab, and then par
ticipated on-line from home. The third group was trained to use comput
ers simultaneously with the face-to-face group sessions, meeting for an
hour face-to-face, moving to computer lab training for one hour, followed
by weekly on-line participation from home. APPLICATION OF CLINIC'A.L PRACTICE STANDARDS IN AN E-HEALTH ENVIRONMENT
Clinical practice standards were initially established for the face
to-face group intervention and then transferred to the Internet-based
group intervention. First, all face-to-face sessions were observed by cli
nician-researchers and recorded for subsequent process analyses. Sec
ond, following thematic analyses of all face-to-face sessions the phases
of the group intervention were identified as well as specific strategies
used by the group facilitators to advance group process. Third, a theo
retical framework that supported the therapeutic approach evolved from
the analyses. Fourth, a group intervention training manual was devel
oped. In a parallel process, a simplified computer training manual was
developed, tested with the caregiver users, and continually revised to re
flect their learning experiences. As well, the web site was revised ac
cording to feedback from the caregiver users. In addition to providing a link to the video conferencing feature, the website provided information about the diagnosis and treatment of dementia and self-care strategies for the caregiver in the form of an online handbook. Also, an easy-to-use e-mail link was imbedded in the website.

Described are the specific stages involved for ensuring high standards of clinical and ethical practice.

Stage 1: Development and Testing of Theoretical Framework and Intervention Model

We developed and tested a theoretically-based model of group therapy for caregivers of spouses with dementia (Marziali, Donahue, & Crossin, 2005). Clinical standards were addressed by building an evidence-based model of intervention, initially by conducting a critical review of the existing caregiver and group intervention literature and subsequently by generating and testing intervention hypotheses during the course of observing the process within each of the three face-to-face phases of the groups. Added to model building were the thematic analyses of the group sessions. The outcome was a group
treatment training

manual that integrated theory, group purpose and process with specified

intervention strategies for advancing the work of the group. In addition,

expected outcomes for the participants were described. Subsequently,

the manual was used to train group facilitators and ratings of group

sessions showed reliable adherence to the model of intervention.

Stage 2: Mutual Consultation Procedures and Ongoing Observation of Face-to-Face Group Sessions

Central to addressing clinical standards in the development of the

theoretical and intervention manual was the implementation of ongoing mutual consultation procedures between the social worker group

facilitators and the clinician researchers throughout the duration of the project. Following each face-to-face session and each on-line group session, the facilitators and clinician-researchers held debriefing consultation sessions. The sessions focused on an analysis of group themes arising from the group sessions, social workers' own observations of the group dynamics, and intervention strategies used. The debriefing sessions contributed to the refine
ment of the theoretical and intervention model and closely monitored
the facilitators' adherence to the evolving intervention strategies in
an e-health environment.

Stage 3: Analysis of Audio-Taped Sessions

Qualitative analysis of the audio-taped face-to-face sessions involved
the establishment of codes, categories and extracted salient group themes.

The analyses yielded descriptions of group dynamics, therapist interven
tion strategies, and group themes by group phase, beginning, middle and
end. Results of this analysis contributed to the refinement of the theoretical
and intervention model as well as specifying practice standards for effec
tive application of the on-line intervention with a group of dementia care
givers.

Stage 4: Development of Intervention Manual and Analysis of Archived On-Line Sessions

For the final refinement of the internet-based intervention model, the ar
chived video-conferencing group sessions were qualitatively analyzed by
research assistants not involved in the analysis of the face-to-face session
analyses. Generated codes and thematic analyses showed that the identified
session themes and intervention strategies paralleled those identified in the analysis of the face-to-face sessions. The analyses showed that the group members transitioned from face-to-face process to online group process maintaining bonding and productive interactions (Intervention Training Manual, Revised Unpublished, Marziali, 2005).

Stage 5: Formal Feedback from Participants

Individual interviews were held with the caregivers six months following participation in the project (Marziali, Donahue, & Crossin, 2005). Overall, the caregivers reported enhanced experience of support from participation in the groups and decreased caregiver stress and burden. In response to specific questions about their physical and mental health status and levels of distress associated with caregiving, the participants reported improvement in several ways: (a) decreased stress levels, (b) more effective management of feelings, (c) ability to anticipate future difficulties, (d) open acknowledgement of emotions (anger, guilt, frustration, grief, humour, inspiration, honesty, safety) which were previously "buried alive," (e) group normalization of feelings, and (f) decrease in feelings of social isolation (Marziali,
Similar to in-person psychotherapeutic groups, the natural progression of themes, group dynamics, and rapport was maintained among group members. The participants reported that unlike text-based communication over the internet, they valued being able to see and hear each other through the Web-based video conferencing link. Important non-verbal cues were captured, and changes in facial expressions of affect were observed.

Development of the Website Based on User Feedback

Using guidelines that specified design criteria for elderly users, an intuitive, user-friendly website was developed (National Institute on Aging, 2001). It included large, obvious icon images (e.g., an envelope for the e-mail link and large font size), and uncluttered pages with subtle color contrasts. Links within the Website included a dementia caregiver handbook, a question and answer forum, e-mail, and a video conferencing link in two formats, a one-on-one video chat and a video group meeting. Unlike most health support interactive Websites that are text-based, our Website supports video conferencing that supports
one-to-one chats and in the conference mode allows up to six group members and a facilitator to be on-line simultaneously. At each stage of development of the Website, the participants' (group members and facilitators) reactions and suggestions were solicited and modifications to the Website were implemented. The aim throughout was to simplify the steps for accessing the Website links and particularly the group video conferencing mode. The greater ease in participants' use of the technology helped prevent technological barriers from negatively impacting the group intervention, and thus helped reinforce clinical standards of care. The Website and training manuals resulting from the pilot phase of the e-health intervention project were subsequently used in a feasibility study with positive results (see Marziali, Damianakis, & Donahue, 2004; Marziali, Donahue, & Crossin, 2005). 

TRANSITIONING FROM A FACE-TO-FACE GROUP TO AN INTERNET-BASED GROUP: ETHICAL ISSUES

In transitioning from an in person to an Internet based group, several ethical issues were considered to insure that participants were informed of any potential risks of their participating in an on-line group. Described
below are steps taken in both the initial recruitment stages and throughout the project, to address adherence to key ethical issues regarding: in formed consent, preserving privacy and confidentiality, and the duty to protect and monitor participants for possible adverse outcomes.

Obtaining Informed Consent

The professional obligation to obtain informed consent is complicated with the use of technology in the delivery of virtual support groups. A letter outlining the study in detail was mailed to interested participants, prior to arranging an in-home visit. This gave participants time to carefully read the information and consider their involvement prior to meeting with the research assistant. During a home visit the research assistant discussed details of the project in terms of risks and benefits and responded to questions. The discussion of potential risks and benefits included reflections on the anxiety associated with the use of technology, potential breaches of privacy and confidentiality, as well as the convenience of being able to participate in a support group in their own homes. With elderly participants, it was especially important to al
low sufficient time for the participants to process the complexities of the information provided. As well, the participants were invited to provide feedback about their participation in a face-to-face group and their anxieties about transitioning to internet video conferencing communication.

Since the technical aspects of the group process involved the use of video cameras as well as a sound system, the participants specifically consented to the use of these features. As with any informed consent procedure participants had the choice of withdrawing from the group at any time without the risk of being refused alternate services from the service providers.

When technology is used to deliver a health care service the service must be universally available to all clients regardless of their capacity to purchase the necessary equipment. In our project, about three quarters of participants did not have computers or high speed Internet access. Consequently, computers with capacity to support the Website features and Internet access were installed in the participants' homes at no cost to them. A contract for the use of the equipment for a period of one year
was signed by all participants. A technician installed the equipment,
trained the participants both in the lab and in their homes and overall
provided ongoing technical support for the duration of the project.

Privacy

Privacy issues are increasingly complex with the use of technology. Pri
vacy issues surfaced at two points in this project: (a) during the initial home
visit, and (b) during the on-line group sessions. Given the realities of
caregiving, there was a great deal of variation concerning the conditions
under which informed consent was obtained. Some caregivers stated from
the onset that they wanted the research assistant to come to their home
when their spouse was not there, thereby specifying their conditions for
privacy. Other caregivers arranged for home care so that they could come
to the clinic to discuss participation in the study. One participant requested
that his spouse be part of the interview process, being sensitive to his wife's
feelings of inclusion. One participant was not able to give consent with his
spouse present, and therefore the interview was rescheduled. An unex
pected factor concerned the amount of awareness that the person with de
mentia had about their diagnosis and about the spouses’ involvement in a dementia caregiver group. Consequently, some caregivers expressed a sense of guilt associated with the wish to protect their own privacy during participation in the support group. Some participants felt guilty for not telling their spouse about their involvement in the group, and chose to discuss this with other caregivers in the initial in-person group sessions. Other group members shared similar feelings of guilt. Discussion within the group led to resolution of individual dilemmas about participation in an Internet group that excluded their spouses. Some solutions included locating the computer in an area that would be least intrusive to the spouse and arranging for their spouse to be out of the home. Furthermore, participant privacy was protected through the use of a password-protected Website, downloading of all video sessions to the server and subsequent backup to CDs.

Confidentiality

Ensuring confidentiality is more complicated on the internet. In order to maximize confidentiality in our support group, three levels of password protected security was developed for the Website. A Website
scheduling feature protected each group from being 'visited' by a non group member.

Therefore, group members had access to their own group members but to no other groups. The social worker facilitators were able to access their own group members, both in the form of the group videoconferencing sessions, one-on-one video chats and e-mail. The system administrator and computer website design consultant had access to all available information including video-chat, video-conferencing, question and answer forum and email. Archived content, both text-based and video was downloaded to the website server and immediately copied to CDs for subsequent analysis by the research team users consisting of the principal investigator, clinician-researchers, and the research assistants. Only active e-mails were accessible to individual users.

The Duty to Protect and Client Monitoring

The duty to warn and protect third parties from harm is another ethical issue in the delivery technology-based health services. Mechanisms for monitoring client responses and outcomes are important when delivering an on-line psychotherapeutic intervention. In this project the monitoring
was achieved as follows: (a) social workers met on-line weekly with the group participants and were available for ongoing contact via one-on-one video chat, e-mail, and telephone; (b) a medication prompt appeared when the participants logged on to remind them to give medications to the spouse with dementia as well as remind them to take their own medications; (c) social workers consulted weekly with the team regarding any concerns about the health risks of participants and their spouses; (d) the research team, including the technical assistant was available throughout the project to deal with any clinical or technical problems as they arose; and (e) open lines of communication amongst team members insured that observations and information about participants was transferred to the appropriate team member for action-taking. The ease of access to some one from the team at different times, allowed for a transparent working system, within careful boundaries and designated roles. Information was privileged and maintained within the designated team. IMPLICATIONS FOR SOCIAL WORK PRACTICE IN AN E-HEALTH ENVIRONMENT Our work has several important ethical and clinical implications for
social workers who are in the planning stages or who are currently using technology to deliver clinical interventions. First, with regard to informed consent, a clinician or research assistant must be flexible in making home visits when necessary to obtain informed consent. When informed consent cannot be obtained in person, the social worker needs to take into account the following: (a) whether the client is of legal age; (b) whether the client is cognitively able to consent; and (c) whether the client has full understanding of the nature of the on-line intervention, and the potential risks and benefits associated with participation. Second, with regard to the on-going use of technology, all potential participants must have equal access to computer equipment and Internet connections, regardless of their financial status. Third, all non users of computer hardware and software must be offered training, free of charge. Providing computer equipment, training participants to use the equipment and to navigate the Internet, will minimize risks to client participation (Maheu, 2001). Particularly with older adults with declining health, it is important to keep in mind the range of abilities for learning
to use computers and software. Websites built to support intervention programs must be continually monitored, and on the basis of user feedback modified to maximize user satisfaction and outcomes. In particular, for older users, a technician must be available for ongoing consultation and trouble shooting. Fourth, before engaging in an Internet-based intervention program, health professionals need to consider the initial development and ongoing costs of maintaining the equipment and software over time. As well, the cost of the Internet service provider needs to be factored into the overall cost projections. Included in overall costs is the provision of equipment and internet access to those clients who cannot afford these costs. Only a universally accessible clinical intervention can be ethically supported by any government-based health care system. Thus, determining ways to make the technology accessible on a long-term basis needs to be considered during the assessment of the feasibility of the intervention. Fifth, ongoing technical and clinical support must be made available to the social workers providing the intervention, and to their clients. Institutional commitment and
Support must be declared at the onset when planning to develop an internet-based service program. In summary, while the use of technology offers unlimited opportunities for reaching isolated populations and offering innovative intervention strategies, important clinical and ethical issues need to be considered during the development and implementation of such programs. CONCLUSION

The development and evaluation of a virtual on-line psychotherapeutic group intervention program provided an opportunity to examine clinical and ethical issues that apply to both face-to-face and on-line models of intervention. The ethical and clinical issues discussed included provision of informed consent, protection of privacy and confidentiality, acknowledgement of duty to protect, the necessity of continual client monitoring, and the reliable adherence to standards of practice. An examination of these issues provided insight into the unique challenges of delivering services using technology.

Highlighted is the need to modify and expand existing practice standards in order to accommodate the issues that arise in an e-health environment.

Contextualizing these clinical and ethical issues with an
aging population is also an important component of an on-line group intervention, as many may not be familiar with the use of technology. Further research is needed to delineate the risks and benefits of interventions conducted in an e-health environment, in order to better inform clients, insure positive outcomes, and to have a better understanding of technology-based environments that are in.


An Evaluation of Dyadic Peer Support for Caregiving Parents of Children with Chronic Lung Disease Requiring Technology Assistance David B. Nicholas, PhD, RSW Krista Keilty, RN, MN, ACNP SUMMARY. This study evaluated a dyadic peer support pilot intervention for parents of technology-assisted children with chronic lung disease. These medically-fragile children, living at home in the primary care of their parents, require continuous or intermittent assistance from technological support such as home oxygen, respiratory or cardiac monitors and/or mechanical ventilators. The intervention consisted of matching parents with similar caregiving responsibilities, in order to reciprocally engage in parent-to-parent support. Results identified mixed outcomes based on quantitative and qualitative methods. Participants conveyed benefits and limitations of this modality of peer-based support. They generally favoured peer support as a clinical resource for caregiving parents as the intervention offered a valued opportunity for mutual sharing with another parent who could understand the unique real

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ities particular to caring for a medically-fragile child. Sharing daily experiences was reported to reduce isolation, increase knowledge, and provide an important sense of feeling understood. Challenges associated with peer support included scheduling difficulties and personality incompatibility. Recommendations for program development in clinical settings are described. doi: 10.1300/J010v44n03_08

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KEYWORDS. Chronic lung disease parents, intervention, caregiving

Children with chronic lung disease include a medically fragile population that require frequent episodes of intervention and the assistance of life sustaining
technologies (Keens, Jansen, Dewitt, & Davidion, 1990). These children, many
of whom resided in health care facilities until recent years, are increasingly now
living at home in the care of family members (Baumgardner & Burtea, 1998;
Wang & Barnard, 2004). Children and their family caregivers are confronted
with technology-dependence and the ongoing need for vigilant family
caregiving (Baumgardner & Burtea, 1998; McKeever, 1992; Nicholas,
1998; Wang & Barnard, 2004). The daily routine of these families includes
activities, schedules and interactions that reflect the ill child's condition, care
and treatment, leaving little time for parental selfcare (Baumgardner &
gests that family caregivers are at risk for social isolation (Baumgardner &
Bmiea, 1998; Kirk, 1999; McKeever, 1992; Nicholas, 1998; Stewart, Ritchie,
McGrath, Thompson, & Bruce, 1994; Traustadottir, 1991; Wang & Bamard,
2004), caregiver burden (Baumgardner & Burtea, 1998; Finch & Grove,
1983; McKeever, 1992; Nicholas, 1998; Stewart et al., 1994), and intrusive
ness of the illness in other m'eas of caregivers' lives including career ad
vancement, and recreation (McKeever, 1992; Nicholas, 1998;
Home-based care for medically-fragile children has also been linked with a greater risk of caregiver illness (Wang & Barnard, 2004), particularly if supportive resources are insufficient (McDonald, 1995; Thyen, 1999; Wang & Barnard, 2004).

Caregiving demands and a generalized inadequate allocation of resources to families with a medically-fragile child remains a barrier to family life (Kirk, 1999; Nicholas, 1998; Wang & Barnard, 2004). Mothers qualitatively describe insufficient social support from husbands/partners (Nicholas, 1998; Stewart et al., 1994), other family members (Nicholas, 1998), friends (Nicholas, 1998, Madiros, 1982), and health care professionals (Nicholas, 1998; Stewart et al., 1994). In a literature review addressing technology-dependent children and their families, Wang and Barnard (2004) conclude that parent/professional relationships lack reciprocity such that contrary expectations (McKeever, 1991) require parents to provide scrupulous care and maintain responsibility while continually deferring to the authority of health care professionals.

Social support, as a resource for coping (Stewart et al.,
as an important variable of health promotion and self-care for family caregivers (Nicholas, 1998; Stewart et al., 1994; Wang & Barnard, 2004). It constitutes a multidimensional concept comprising, "relational provisions in the form of attachment, social integration, opportunity for nurturance, reassurance of worth, sense of reliable alliance, and the availability of guidance" (Neville, 1998, p. 38; also in Weiss, 1974, pp. 23-24).

Social support contributes to family caregivers' mental and physical health (Barakat & Lenney, 1992; Koeske & Koeske, 1990; Stewart et al., 1994; Hart, Meagher-Stewart, Stewart, MacPherson, Doble, & Makrides, 2000); is reported to be the most significant determinant of employment for caregiving parents (Wang & Barnard, 2004); and may be vicariously linked to the quality of care provided to ill children (Barakat & Linney, 1992; Bailey, Blasco, & Simeonsson, 1992, in Stewart et al., 1994; Thyen, 1999; Wang & Barnard, 2004). Accordingly, the literature concludes that social support offers substantial promise by buffering the strains associated with family caregiving. Unfortunately however, so
The literature increasingly demonstrates that social support does not need to be confined to conventional programs with limited accessibility (e.g., Madara, 1997; Rounds, Galinsky, & Stevens, 1991; Tilden & Galyen, 1987; Vachon, 1980; Goodman, 1990). La Greca (1990, 1992) and Tilden and Galyen (1987) advocate peer support as a way of achieving the benefits of social support while minimizing the intrusion upon other restrictions, priorities and responsibilities of specific populations. Stewart and colleagues (1994) argue that peer-based support offers relational reciprocity in addressing support needs. In a study of 90 mothers of children with chronic illness, participants most frequently recommended the provision of social support from peers with similar caregiving experiences (Stewart et al., 1994). As such, insufficient social networks may be augmented by meaningful peer support that can accommodate parental limits of time, mobility and energy. The potential of peer support invites implementation and evaluation within clinical programs. There are no studies in the related literature assessing peer support specifically for parents of
medically-fragile child
dren requiring ongoing technology and extraordinary life-sustaining
care. Toward this end, this study evaluated a peer support intervention
for caregiving parents of technology assisted children with chronic lung
disease. DESCRIPTION OF THE INTERVENTION
Peer support was operationalized in this pilot intervention as a process
of dyadic (one-to-one) peer matching in which a caregiving parent was
matched with another parent with similar caregiving responsibilities. Parents were introduced and invited to engage in mutually beneficial infor
mation sharing and support. Peer support was presented as, "empathetic
listening, providing encouragement, and sharing personal experience."
for the specific peer intervention was developed jointly by the peer dyad.
Basic parent-based information about support and communication was
provided. Parents discussed pertinent issues, concerns and interests, as
mutually desired. Standard professional health care support and educa
tion were not altered, but rather this peer support intervention augmented
current health care services. RECRUITMENT
Participants were introduced to the study by a familiar health care
provider who described the aims and procedures of the study, and in

vited their participation. Participants were informed that study partici

pation was voluntary. Upon followup by a research assistant if parental

interest was expressed, a meeting was scheduled in order to obtain writ

en consent. Following study enrollment, participants were matched

with their peer. This was based on an attempt to match the following cri

teria for each parent dyad: ill child’s age, condition (including severity),

length of time since diagnosis, parental tasks required in caregiving,

preferred method of parent-to-parent communication (e.g., telephone,

Internet, in person), and language spoken. Paired participants were in

vited to mutually determine how their support intervention would pro

cceed (e.g., planned telephone communication, etc.). Participants were

encouraged to remain in contact once a week for a minimum of four

months (length of the evaluation). METHODS

To evaluate outcomes and processes of the intervention, a mixed

method approach (Creswell, 2003) was utilized, comprising preand

post-intervention questionnaires followed by qualitative interviews.
Questionnaires measured clinical changes in participant coping, social isolation and illness intrusion (meaning of illness). Ethnographic interviews, using the "long interview" approach (McCracken, 1988), were conducted among a sub sample of participants who evidenced diversity in interventional outcomes. Perceptions and subjective processes of the intervention were illuminated through this qualitative component.

Interviews were conducted either in participants' home or out-patient clinics, audiotaped and transcribed verbatim, and subsequently analyzed. Computer software for qualitative data analysis (NVivo, see Richards, 1999) assisted in theme generation. Qualitative rigor was verified through multiple blinded transcript reviewers; referential adequacy in which text quotes were used to verify themes; negative case analysis in which disconfirming or incongruent findings were sought in order to ensure the credibility of themes; and peer debriefing in which clinical experts were consulted about the relevance and 'fit' of study findings. Finally, member-checking was conducted whereby a subset of study participants reviewed and subsequently corroborated the viability and
acceptability of identified themes (Lincoln & Guba, 1984). Through this well-accepted and rigorous process, trustworthiness of qualitative findings can be assumed. THE SAMPLE

Participants comprised 34 family caregivers drawn from a database of technology assisted children with chronic lung disease being treated on an out-patient basis at a regional pediatric acute care hospital in a large multicultural city in central Canada. This sample size provided approximately 80% power to detect an effect size of .5 at a 5% level of significance. Family caregivers were invited to participate in the study if they had provided a minimum of 2 months of caregiving in the home for a child (≤17 years) dependent on continuous or intermittent assistance from technological support such as home oxygen, respiratory/cardiac monitors and/or mechanical ventilators. All family caregivers were biological parents (33 mothers, 1 father). They were matched with the parent of a child of similar age and diagnosis. III child's diagnoses included a range of neurological disorders (spinal muscular atrophy, Leigh's disease, central alveolar hypoventilation);
airways disease (bronchiolitis obliterans organizing pneumonias, desquamative interstitial pneumonitis); chronic lung disease (bronchopulmonary dysplasia, recurrent pneumonia); and congenital lung lesions (congenital diaphragmatic hernia). Children's age ranged from 2 months to 6.5 years with a mean = -2.2 years (median = -1.5 years; mode = < 1 year). Participating parents provided varying amounts of care; however, in all cases parental care extensively exceeded that of typical infant or child care.

Parents recruited into the study experienced varying levels of personal and family strain, and difficulties associated with their child's condition. Identified difficulties included the physical demands of care and resulting exhaustion. Many participants simultaneously managed households, provided extraordinary daily care to their ill child, and a few parents also juggled external employment. Many parents had been required to terminate their jobs because of the extensive care requiredments of their child which, for some families, resulted in financial strain. Several participants stated that prior to the study, they had expe
rienced minimal or diminished support from partners, family members
and friends, particularly as the child’s condition persisted; hence most
appeared to be socially isolated. FINDINGS

A series of paired t tests were conducted to determine differences be
tween Time I (pre-intervention) and Time 2 (post-intervention) scores
on standardized instruments addressing social support, coping and
meaning of illness. Montgomery (1991) states that a t test is robust un
der departures from normality. Accordingly, we used parametric statis
tics (t test). Means, standard deviations, differences and p values on the
three standardized instruments evaluating social support, coping and
meaning of illness, are reported in Table I.

Preand post-intervention standardized instruments demonstrated
largely non-significant outcomes associated with the peer support inter
vention. Differences in coping and social isolation scores before and af
ter the intervention did not achieve statistical significance. Moderate
improvement approaching significance was noted on the 'meaning of
illness' or illness intrusion subscale 'caregiver stress, change in com
mitments, and secondary illness appraisal' (p = 0.079)
based on the Meaning of Illness Questionnaire (MIQ) (Browne, Byrne, Roberts, & Streiner, 1988). The MIQ demonstrates fair internal consistency reliability (Chronbach's alpha) ranging from .71 to .79, and test-retest reliability is satisfactory (kappa = 0.45 to 0.99).

While it could be interpreted that quantitative findings suggest limited benefit from the intervention, a lack of instrument sensitivity for this unique population may have impeded the achievement of statistical significance on outcomes of coping and social isolation. Also, participants described varying levels of diminishing support or stresses in other relationships (e.g., family, marriage, home-based care assistants) that ultimately may have negatively skewed outcomes on selected variables of support and coping. Given these considerations, findings from qualitative interviews, discussed below, assist in describing, augmenting and offering participant commentary about perceptions, perceived outcomes, and processes of the intervention.

| TABLE 1. Measures at Pre-Intervention (Time 1) and Post-Intervention (Time 2) |
|-----------------------------------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| Variable                                      | Time 1 M SO        | Time 2 M SO        | Difference         | p-value           |                   |


1a. Perceived Social Support 10.57 5.88 9.79 6.51 -0.79 0.530 from Friends

1b. Perceived Social Support 13.14 7.24 12.07 6.02 -1.07 0.307 from Family

2. Coping Health Inventory 88.29 24.71 93.07 18.34 4.79 0.389 for Parents

3. Meaning of Illness 3.586 1.04 4.043 0.666 .457 0.079 Questionnaire (subscale: care-giver stress, change in commitments & secondary illness appraisal)

Post-Intervention Qualitative Interviews

Participants generally described appreciation for the peer support received from their matched parent: "To talk with (the peer), it was really nice because it's nice to talk to someone who has something so much in common with you." Interaction was initiated by meeting in-person or, if this was not possible due to distance or scheduling difficulties, over the telephone. Consistently, participants described their preference for initially meeting face-to-face, and concluded that this inaugural meeting heightened motivation for follow up contact between peers. Participants also identified greater engagement in the peer relationship when they were able to visualize their peer after having met in person. This, in turn, was thought to result in greater identification with and
empathy for the
peer and her/his child as well as greater depth and
intensity within peer
communication.

Impacts of Support
Peer dialogue reportedly commenced with, but extended
beyond, a
description of the child and family. Parents shared
experiential elements
of their lives and strategies, as well as intense emotions
such as grief,
anger and fear. Content of peer-based dialogue comprised
both unique
and common realities including children's diagnoses,
condition and
treatment trajectories, experiences of adjustment,
resources, interac
tions with health care providers, strategies for addressing
child/family
needs, parenting issues, and various other topics of mutual
interest. In
illustrating the range and intensity of discussion, one
parent stated: "We
were talking about (the children), our fears, (and) how to
cope with
them."

In seeking to counter the difficult elements of family
caregiving, par
ticipants described considerable benefits resulting from
their relation
ship with the peer. The opportunity for sustained
communication with a
"friend" who was perceived to "really understand" was deemed to be critical in feeling "connected" and fostering coping. The commonality of peers' experiences often resulted in a sense of camaraderie, as explained by one parent's description of speaking to someone, "who had gone through exactly what we were going through." Accordingly, the matched peer was often described to appreciate the complexities, challenges and struggles inherent in parents' daily lives:

It was really good. She 'I been through it, and I was going through it, and we could both relate to each other because of that. That is definitely the plus of the whole thing. . . . when (the hospital) hooked us (the peers) up together, that was the very first time I could open up to somebody who could understand.

Some participants predicted that a long-standing relationship with their peer would result from the intervention. A parent who was largely isolated in her home gratefully stated, "I was expecting it (the peer support intervention) to be somebody to talk to, but I didn't expect to make a friend." Several contrasted this beneficial support to other relationships within their natural network, and suggested that this matched peer uniquely offered extended support over time each peer could mutually understand the daily realities encountered. Whereas family and friends
may have expected that children would more rapidly improve, caregiving parents could understand the nuances, chronicity and uncertainty of the disease. Accordingly, not having to explain or justify the child's condition or symptoms to the peer was reported to be a critical and appreciated benefit.

Elements of Support

Participants described specific components of peer support that promoted meaningful peer connection and positive outcomes. These components included peers' mutual search for meaningful commonalities.

Examples of commonalities between peers included parent-to-parent similarities in their children's conditions, care requirements, and/or parental circumstances. I think it helped a lot because they (both peers' children) are so similar, ... and both of us (matched parents) are here (in hospital) so q{ten . ... She (the other parent) does the same things, and we could always speak for each other because we know the things we're going to say next, because we've done the same things before.

Several parents described an initial commitment to help another parent and attributed their involvement in the study to their motivation to be of assistance: "When (the study) came up, I thought maybe this is some way to give something back to someone who maybe hasn't been
able to deal with it as well as we have or, you know, had some (things that are) harder than we've had." In turn, this motivation to assist an other parent appeared to sustain ongoing commitment to the peer sup port process. Other parents described enjoying positive interpersonal dynamics and personal compatibility between matched peers. For in stance, several felt affirmed and supported by the other parent which was reported to leave them satisfied with and appreciative of this com munication: "It always appeared to me that (the other parent) was so much stronger than I. And talking with her, she seemed to be sending me her strength."

Parents described peer support as a dialogical exchange about child, parent and family experiences and strategies utilized. For many, utiliz ing the telephone and on occasion, the Internet, reportedly increased convenience and ultimately participants' ability to engage in the peer support process.

Elements Limiting Benefits

While many parents found dyadic peer support gratifying and helpful, a minority of parents experienced limited or negligible
benefits (although none described the intervention to be harmful). Several described experiencing a lack of meaningful peer connection and attributed this to scheduling difficulties, prohibitive telephone 'tag,' and a lack of similarity in their ill children's age or diagnosis. A notable impediment to personal investment in the peer support process was parents' lack of time to address their own needs for self care. A mother stated, "One part of me says, I really don't have time for a new friend ... I don't know how I could have time for another relationship." In such cases, it was perceived that ongoing contact could not be sustained due to the extraordinary and frequently changing requirements of the ill child's care and other family responsibilities. In other cases, peer contact was not well-established due to a parent's reluctance to dialogue with a previously unknown person and discomfort in divulging personal information.

Parents who did not initially meet their peer in-person reported feeling awkward when speaking over the telephone, and found it more difficult to establish and sustain contact. A notable trend was the reported benefit of initial face-to-face contact in allowing peers...
to "put a face to
the name" of their peer; which appeared to increasingly
forge a tangible
connection and solidify this emerging relationship.

Several participants described interpersonal difficulties
in which the
disposition or personality of the peer was
non-complementary. In these
instances, peer support was reported to be unsatisfactory
and often was
not sustained. As an example, one mother who viewed herself
as hopeful and positive, stated that it was not helpful to
communicate with a
parent who was more pessimistic about the future.

In a few cases, parents hesitated to contact their peer in
order to avoid
learning about potential medical problems. In these cases, it appeared
that the content of peer support (rather than process of interpersonal
communication) hindered potential communication. For instance, a
mother commented about her matched peer: "Since her son started to
go ahead where (my child) is still at the same level, it gets just so hard to
talk to them." She explained the personal pain of being indirectly reminded of her child's lack of improvement and/or deterioration: "I
think that you're happy that their kids are well, but . . . it's like they're
rubbing it in. " A few parents conversely were cautious about sharing personal or health information that potentially could discourage the other parent. Accordingly, sharing appeared to be limited by a range of process and content-based considerations. Clearly in hesitating within this peer engagement, parents demonstrated sensitivity as they carefully weighed potential impacts and consequences of information shared. CONCLUSION

Benefits of dyadic peer support included feeling understood, decreased isolation, and enhanced learning. Findings thus identified dyadic peer support to be a resource for parents of medically fragile children with chronic lung disease. Impact of peer support entailed the opportunity for mutual sharing of experiences and strategies. Desirable elements included the flexibility of a peer interaction, permitting in-home access. Limitations of contrived relationships, lack of motivation and incompatibility, limited outcomes, as did parents' lack of time for self-care. IMPLICATIONS

This study yielded diverse findings in that outcomes demonstrate limited beneficial impacts of a peer support intervention, and qualitative findings provide both participant perceptions and inherent
processes undertaken in forging supportive peer relationships among this parent population. Several considerations are helpful in interpreting the diverse outcomes and, specifically, in interpreting the general lack of statistical significance for interventional outcomes. For instance, decreased informal support (e.g., marital discord) and/or increased health-related strain (e.g., deterioration in the child’s condition) during the intervention timeframe, may have impeded potentially beneficial outcomes. In such cases, interventional effects on selected variables of parental coping, social isolation and illness intrusion may have been lessened by circumstances beyond the scope of this solitary and targeted intervention of dyadic peer support. Accordingly, current instruments appeared limited in identifying and measuring specific effects of this intervention. We agree with Stewart and Langille’s (2000) contention that global measures of psychological outcome, such as the stress, burden and coping instruments used in this study that are commonly used to capture intervention effects, may be more effectively replaced by measures of specific behav
ior changes that closely reflect the intervention itself.

It was anticipated that integrating qualitative and quantitative methods appeared ideal in evaluating this multi-faceted intervention. The addition of qualitative interviews, for instance, yielded important and detailed commentary about the perceived impacts and processes of the intervention that would not have been elucidated with a solely quantitative evaluation. Specifically, qualitative interviews illuminated the finding that when participants followed through and engaged with their matched peer, perceived benefits often ensued. Moreover, qualitative interviews revealed that face-to-face introductory meetings evoked interest in and commitment to the peer support process. Accordingly, inaugural meetings appeared to comprise an important window for peers to mutually identify with one another, negotiate reciprocity, and develop rapport. In clinical practice, ensuring opportunity for such an initial face-to-face encounter may need to be structured by health care providers to correspond with health care visits.

Qualitative findings in this study generally appear consistent with earlier literature which identifies social support as a
resource that promotes coping (Ritchie et al., 2000; Stewart et al., 1994). Flexibility in offering a variety of peer support opportunities may be most effective since varying forms (e.g., dyadic support, group support, mutual aid, professional support) may be needed to optimally accommodate the demonstrate that support is desired by many participants but dyadic peer support is not sought by all. Finding a flexible array of resources, therefore, is necessary in easing the many daily challenges of caregiving parents.

In delivering this resource within clinical programs, several pragmatic barriers need to be overcome. Examples of barriers include the intensity and relentless nature of parental caregiving requirements. These caregiving demands inherently reduce parental access to support, even though this support is needed and has the potential to be helpful. In this study, recruitment was limited by some parents' perception that they simply were too busy to participate in a peer support intervention. Family caregivers' were highly committed to their child's needs and well-being, yet often simultaneously denied their own need
for support
and self-care. The apparent contradiction illuminates a population of
parents at considerable risk for isolation and caregiver burden. Off
loading extraordinary patient care to parents (usually mothers) at signif
icant personal costs, including personal well-being, constitutes a larger
concern meriting careful review at clinical, structural, societal, and
ideological levels. Finding adequate resources to effectively support
caregiving parents and ill children is crucial to their quality of life.
In considering ways to implement dyadic peer support, the process of
optimally matching parents continues to present a challenge. Potential
personality incompatibility, as an example, may impede ongoing partic
ipation in and/or benefit from peer support. This challenge highlights
the need for future research formulating optimal matching strategies in
seeking best practices in peer support.
Notwithstanding these considerations, offering flexibility of psycho
social resources that includes dyadic peer support appears to be an im
portant and viable complement to family-centered pediatric care. Given
the extensive demands and unique circumstances confronting
caregiving parents and their ill children, finding ways to ease their burden and


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Knowledge and Social Work in Health Care: The Case of Finland. Johanna Bjorkenheim, MSS

SUMMARY

Studies carried out in different countries have shown that there is a lack of a common and up-dated knowledge base in social work, and that social workers make use of research in their everyday practice only to a very limited extent. On the other hand it has been shown that social workers feel they need knowledge but not necessarily in the form it is produced by the researchers. This paper explores issues of knowledge and competence in health social work based on the results of a survey and a focus group interview conducted among social workers in Finland. According to the results, social workers in health care do feel they need new knowledge. Some significant differences were found in the way health social workers view the acquisition and maintenance of professional competence and in the way they seek knowledge, when compared to social workers working in the municipal social services. doi: 10.1300/JO10v04n03_09

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haworthpress.com I. Available online at http://swhc.haworthpress.com © 2007 by The Haworth Press. Inc. All rights reserved. doi: 10. I300/JOIOv44ntB_09 261 <http://www.HaWOl1hPress.com © 2007 by The Haworth Press, Inc. All rights reserved.] KEYWORDS. Knowledge, knowledge seeking, professional competence, social work in health care

INTRODUCTION

This paper explores issues of knowledge and competence in health social work in Finland based mainly on the results of a survey con ducted among social workers in different parts of the country and in dif ferent work settings. Knowledge building and competence in social work have become burning questions in Finland, where the social work education and the societal context for social work has changed rapidly during the last decades. Social work becoming an academic profession
and being established as a discipline of its own at the university has pro
duced quite a lot of new research in social work, but this research does
not seem to have affected practice very much. The government is now
running a reorganisation of the social services with the aim of develop
ing knowledge-based good practices. This work is supported by a coun
try-wide network of eleven government-funded centres of expertise and
excellence in the field of social welfare with the task of enhancing col
laboration between research, education, and the practice field, and of
promoting and ensuring basic and specialist expertise in social welfare,
including social work.

So far social work in health care has received little attention in this pro
cess of developing the social work practices. Practically all health social
workers in Finland work in the public health sector, which compJises
both generalist care and specialist care, from local health centres to re
gionaluniversity hospitals. Public health care services are generally, like
in the other Scandinavian countries, provided for people from all socio
economic backgrounds as part of the universalistic welfare state model.
However, after the economic depression at the beginning of the 1990s the public health sector is having increasing financial difficulties, and cuts have been made in health care like in other welfare services. There are even signals indicating a change towards a more selective service system. In this new situation social work in health care is facing big challenges due to factors such as an aging population, a shift in the service structure from institutional to home care, a shift in the service production from publicly produced services to more private and other types of services (welfare-mix), an increasing need to involve volunteers and families as resources, a growing demand for evaluation of social services and social work, and legal and ethical issues in the frame of the new public management. Financial cuts, increasing demands for effectiveness, and new professions claiming competence in the social field add to the need for redefining the role of social work in health care. (This issue has been discussed, e.g., by Heinonen et al., 2001.) In this process of redefinition issues of knowledge, competence and research will have to be discussed and considered.
Knowledge in social work practice has been discussed for many years and from different perspectives. Social work has been said to lack a common and up-dated knowledge base (e.g., Bergmark & Lundstrom 2002), although in health care attempts have been made to define a knowledge base for social work (e.g., Ma 1997). Knowledge has been debated in terms of differences in communication between practitioners and the academic world (Osmond & O'Connor 2004), and it has been defined and categorized in different ways (Rosen 1994; Lyons 2000; TynjiiHi 2004). Often when talking about knowledge what is meant is so-called evidence-based knowledge. Nonaka et al. (2000) define knowledge in a broader way as "a dynamic human process ofjustifying personal belief toward the 'truth,' " as being created in social interaction, and as being context-specific, related to human action, and relational. They see knowledge as being created through interactions between tacit and explicit knowledge.

The Swedish researchers Bergmark and Lundstrom (2002) found that only a minority of the social workers working in the
individual and family
care of local government administrations actively seek new
knowledge in
their field. The authors lay the responsibility for this on
social work education, on researchers, on employing organisations, and on
the social
workers themselves. In the U.S. researchers have found that
compared to
other professions, in particular to psychiatrists and psychologists, social
workers make use of research or research-related literature
in their everyday practice only to a very limited extent (Mullen & Bacon
2003). In
Great Britain knowledge and practice in social work have been criticized
for being deficient and lacking in competence, particularly in the field of
childcare (e.g., Vass 1996). The Swedish researchers Nordlander and
Blom (2002), however, showed that social workers do not dislike evidence-based knowledge but tend to find it less useful than, e.g., novels,
when it comes to understanding the existential problems of the clients.
Social workers were found often to acquire knowledge from colleagues,
internal courses, and fiction rather than from scientific journals. This was
attributed to insufficient searching skills in looking for evidence-based
knowledge, and to lack of time to read and reflect upon new knowledge.

Most studies performed on social workers' attitudes towards knowledge and research concern social workers working in the public (municipal) social services. This is true at least for the two Swedish studies mentioned above, where the context is similar to that of Finland. This paper aims at studying issues of knowledge from the point of view of social work in healthcare, although it does not directly compare the results with those of the Swedish studies. In this article, the term 'knowledge' is used in a broad sense without any precise definition. The social workers participating in the study have been free to understand 'knowledge' in their own way.

The results presented are preliminary but give us some ideas about trends and challenges in healthcare social work of today. The results discussed in this article serve as a basis for further analysis of data, which will provide more knowledge on the characteristics of and the expertise in healthcare social work.

AIM AND METHODS OF THE STUDY

The aim of this paper is to study healthcare social workers' views on the use of knowledge for their work by addressing three questions:
I. How is professional competence in health social work acquired and maintained?

2. How is knowledge and research perceived by health social workers?

3. Do health social workers differ in this respect from social workers working in other settings (the municipal social services)?

Data was collected mainly through a survey. The study is part of a larger research project, which examines the mechanisms, structures and practices in professional knowledge production, innovations and the development of expertise in social work in Finland (Karvinen-Niinikoski et al., 2006.), and the survey data was drawn from a larger survey conducted within this research project. A questionnaire was sent out in October 2003, and a reminder a month later, to a total of 1,582 social workers, all members of the largest trade union for social workers in Finland. Answers were received from 716 social workers, i.e., 45.3%.

The sample consisted of one third of the Finnish-speaking members and all the Swedish-speaking members of the union. Finland is a bilingual country, and union members are registered by mother tongue. Because the survey results of the Swedish-speaking social workers are to be ana
lysed separately and since this group is small—only 333 union members—the questionnaire was sent out to all the members of this group. The response rate was the same in both language groups. The final data was weighed accounting for language and consists of answers from 583 social workers, 110 of which work in the public health sector.

In order to see whether social workers working in the health sector differ in their attitudes to knowledge compared to social workers in other work settings, the survey results of the health social workers (N :::: 110) have been compared to those of the social workers working in the municipal social services (N = 295), which is the largest employer of social workers in Finland.

The questionnaire used contained a large amount of questions, a number of which, dealing specifically with knowledge and research, were analysed for this article. The data was analysed using frequencies and crosstabulation, and, where possible, significance was tested using the Chi-square test for independence; due to low expected count in some cells this was not always possible. In addition, data from a focus
A group interview conducted with seven health social workers from one social work department in a university hospital in September 2002 have been used for reflection of the survey results.

**DATA OF SURVEY RESPONDENTS**

Background data of the survey respondents (Table I) show that social workers in health care are significantly older than their colleagues in the municipal social services. About 70% of the respondents in health care were over 45 years old compared to 53% of the respondents in the municipal social services. A large majority of all respondents were women, as in the profession in general.

Social work education in Finland has been at a Master’s level for about 20 years, but due to certain criteria for competency many social workers do not have a Master’s degree. This is particularly true in health care.

<table>
<thead>
<tr>
<th>Table 1. Background data of social workers in health care compared to social workers in the municipal social services (%)</th>
<th>Social workers</th>
<th>Social workers in health care</th>
<th>Municipal social services</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE*</td>
<td>(N = 110)</td>
<td>%</td>
<td>(N = 295)</td>
</tr>
<tr>
<td>Under 34 yrs</td>
<td>9.1</td>
<td>20.3</td>
<td></td>
</tr>
<tr>
<td>35-44 yrs</td>
<td>20.9</td>
<td>26.8</td>
<td></td>
</tr>
<tr>
<td>45-54 yrs</td>
<td>45.5</td>
<td>33.6</td>
<td></td>
</tr>
</tbody>
</table>

*AGE*
Over 55 yrs 24.5 19.3
Mean age 47.9 yrs 44.2 yrs
Median age 48.5 yrs 46.0 yrs
Age range 25-62 yrs 23-62 yrs
SEX
Female 94.5 93.6
EDUCATION
M.Soc.Sc. in Social Work 22.7 29.2
Master's degree in other subject 10.9 13.6
University Diploma in Social Services 1) 36.4 20.3
B.Soc.Sc. in Social Work and Social Policy 10.0 10.8
FORMAL COMPETENCY 85.3 83.7
WORK AND WORK HISTORY
In present job for more than 15 years 34.3 25.8
In social work for more than 15 years 69.3 45.2
1) Corresponding to a BSW exam.

* p <= 0.05, ** p <= 0.001 (Qui-square test for independence)

care, where social work started out with nurses being educated to 'social
nurses,' some of whom are still in work. The difference in education
level compared to social workers in the municipal social services is sig
nificant, although the proportion of persons with formal competency is
about the same. The professional education can be expected to have im
Applications for how social workers view knowledge.

Social workers in health care have generally been working in social work longer than their colleagues in the municipal social services, which is in consistence with the fact that they are older. Almost 70% of the respondents in health care had been in the profession for more than 15 years compared to less than half of the social workers in the municipal social services. One third had held their present job for more than 15 years. A long working career can be expected to have an impact on how theoretical knowledge is valued in relation to experiential knowledge. ACQUISITION AND MAINTENANCE OF PROFESSIONAL COMPETENCE

The social workers' views on how they had acquired and how they maintained their professional competence was studied by looking at the survey results on questions dealing with four perspectives: the most important factors in building up professional competence, knowledge creating with co-workers and social work colleagues, learning from work, and the use of supervision. The term 'professional competence' was not specified; the respondents could give the term whatever meaning they chose to.
Most Important Factors in Building Up Present Professional Competence

When it comes to rating the four most important factors in building up professional competence, there is no difference of opinion between the social workers in the two different work settings (see Table 2). Even the order of importance is the same: work experience is regarded as the most important factor followed by life experience, social work education, and further education. However, the survey also showed some differences. Social workers in health care seem to rely more on in-service training and supervision (supervision in the form it is provided in Finland; see below Supervision) than their colleagues in the municipal social services, who instead rely more on feedback and support given by the managers.

About one third of the social workers in both groups were taking some kind of study course at the time of the survey. When asked about the reasons for not having taken part in any further education during the past two years, the health social workers mentioned lack of interesting educations and lack of time, while their colleagues in the social services...
mentioned lack of time and being too tired.

The impact of life experience on professional competence was articulated by the participants in the focus group interview as adding to their humanity and humbleness, as being able to view clients more as human beings than as clients, and as realising that as social workers they do not know everything. Professional competence was considered to include

TABLE 2. Most important factors in building up professional competence as viewed by social workers in health care compared to the view of social workers in the municipal social services (%).

Question: How important have the following factors been in building up your present professional competence?

Answering alternatives: Of areat importance-of some importance-of no importance

OF GREAT IMPORTANCE Social workers Social workers in health care municipal social % (N = 110) services % (N =295)

Work experience 93.8 93.2
Life experience 73.6 62.6
Skills learned from co-workers/colleagues 34.6 35.4
Skills learned from managers 10.0 19.8
Social work education 54.6 50.7
Further education 50.4 40.7  
Feedback and support from co-workers/colleagues 33.3 40.3  
Feedback and support from managers' 17.1 29.9  
Independent studies 48.4 32.9  
In-service training* 30.0 18.2  
Professional literature (magazines, research, etc.) 29.7 20.2  
Supervision *** 38.6 18.8  
Consultations with experts 40.8 29.5  
Art and culture (films, fiction, etc.) 8.7 6.3  
Other, what? 12.5 24.4  
* P < =0.05, *** P < =0.001 (Qui-square test for independence) Due to low expected count in some cells the Chi-square test could not be used to test the significance for other variables with great differences in outcome.  
as important elements taking time for listening to and processing with the client, giving the client space and options, and not pushing him or her in a certain direction.  
Knowledge Building with CowWorkers and Social Work Colleagues  
Social workers working in the same work agency presumably meet more or less often during the day, not just for formal meetings but informally as well. They have many opportunities for dialogues on work-related
issues promoting and stimulating knowledge building. This possibility is lacking in work agencies where there is only one social worker, or where the social workers are scattered into different units and mostly working with other professionals, as is often the case in health care. On the other hand, working with colleagues of other professions offers many chances for learning and for knowledge building of a different kind. Some of the questions in the questionnaire aimed at capturing the respondents' views on the importance of knowledge building with co-workers and social work colleagues as opposed to working in a very routine way (Table 3).

The social workers generally seemed to think that discussing with colleagues and co-workers helps them in solving problems, and they are themselves prepared to share with others what they know. The social workers in health care, however, seem to have informal discussions about problems in their work much less often than their colleagues in the municipal social services, which suggests that they have to work more independently. Social workers in health care also spend significantly more time finding and providing others with
knowledge than do

the social workers in the municipal social services. This
may have to do

with the fact that social workers in health care serve as
experts in their

own field for professionals in other fields.

Learning from Work

Most social workers in both groups said they encountered
new situations and problems in their work all the time (Table 4).
This can of

course be both challenging and tiresome. However, most
social workers

felt they continuously learned new things in their work,
and this was

generally seen as a positive challenge. Sometimes the
demands of

knowing, learning and developing can become too much, but
this seems

to happen less often in health care than in the municipal
social services,

where to a significantly higher degree the social workers
felt that they
did not have the time to get informed enough to do a good
job, nor that

they had time to develop their practice.

Supervision

In Finland the word for supervision-'tyonohjaus' in
Finnish, 'handledning' in Swedish—generally has a different meaning than the
term 'supervision' in the Anglosaxon world. 'Tyonohjaus'/'handledning'
is by definition usually provided by a person not connected to the workplace, i.e., not by the line manager but by a professional, who has been accredited as a supervisor. 'Työohjaus' 'handledning' is more oriented to

TABLE 3. The importance of collaborate knowledge building with colleagues!

co-workers as perceived by social workers in health care compared to social workers in the municipal social services (%).

<table>
<thead>
<tr>
<th>Statement</th>
<th>Social workers</th>
<th>Social workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>By discussing with my colleagues/co-workers I can solve more difficult problems than I could otherwise.</td>
<td>91.7% (N = 110)</td>
<td>90.0% (N = 295)</td>
</tr>
<tr>
<td>I am ready to teach my colleagues/co-workers every thing I know.</td>
<td>93.5% (N = 110)</td>
<td>88.9% (N = 295)</td>
</tr>
<tr>
<td>We usually tell each other how we have managed to solve a complicated situation.</td>
<td>79.0% (N = 110)</td>
<td>82.4% (N = 295)</td>
</tr>
<tr>
<td>My colleagues/co-workers and I often have informal discussions about problems in our work.</td>
<td>84.6% (N = 110)</td>
<td>68.2% (N = 295)</td>
</tr>
<tr>
<td>A great part of my work consists of finding knowledge for the use of others.</td>
<td>28.8% (N = 110)</td>
<td>72.0% (N = 295)</td>
</tr>
</tbody>
</table>


*** p < = 0.001 (Qui-square test for independence)
wards reflection, dialogue, support and professional growth than towards consultation, direct advice and management. It can be provided on an individual basis, or to a group of social workers, to a multi-professional team or other,

During the previous 12 months, 61.8% of the health social workers responding to the survey had participated in this type of supervision. Supervision received in a group was significantly less common in health care than in the municipal social services. This may reflect the fact that social workers in health care more often work alone and therefore receive supervision individually. Supervision for multiprofessional teams is still quite rare. It is interesting to notice that, although the proportion of social workers having received supervision was about the same in both groups, the social workers in health care found supervision significantly more important in building up their professional competence than did their colleagues in the municipal social services (as shown in Table 2).

**VIEWS ON KNOWLEDGE AND RESEARCH**

What is Knowledge?

What is relevant knowledge in social work? As already mentioned, the social workers participating in the survey were free to
TABLE 4. Work as a learning experience in the view of social workers in health care compared to social workers in the municipal social services (%).

AGREE TOTALLY OR PARTIALLY 1) Social workers Social workers with the following statements: in health care in social services % (N = 110) % (N =295)

In my job I encounter new situations and problems 94.5 95.9 all the time.

I continuously learn new things in my job. 89.0 86.2

Situations where I can learn and see things in a new way are challenging.

I do not have time to get informed enough about the problems I have to solve at work. 37.0 68.3

There is no time to develop my practice. 50.9 71.7

1) Answering alternatives: Agree totally/partially-disagree totally/partially)

*** p < =0.001 (Qui-square test for independence)

knowledge in whatever way they wished. This was a conscious choice made by the research group. Since the social workers were not asked to specify what they meant by the term, it is not possible to know exactly what their conceptualisations have actually been in answering the survey.

The health social workers participating in the focus group interview articulated some thoughts on their perceptions of knowledge.
They defined 'knowledge' in the following ways: Knowledge is what social workers learn through education. Knowledge is knowing how society functions and what the societal conditions are for individuals and families. Knowledge means social work theory, concepts, terminology, social work methods, and legislation. Knowledge is knowing how to interact with clients, how to approach individual clients differently, how to make tailored solutions with them. It is also knowing what you do not know, knowing how to process, how to get informed, and knowing that you have to limit what you do and how you can do it. Knowledge is knowing how to use knowledge in flexible ways. It is knowing something other professionals do not know.

Ways of Seeking Knowledge

Knowledge building can be facilitated or hindered by the organizational structures of the workplace. In the survey the social workers were asked how they go about to get a particular piece of knowledge that they need in their work (Table 5).

TABLE 5. Health care social workers' ways of seeking knowledge compared to
social workers in the municipal social services (%).

Question:

If you need a specific piece of knowledge, how do you go about to get it?

Answering alternatives:

Often-quite often-sometimes-seldom-never.

OFTEN OR QUITE OFTEN Social workers Social workers in health care in social services % (N=110) % (N=295)

I ask the manager'' 20.0 42.6

I ask fellow employees 59.6 76.7

I ask social work colleagues out31.2 25.7

side of my workplace

I ask friends and/or relatives 2.7 1.0

I ask clients 7.3 8.9

I ask authorities supposed to 83.6 57.7

know

I look for it in professional litera54.5 37.9

lure or magazines

I search on the internet 62.7 38.2

In some other wav 54.5 26.3

Has unlimited access to Internet 89.9 97.6

, • • P < 0.001 (Qui-square test for independence). Due to

low expected count in some

cells the Chi-square test could not be used to test the

significance for other variables with

Igreat differences in outcome.

The most common ways of seeking information in health social work
seem to be contact authorities supposed to know, to search on the Internet, and to ask colleagues/co-workers. Professional literature or magazines are not uncommon sources of information either. Asking the manager is significantly less common among the health social workers than among their colleagues in the municipal social services. It seems that searching for relevant knowledge often happens through some kind of personal interaction with colleagues, authorities, etc., although the Internet and professional literature have become important tools as well. A majority of the social workers nowadays have access to internet as a source of information.

Use of and Attitudes Towards Research

The respondents of the survey were given four statements on research, which they were asked to agree or disagree with on a four-graded scale (Table 6). Most social workers seem to think that research helps them in structuring their thoughts and in finding new perspectives. Surprisingly, it is significantly more common for social workers in health care to think that research gives them ideas that they can apply in their work than for
their colleagues in the municipal social services. A majority of the health

social workers also seem to value collaboration with the university and/or

other educational institutions. In spite of this, most social workers seem to

think that it is very important to work in accordance with the rules. This is

understandable when it comes to social workers working in the municipal

social services exercising power of authority but is maybe more surpris

ing with social workers in health care.

Some elaboration of health social workers’ views on research can be

found in the results of the focus group interview. The health social

workers participating in this interview, on one hand, said there is a lot of

knowledge and research they should make more use of, but, on the other

hand, they thought that there is not enough research relevant to social

work in health care. Some even doubted the usefulness of research at all.

A wish for more research based on value discussions was expressed.

For instance, the impact of financial cuts in the welfare services on cer

tain client groups was seen as an important objective for research. A

need for more research to help them advocate for their clients and client
groups in multiprofessional teams, with authorities, and in society was expressed. The social workers thought researchers should be more active in bringing out their research results, because it seemed impossible to be continuously keeping up with new research. They also wished that research reports be shorter and written in a more comprehensible way.

The participants in the focus group interview felt it would be good to do some research themselves, because it would give them a higher status in the university hospital, where research is highly valued. They wanted to do research in order to get "hard facts" that they could present to their colleagues of other professions, and they also wanted to do research on how to work with clients, so that they could improve their own practice. However, one problem with doing social work research in a multiprofessional setting is that it is hard to distinguish the social work part from the work of other professionals. When doing research within a multiprofessional team, there is also a risk that other professions take the lead. But the social workers felt that doing multiprofessional re search could be rewarding as well. What prevented the social workers
from doing more research was above all the lack of time and money, in
sufficient research skills, and the lack of support from the university and
from the centres of expertise.

TABLE 6. Health care social workers' use of and attitudes towards research
compared to social workers in the municipal social services (%).

<table>
<thead>
<tr>
<th>AGREE TOTALLY OR PARTIALLY (1)</th>
<th>Social workers</th>
<th>Social workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>with the following statements: in health care in social</td>
<td>% (N = 110)</td>
<td>% (N = 295)</td>
</tr>
<tr>
<td>What do you think of the usefulness of research?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research helps me in structuring my thoughts</td>
<td>98.1</td>
<td>95.1</td>
</tr>
<tr>
<td>and in finding new perspectives</td>
<td>83.3</td>
<td>72.9</td>
</tr>
<tr>
<td>Research gives me ideas that I can apply in my work*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I try first and foremost to work according to the rules.</td>
<td>87.0</td>
<td>84.3</td>
</tr>
<tr>
<td>Is collaboration with the university and/or other educational institutions important? Yes.</td>
<td>86.2</td>
<td>80.3</td>
</tr>
</tbody>
</table>

* p ≤ 0.05 (Qu-square test for independence) CONCLUSIONS AND DISCUSSION

The study shows that, even though the Finnish social workers in health
care are older and have a somewhat lower academic education than their
colleagues in the municipal social services, they do not lack interest in knowledge and research, whatever their definition of 'knowledge' is. A vast majority of the health social workers participating in the survey expressed a wish for more collaboration with the university and/or other educational institutions, which can well be interpreted as experiencing a need for more knowledge and maybe also a need for a higher academic education.

A majority of the respondents said they are interested in research, because it gives them ideas that they can apply in their work. This seems to imply that they actually acquaint themselves with research results, which contradicts the assumption that because of lower academic education health social workers are less interested in research. However, the respondents do not say that they actually apply the research results, only that they get ideas that they can apply. This could mean that hearing and reading about research results stimulates their thinking about their own work, which affects their practice indirectly, even if not directly. This conclusion is supported by the fact that almost all the respondents an
answered that research helped them in finding new perspectives.

The fact that a majority of the social workers stated that they first and foremost try to work in accordance with the rules may not exactly be what you expect to hear from an autonomous professional social worker. On the other hand, it may reflect social workers' increasing awareness of patients' and clients' legal rights. On one hand, the Finnish welfare system is quite complicated and currently changing, and social workers need to keep themselves continuously updated about rules and regulations in order to give clients and colleagues in the multiprofessional teams adequate information about benefits and services available to every individual client.

However, the interest in knowledge, which the social workers express, hardly means just an interest in knowledge about the rules. There is, on the other hand, an increasing awareness of the subjective rights of clients.

The social workers in health care spend significantly more time than their colleagues in the municipal social services finding and providing others with knowledge. This fact may reflect the character of health social work as providing specific expertise in the teamwork of multipro
fessional settings, but it may also reflect a different attitude towards the clients. In health care an important part of the social worker's job is to provide clients with information and advice and enhance clients' 'knowledge,' whereas in the municipal social services the main task probably still is to make possible decisions of authority with less time to inform clients about services other than their own and to process new plans with the clients.

In acquiring and maintaining their professional competence, social workers in health care seem to rely significantly more on supervision and in-service training than do the social workers in the municipal social services, who instead rely more on the support of their managers.

This catches the difference of work setting in a nutshell: Social workers in health care work more independently networking, consulting authorities, and searching for knowledge relevant to individual client situations. There is seldom a manager to turn to with questions and for support. In health care the manager of social workers is often physically situated elsewhere or has a different education and is therefore less
available or is not able to give advice relevant to social work. Social workers in the municipal social services in the Nordic countries, on the other hand, have a double role, which health social workers do not have:

Besides the role of helping their clients in finding solutions to problem situations, they are at the same time exercising power of authority. It is evident that they often need to discuss with their manager the decisions they are about to make. This difference most probably explains why supervision and studies are more important to social workers in health care than to the colleagues in the municipal social services. Further more, working in a multiprofessional context constitutes a particular challenge for a social worker’s professional competence and professional identity, especially if she is the only social worker in her work place. Supervision and studies offer good opportunities for meetings with other social workers and for strengthening professional identity,

And, besides general social work knowledge, social workers in health care do need some knowledge related to sickness and health, which they can often easily acquire through in-service training.
To be continuously confronted with new situations and problems seems to constitute a main challenge for social workers in general, although it offers many learning opportunities as well. The learning aspect was appreciated by the majority of the social workers in health care, although about half of them seemed to think that they did not have time to apply the new knowledge for developing their practice. Learning, studying research results, and transforming new knowledge into practice takes time. It is difficult to see how social work practices can develop and become more reflective and knowledge-based, if the working conditions do not allow for this to happen.

In the questionnaire there was an open question about the respondent's views on the future. It seems that Finnish health social workers are at the moment rather pessimistic about the future of their profession. They fear that, with the continuing financial constraints, cuts will lead to a diminishing demand for their services. Some of them feel that they are put to do secondary tasks leaving them with less possibility to do the work they are qualified for. The status and salary of health social work
ers are low, and there is pressure to lower the educational standards. Va
cancies are left unfilled or filled with persons with less
competence and
less education. The social workers feel that other
professions are taking
over the "social" part in health care.

It seems reasonable to assume that the social workers' interest in re
search reflects a hope that research could help them do a
better job and
increase their professional status in the health care
setting. The long ac
ademic research tradition in health care presumably also
contributes to
enhancing health social workers' positive attitude to
research. Efforts to
produce data bases of social work research will hopefully
meet social
workers' need for easier access to research in the future. However, be
fore research results can be adequately applied into
reflexive social
work practices, they will have to be processed and assessed
by the social
workers themselves to fit the work context and the personal
way of
working. More systematic sharing and processing of new
knowledge in
study groups with social work colleagues could be an
effective way of
learning about and implementing research-based knowledge, since the
social workers’ way of working is through interaction with people, be it clients, colleagues, other professionals, authorities or other. Such study groups could provide a more structured forum for the kind of collaborative knowledge building that seems to be such an important way for social workers to acquire new knowledge.

In spite of the pessimistic views on the future of their profession, many social workers in health care still do find their work challenging and necessary, and show a strong commitment to their work, as the social situation for many of their clients is getting worse. Health care represents a particular type of setting for social work with special demands for independent working skills and a strong identity acting as a professional expert in a multiprofessional environment. This has implications for both the basic and the further social work education. The new centres of excellence on social welfare could also offer social workers in health care an important arena for exchanging and creating knowledge.

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