

# Caritas Research

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This publication stresses the importance of mental health and the impact on physical health. Tobacco abuse and eating disorders are examples, but attention deficit disorder in children may interface with family dynamics and future relationships. A novel treatment approach is described by the Misericordia Community Pediatric Research Group. Caregiver reviews and research completes this issue of Caritas Research.

Dr. Fred MacDonald  
Medical Director, Caritas Research Centre

## Capacity Building through Integrative Programming: The Tobacco Reduction and Cessation (TRaC) Project

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### Background:

C. Everett Koop aptly described the tobacco epidemic as the public health disaster of the twentieth century. Public health measures including taxation, policies to restrict smoking, counter advertising, bans on advertising and promotion, and cessation support are effective in reducing tobacco consumption yet tobacco use remains the leading preventable cause of disease and death.

Tobacco cessation is effective in reducing disease burden and mortality, and is considered a key variable in tobacco control over the next few decades. The National Commission on Prevention Priorities findings stated that developing the infrastructure for tobacco cessation is among the most important actions that can be taken to save lives, and dollars, and to improve the quality of health for people. Currently, only twenty to twenty-five percent of smokers who are trying to quit use any evidence based treatment. Simply improving the delivery of effective cessation methods has the potential to achieve substantial gains in reducing prevalence of tobacco consumption, and this role has

been suggested as the task of the public health community.

People with mental illness are disproportionately affected by tobacco dependence when compared to cohorts in the general population. They are more likely to smoke and are reported to consume 44% of cigarettes smoked in North America. Smoking remains the most salient risk factor for premature death, disease, and disability in the mentally ill and certain subgroups of mentally ill persons are at higher risk of developing cancer than non-mentally ill smokers. Yet the focus of health promotion and tobacco control efforts has not reflected this reality. Interventions to reduce tobacco consumption for this special population have been burdened by numerous systemic obstacles as well as ignorance of the available tobacco control opportunities.

Those with mental illness are interested in quitting smoking, and are capable of doing so, when provided a supportive environment that includes evidence-based tobacco cessation interventions.

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Tobacco dependence is a chronic, relapsing psychiatric disorder, classified as such in major global nomenclature systems, and which requires ongoing treatment. A body of evidence and guidelines exist which support the incorporation of tobacco dependence treatment into routine clinical and hospital care. Cessation interventions, including motivational enhancement therapy (MET), cognitive behavioral therapy (CBT), and nicotine replacement therapy (NRT), have documented evidence supporting its safety and efficacy and have the potential to help many more tobacco consumers than they do now.

Phase I of Tobacco Reduction and Cessation (TRaC) Project targeted professional capacity enhancement (including development of knowledge, skill and attitudinal paradigm shifts conducive to successful tobacco control and advocacy) and the integration of these interventions into existing programming directed to those with mental illness and tobacco dependence. The second phase of the project, a clinical trial to determine efficacy of the approach on tobacco consumption, quality of life, and economic measures, is currently underway, and preliminary reporting will be presented.

### Methods:

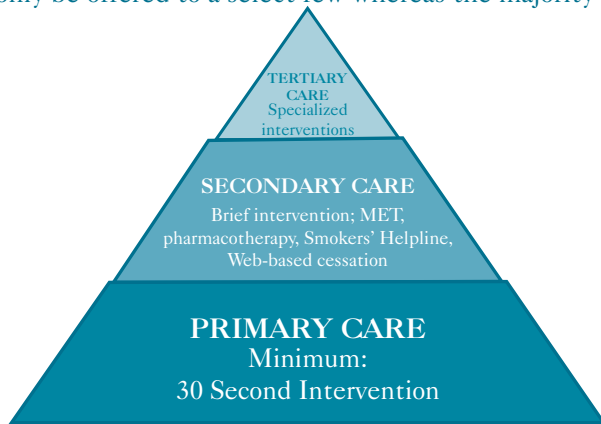
The project's objectives are: to build professional capacity for treating tobacco dependence; increase evidence-based programming in regional healthcare sites; conduct a clinical trial to assess the effectiveness of the newly established model for tobacco dependence treatment on consumption and quality of life measures of tobacco consumers with mental illnesses, and; to establish a pervasive link between such interventions and other cessation resources. Approval was obtained from the University of Alberta Health Research Ethics Board prior to initiation of the project.

A framework of care for the project was developed for treatment seeking individuals to maximize the benefits of interventions. The intervention in this model requires a time commitment from front line health professionals of a minimum of thirty seconds which includes assessment for tobacco consumption, documentation of such, and referral for treatment, and thereby fulfills the minimum systems strategy recommended in the USDHHS guidelines. Enhanced intervention at this level includes providing support to prevent nicotine withdrawal during periods of abstinence while receiving care (for example, during hospitalization for treatment) or more complex interventions, such as MET, as fits the health professional and/or the setting.

Using combinations of effective tobacco dependence treatment is strongly recommended for all populations, especially those with high and heavy rates of smoking such as psychiatric populations. Secondary level intervention in this model consists of individualized combinations of interventions including MET (individual or group therapy with focus on treatment engagement, tobacco reduction, cessation and relapse prevention), CBT (weekly

group therapy for ten weeks), NRT (individualized regimes), as well as referrals to the telephone and web-based cessation resources. This secondary level of care is best integrated at community-based clinics and primary care settings.

The tertiary level of care in the treatment paradigm is for those with complicated tobacco-related issues, treatment resistant tobacco dependence, or challenges interfering with treatment which require the interventions of a specialist. This highly skilled treatment, delivered by a fellowship-trained addictions psychiatrist, would only be offered to a select few whereas the majority



A 30 second interview of all primary care interventions is advised. This consists of three simple steps:

1. Ask: Do you smoke?
2. If yes: Do you want to quit?
3. If yes: Provide with quintet and/or helpline and/or community-based clinic information ([www.trac-project.org](http://www.trac-project.org))

of clients are managed on the primary and secondary levels of care.

Within this treatment framework, treatment-seeking tobacco dependent individuals can be offered individualized interventions for tobacco dependence based on their unique requirements.

### Consequences:

The original project design provided learning opportunities for thirty to forty-five health professionals on tobacco dependence treatment to support the establishment of interventions in the mental health sites in the region. The timing of the two-day training workshops coincided with the implementation of the extensive tobacco control policy and resulted in an overwhelming response for training. Two hundred staff members from other disciplines and treatment areas, medical residents, representatives from other health regions, community pharmacists and community agencies

members were accommodated during three two-day sessions.

Additionally, three health professionals were sent to the Mayo Clinic to obtain Tobacco Specialist Certification status and a further eight people attended the specialized Tobacco Intervention Program for Smokers at the Centre for Addiction and Mental Health (CAMH) in Toronto. There were two purposes for this adjunct to the TRaC training: to import learning and to ensure consistency in practice with global key opinion leaders and best practices.

Graduates of training received support through site visits to identify and facilitate the administrative and management processes required to effectively implement tobacco reduction activities. A TRaC information website was maintained for the duration of the Phase I to operate as a communication mechanism for graduates, and to provide access to resource materials, news, and updates. A bi-monthly discussion group on case management was available through teleconferencing. A resource manual was developed based on the two-day training and distributed to local sites, and other regional health authorities. After the launch at an international scientific meeting, wide provincial dissemination, and a local press release, requests for information regarding the project and copies of the manual have been received from local, provincial, national, and global sources including sites in the United States, England, and Australia.

The development and implementation of the revised tobacco control policy throughout the region went smoothly and support by some for tobacco reduction and cessation measures subsequently waned. Internal funding for the facilities to accommodate two more planned sessions was denied which forced cancellation of training for a further one hundred fifty health professionals. Nor was support sufficient to proceed with a working committee to identify and resolve integration issues; an activity considered crucial by many. Management of the TRaC clinics was formally transferred from the TRaC Project to Ms. Nancy Fraser at the Mental Health Division. Three of eighteen sites have fully integrated the model and are involved in the quality assurance and evaluation component of the project.

### Interpretation:

Because of their interaction with tobacco consumers as care providers, and their role as health

communicators in societies, training of health professionals is an essential part of a cost-effective, evidence-based strategy of the treatment of tobacco dependence. Phase 1 TRaC Project was successful in training almost two hundred health professionals in one of the following: the five-day Tobacco Certification Course at the Mayo Clinic; the training from the Centre for Addiction and Mental Health; or the two-day TRaC workshop. Phase II of this project, a clinical trial of the effectiveness of this approach, is currently underway. Preliminary outcomes data of this approach are optimistic, compatible with other international studies, and indicate substantial improvements in cessation rates and subsequent quality of life measures.

For this tobacco reduction and cessation approach to be fully integrated, and the health region experience the health benefits, and reduced costs, of tobacco cessation, the ongoing leadership for tobacco cessation requires identification and is a necessary endeavor. This raises the difficult question of who should be the rightful “custodian” and leader

for tobacco cessation within a regional health authority. Health care providers can do much by implementing cessation counseling. The task of creating a system to help tobacco consumers obtain the quitting assistance that they need is an undertaking best implemented at the level of policy makers and leaders of health systems. Building this infrastructure can yield benefits that extend beyond tobacco control to other areas of chronic disease prevention.

This project partnered Addictions Psychiatry and Public Health, and provided opportunities for many disciplines and services develop the skills to treat tobacco dependence. The most pressing challenge is to continue working towards maximizing the implementation of tobacco reduction and cessation activities to optimize the benefits of tobacco cessation for the region. Without a clearly defined mandate, responsibility, and resources for leadership in tobacco cessation, it is unclear how this may be actualized.

#### Acknowledgements:

We recognize the following organizations for their financial support to the Tobacco Reduction and Cessation (TRaC) Project: Tobacco Control Program, Health Canada; Pfizer Consumer Healthcare; Alberta Tobacco Reduction Strategy, AADAC

The views expressed within this manuscript may not necessarily represent the view of the funding agencies or Capital Health or the University of Alberta.

#### Note:

Phase 1 of the TRaC study was recently published in the CDC's journal: Preventing Chronic Disease, and a full text version, including references, can be accessed at: [http://www.cdc.gov/pcd/issues/2007/apr/06\\_0095.htm](http://www.cdc.gov/pcd/issues/2007/apr/06_0095.htm)

## Dietitians and Eating Disorders:

### An International Issue

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Dianne Drummond & Suzanne Hare have been doing practice-based research at Grey Nuns since the early nineties. Their current project is called Dietitians and Eating Disorders: An International Issue. Interest for this came from an earlier student project in 2000 which found more than 30% of nutrition students with eating disorder behaviors, a rate higher than noted in the literature in other university groups. When they presented a poster on this topic at the 2004 International Congress of

Dietetics conference in Chicago many colleagues from around the world expressed interest and shared like concerns for this group. However, discussion revealed that few had formal protocols to assist students with eating disorder concerns. Additionally, anecdotal reports revealed that some schools were screening students for eating disorders and excluding them from their programs, while others were removing discussion about eating disorders from their curriculum because the topic was problematic

to many of their students. This obvious concern for the problem and gap in knowing how to deal with it spurred Drummond and Hare to develop a research project to begin to address this issue. Funding for this research study comes from the Canadian Foundation of Dietetics Research.

Early steps in the project involved the development of a questionnaire. Nutrition students at the University of Alberta assisted with this stage, developing and pilot testing it with local professionals. Following this, Emma Smid, an international student from the Hogeschool van Amsterdam School of Food & Nutrition in Amsterdam worked with Drummond and Hare last spring to begin distributing the questionnaire around the world. They partnered with Dietitians of Canada and the International Congress of Dietetics to create a list for distribution to international colleagues. The questionnaire was sent to 664 heads of undergraduate university nutrition programs, university nutrition professors and dietetic internship coordinators, asking questions to assess the concern, and determine if screening for eating disorders exists, as well as what supports are available for individuals identified with an eating disorder.

To date ninety-two questionnaires have been returned from, Australia, Brazil, Canada, Denmark, Fiji, India, Israel, Italy, Jamaica, Netherlands, South Africa, Trinidad, Turkey, UK, & USA. Preliminary analysis has been completed on the first fifty. The following results reflect this preliminary analysis. Pertaining to demographics, all respondents were female. 86% were educators, 14% were faculty heads, Deans, or administrators. 80% had more than 3 years experience in their current role. When looking at questionnaire responses, 80% felt that eating disorders are a concern among nutrition students. While 56% thought that nutrition education programs should have policies/procedures in place to assist undergraduate students and dietetic interns, only 16% had such in their programs. Additionally, 50% thought it would be good to screen nutrition students for eating disorders; however, 86% felt that there would be ethical issues in screening for eating disorders. Many felt that having an eating disorder

should not affect acceptance into an undergraduate nutrition program of study (58%), nor a dietetic internship (42%). A further 96% felt that discussion about eating disorders should be included in the university curriculum, while 26% recognized that this might trigger or reinforce eating disorder behavior in some students. When looking at the ethics of professional practice, 42-46% felt that having an eating disorder (by a student or practicing dietitian) could put the public at risk; however, most said that having an eating disorder shouldn't affect a student's continuation in the program (78%), nor a dietitian's licensing or permission to practice (56%). And finally, only 20% of respondents said that there was a local regulated body available to protect the public from dietitians who may not meet accepted standards of practice in nutrition counseling because they have an eating disorder.

Some of the Anecdotal responses in the questionnaires were very interesting. Mixed feelings about screening for eating disorders were reflected in the following two comments, one from USA and the other from Israel: "(Screening students for eating disorders) should not be an issue if it is impacting their performance or the safety of others." and "(Screening practices for health concerns) are outside the responsibility of the university. In addition, we do not have the budget or professional staff to address this issue. Screening of students for any medical/mental disorder is an infringement of their rights." Another from Turkey said "Any (screening) action stimulating the disorder can be harmful." Regarding the ethical concerns about someone with an eating disorder providing nutrition counseling, an American colleague said "Someone with an active eating disorder, depending on the degree, would not be appropriate to work with patients who have weight/dietary issues." Additionally, a respondent from Trinidad & Tobago felt that "Having an eating disorder should affect a dietitian's licensing or permission to practice if the professional does not take steps to address/correct the disorder."

It is apparent that eating disorders are a concern in nutrition faculties around the world; however, few



*Workbook utilized in an 8 hour instructional programme entitled: "Making the Most of ME"*

programs have policies in place to address this concern. From responses on the questionnaires, there is controversy about how to address this. While screening students for eating disorders might be a desired option to address this concern, ethical issues would first need to be addressed. And the final question raised, that is the ethical concern for public safety, is another worry expressed by many respondents, but how to deal with this is an additional questionable area.

The next step of this project will be to develop recommendations for addressing the rising concern of eating disorder in the dietetics profession worldwide. Enthusiasm for the project has been remarkable. One person commented “I think this type of research is long overdue. Thanks for taking this on.” Another said “I feel this is an area of great concern, and feel that we are not well prepared to address it.” Already, 39 dietitians from countries around the world have expressed interest in looking at the data and making recommendations. Recently a

dietitian from Australia contacted Drummond looking for information, as her group is planning to contact their local university about this concern. Clearly, people are wanting to tackle this issue.

This research is another example of Hare & Drummond's initiative and creativity. While their jobs have changed over the years, their work together on research continues. This current project represents a partnership between Caritas Health Group Food & Nutrition Services and Capital Health Regional Mental Health Program. This research project will also result in international partnerships which will make a significant impact on the health of nutrition students and dietitians around the world. Plus, it will facilitate discussion globally on the rising concern of eating disorders in the nutrition field, and provide bench-mark knowledge and information to assist in developing policies and procedures to address this rising concern. It is yet another example of Drummond & Hare's remarkable ability to “think outside the box” and explore new opportunities.

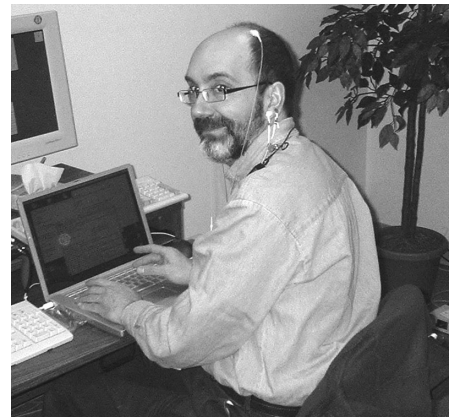
## ADHD and Neurofeedback

Attention-deficit/hyperactivity disorder (ADHD) affects 3% to 5% of all children and is the most common presenting disorder seen in children's mental health settings. Symptoms of hyperactivity, impulsivity and distractibility often begin in early childhood and sometimes continue into adulthood. The impact of ADHD on an individual's psychological development, education, relationships and family is immeasurable.

Conventional treatment for children with ADHD is a stimulant called methylphenidate a common brand name for this drug is Ritalin. However there are concerns about the short- and long-term effects of this and other medication. As well, research studies show that no one single treatment provides long-lasting improvement in ADHD, especially once treatment is terminated.

“It's not surprising that there's a lot of interest in a more natural or less invasive approach to therapy for ADHD,” explains Dr. Lola Baydala, an Edmonton pediatrician and director of the Misericordia Community Pediatric Research Group. “Parents commonly seek alternative therapies to stimulant medications for the management of ADHD symptoms. Neurofeedback is one alternative treatment that has received a lot of attention.”

Neurofeedback is a technique that can train people to change their brain wave patterns. An electroencephalograph (EEG) is used to monitor brain waves; individuals are taught to use the real-time EEG feedback to modulate certain aspects of their brain wave activity. As a treatment for ADHD, neurofeedback is based on findings that measurements of brain activity in many individuals with ADHD differ from what is considered normal.



*Dylan Lampman - neurofeedback trainer*    *Dr. Erik Wikman - psychologist*

*Dr. Jim Hoover - computer scientist*

For example, individuals with ADHD tend to exhibit increased slow wave activity (a pattern associated with daydreaming and distraction) and decreased fast wave activity (a pattern associated with sustaining attention). Neurofeedback treatment is designed to train individuals to increase fast wave activity and decrease slow wave activity. By modifying these brain wave patterns, it may be possible to reduce or eliminate many ADHD symptoms.

But does neurofeedback really work? This question is top-of-mind for a research team from the Misericordia Children's Health Centre. The Centre has had a long-standing interest in neurofeedback. There is a neurofeedback laboratory at the Misericordia Hospital; researchers and clinicians from the Centre have been trained to provide this treatment.

“Prior to routine use of this equipment, a decision was made to more closely investigate the effectiveness of neurofeedback therapy for specific childhood disorders,” explains Dr. Baydala. “Our own research team published a review that showed that numerous neurofeedback studies have had positive results. However those studies have been criticized for a number of reasons—small sample sizes, lack of controls, and lack of comparison to other treatments. It became clear to us that we needed to conduct a randomized controlled trial to compare neurofeedback to treatment with stimulant medication. This would be the only way to establish the relative effectiveness of neurofeedback as a treatment for ADHD.”

The researchers took the first step toward this goal in 2004 with the launch of a feasibility study for a controlled, randomized trial comparing Ritalin and neurofeedback therapy for ADHD. It involves researchers from the Misericordia Children's Health Centre, Child and Adolescent Services Association (CASA), Stollery Children's Hospital, University of Alberta and the Children's Hospital of Eastern Ontario Research Institute. Funding for the feasibility study was provided by the Hospital for Sick Children Foundation.

Beginning with a feasibility study, rather than a full-scale trial, is absolutely vital, explains Dr. Liana Urichuk, research director for CASA. “The full-scale randomized controlled trial must be a double-blind trial—the people who receive the treatment as well as the people who administer the treatment must not know whether the neurofeedback treatment is real or not. This isn't difficult to do when testing something like a pill. But we require a sham neurofeedback technique—one that looks and appears to work exactly like real neurofeedback, but is not actually doing anything. That is a huge challenge. Our feasibility study is designed to test whether a sham neurofeedback technique will work.”

Computer scientists from the University of Alberta developed the sham neurofeedback program for the study. It appears to function in the same way as the real neurofeedback program—if the child keeps their brain waves within certain parameters, the computer game they are playing works smoothly and quickly. The sham treatment has the same set-up, except that the brain waves being displayed are a

shuffled version of the person's baseline EEG. Another key innovation is that the sham neurofeedback is sensitive to excessive head and body movement, just like a real neurofeedback program. Too much movement will cause the computer game to stop functioning.

The feasibility study began enrolling subjects in October 2004. About 30 participants entered the study, which involved 40 neurofeedback sessions over five months.

“The feasibility study will also help us answer some key questions about recruiting participants for the full-scale trial,” adds Dr. Urichuk. “We need to determine whether we can find enough children with ADHD who are not on medication, and whether we can we retain them in the study for five months.”

Data collection will be complete at the end of April 2007 and data analysis will then take place. The team hopes to have preliminary results by June 2007. “Depending on the results, we may be able to go forward and apply for funding for a larger trial,” says Dr. Urichuk.

The feasibility study has already had some interesting spin-offs, prompting the researchers to look at other questions. The team received a lot of unsolicited feedback from parents who said they felt pressured by the school system to start their children on medication for ADHD. Some were home schooling their children as a result.

“We want to look more closely at this by doing a small number of structured interviews with teachers

and parents, as an adjunct to the main study,” says Dr. Urichuk. “We want to investigate what drives decisions on how to treat ADHD. Do schools make recommendations for treatment? What role does pressure from parents play?” This adjunct research project has received funding support from the Caritas Research Centre. “We're very fortunate that Caritas offers funding for small projects such as this,” says Dr. Baydala.

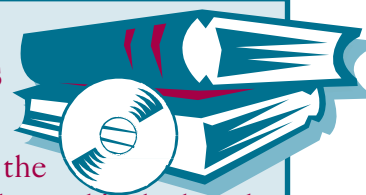
The information may provide insight into the potential barriers parents may face when seeking complementary and alternative treatment options. It could also lead to recommendations to parents and schools regarding communication strategies, continuing education opportunities and behaviour management curricula for education students. Interviews for the adjunct study are still underway.

The team has also developed a proposal for a randomized controlled trial to examine the use of neurofeedback for childhood anxiety and depression. The idea stems from observations made during the ADHD study. For some participants, it was noted that their symptoms of anxiety and depression were alleviated after neurofeedback treatment. This project is not yet funded.

“We're eagerly awaiting the results of the ADHD study,” says Dr. Urichuk. “ADHD is one of the most common childhood disorders. Many children have a hard time with the medication they say it makes them feel 'different'. Adolescents are often extremely resistant to taking the medication. There's real need to find alternative treatments.”

## Library News!

## Caritas Libraries



CINAHL (Cumulated Index for Nursing and Allied Health Literature), the most comprehensive Nursing and Allied Health research database, has changed its look and search process. CINAHL is available on the internet at <http://search.ebscohost.com>.

Please contact Library Staff for more information or to arrange a training session : GNCH 735-7301 or 735-7313; MCH 735-9303.

To register for remote access, please contact Sheila Fynn at 735-7301 or [sfynn@caritas.cha.ab.ca](mailto:sfynn@caritas.cha.ab.ca).

# Practical Implications of Male Caregivers' Experience of Support and Nonsupport

*Authors: Anne Neufeld, RN, PhD; Kaysi Eastlick Kushner, RN, PhD*

## **Background:**

Nearly one-third of family caregivers are men, including spouses and sons, however, they have often been neglected in research about caregiving. As caregivers, men rely on help from family and friends, as well as professionals but may find that these individuals are not always helpful, despite good intentions.

## **Purpose:**

This ongoing research is to develop a better understanding of the types, characteristics, and patterns of nonsupport and support experienced by men who are caring for a relative with Alzheimer disease or other dementia.

## **Method:**

Men who are spouses or sons and who care for a relative with Alzheimer disease or other dementia were interviewed in their homes and asked to complete a brief diary. Focus group discussions with men caregivers and professionals are planned to assist us to identify implications of findings for change in programs and policies. Data are analyzed using a thematic form of content analysis.

## **Results:**

Men described experiences that were unhelpful (nonsupportive) in their interactions with family and friends as well as professionals. Examples of unhelpful interactions with family and friends included: failure to follow through on expected assistance, helpers who lacked essential skills to assist, and supporters who were unavailable, or who withdrew support. In their interactions with professionals men described a lack of needed information about resources or the condition of the care recipient, absence of a sufficiently detailed assessment, or a poor fit between available resources and the assistance that they required. In interactions with family and friends, men experienced support when others affirmed their efforts as caregiver and offered a nonjudgmental, listening ear. Men also described supportive interactions with professionals that included: provision of respite care, a relationship with a professional that offered reliable and consistent assistance, and aid from professional

facilitators and peer caregivers in situations similar to their own.

## **Conclusions:**

The findings of this study will provide information useful to professionals in tailoring support programs and policies to help men as caregivers. Information about nonsupport can also assist family, friends, and professionals to avoid actions that result in unintended nonsupport. These examples of men's experience suggest that comprehensive assessment should document the caregiver's anticipated contribution from others, not just the presence of potential helpers. Additionally in planning interventions it may be useful to tailor interventions to the specific characteristics of caregivers. For example, in support groups men found connections with others in a similar role (e.g. spouse) and stage of caregiving trajectory to be valuable, but participation in groups where others' experience differed (e.g. in role or caregiving trajectory) was not supportive. These implications may also be useful in understanding program evaluation results or in designing evaluations because differences among caregivers may explain differences in response to an intervention such as a support group. It is also useful to recognize that actions intended by family and friends to be helpful may nevertheless be experienced as nonsupportive by caregivers.

## **Challenges:**

Addressing the immediate issues of clients and caregivers may make it difficult to assess support resources comprehensively and tailor interventions accordingly. More research is needed to examine male caregivers' experience of support and nonsupport in-depth.



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# Satisfaction Survey on Postoperative Transgender Patients

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Gender Identity Disorder (transgenderism) is listed in DSM IV TR and is defined as a condition that has persisted for at least two years in which the individual has a persistent desire to change his or her anatomical primary and secondary sexual characteristics.

Although classified as a disorder in DSM-IV, in this author's opinion, this condition is a normal variation on the theme of gender identity. In Western society there is little if any tolerance for individuals who are on the gender spectrum somewhere between the traditional genders of being either male or female. For example this could be a biological female who has strong masculine interests and behaviors (somewhat better tolerated) or a biological male who has strong feminine interests and behaviors, or a biological male or female who feel they are of the opposite gender trapped in the wrong body.

This is in stark contrast to over 134 North American Indian cultures which have a written history. In the past each of these cultures had a specific word for and a strong acceptance of transgendered individuals amongst them. These transgendered individuals were referred to as being 'two spirited' and they had a very special place in the native communities. They were usually very highly regarded and even revered. The early Spanish explorers used the derogatory word 'berdache' for such individuals and they were regarded as abominations, a heresy against the church and were systematically eliminated, although it took three centuries to do so.

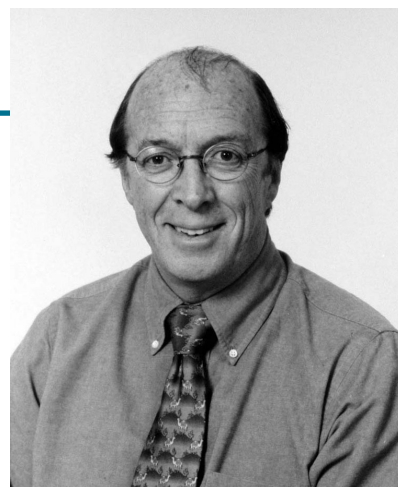
Although there are recorded cases of 'sex reassignment surgery' being done as far back as the 1930's, it was the case of Christine Jorgensen that brought this condition to medical and public attention. Born as George Jorgensen, traveling to Denmark at the age of twenty one, receiving

hormone therapy and sex reassignment surgery there (completed in the USA),

Christine returned to the USA in 1951 very much in the public eye which was mostly negative at the time. It was this event that prompted Dr Harry Benjamin to interview Christine on many occasions and then to write the first medical book on the subject entitled 'The Transsexual Phenomenon'.

For many years it was felt that gender identity was determined by the gender that was assigned at birth (male or female) and that after 2-3 years of age, gender identity could not be changed. In other words, gender identity was felt to be due to psychosocial factors. There is little doubt, from various areas of research, and many case studies, that gender identity is a biological phenomenon, probably determined prenatally by hormonal factors. No one chooses their gender identity, but everyone become aware of their gender identity around the age of three or four. For most individuals this is an unremarkable event. However for the individual who is transgendered, this becomes a painful awakening, an internal pain that can continue for many years.

The exact prevalence of transgenderism is not known with certainty, but clearly earlier estimates of 1/40,000 for M to F and 1/130,000 for F to M are incorrect. A recent survey from Holland suggests that the prevalence of transgenderism may be as high as 1/50,000, with males coming for help versus females in a ratio of 3:2. Other surveys suggest a prevalence of 1/2000 (USA), 1/3000 (Britain), and an approximate rate of 1/4000 for Edmonton calculated by this author based on referral rates.



*Lorne Warneke, MD, FRCP*

Treatment requested by and given to transgendered individuals ranges from psychotherapy to hormone therapy to sex reassignment surgery. A large number of individuals never request help, preferring to remain in the 'gender closet' totally or partially for a number of psychosocial reasons. For those who request hormone therapy and sex reassignment surgery, there are treatment guidelines established by the Harry Benjamin International Gender Dysphoria Association. These guidelines are followed by the gender clinic at the Grey Nuns Hospital.

A gender clinic has existed at the Grey Nuns Hospital since 1995. With the closure of the clinic in Calgary because of internal funding cutbacks in 2001, the clinic at the Grey Nuns Hospital has become the only gender clinic in Alberta. Almost all individuals who are transgendered and wish to have hormone therapy and SRS funded by Alberta Health must be assessed at the clinic at the Grey Nuns Hospital.

Since 1996, a total of 279 individuals have been assessed, the vast majority of whom were confirmed to be transgendered. Alberta Health funds up to 14 SRS's a year, all done in Montreal at the Menard/Brassard Clinic (with one or two exceptions). Over this period of time two demographic analyses have been done, and two satisfaction surveys completed on this group of individuals.

## Demographic analysis

### Origin of referral

Northern Alberta	11.5%
Edmonton area	33.0%
Southern Alberta	30.5%
Calgary area	25.0%

### Age range      10 to 78 years

11.75%	10-18 years of age
41.50%	19-35 years of age
43.5%	36-55 years of age
3.25%	over 55 years of age

	<u>M to F</u>	<u>F to M</u>
Type of patient	73.5%	26.5%
Marital status	34	17
Children	29	11
In preferred gender role before first visit	50	87

On hormones before first visit	47	48
Family supportive	64	70
Employment status	83	76
Previous psychiatric illness	19	28*

\* The majority of patients had become depressed during adolescence, more like an adjustment reaction with depressed mood which quickly resolved. Only about 5% of patients were taking psychotropics when first assessed.

### Educational status

38% had a University degree
36% had a college degree
36% had high school only

## Satisfaction surveys

### 1996-2001

The first survey was conducted with the help of Sandi Barsi RN.

- 21 questionnaires sent out, fifteen replied
- the six that did not respond was because of change of address
- of the fifteen who replied, none had any regrets regarding the SRS and all felt that their life was either the same as before or had changed for the better.

### 2001-2006

The survey was conducted by Danielle Straub (nee Fullerton), a PhD psychology student, as a summer project in conjunction with this author.

A survey questionnaire was developed, asking such questions as satisfaction with the function and the cosmetic appearance of the SRS, and whether or not there were any complications with the surgery. Satisfaction with sexual functioning after the surgery, quality of intimate relationships as well as relationships with family, colleagues and friends were asked about. A life satisfaction survey questionnaire was included in the package as well as a description of the study and consent form. The study was approved by the Ethics and Research committee at the University of Alberta.

Twenty questionnaires were mailed out. Nine were returned completed. The remainder were returned because of change of address.

Of the nine returned surveys:

- on average the wait time to be seen in the gender clinic was 11.5 months
- no patient had any complaints with the way they were received and treated at the clinic
- all of the patients were very happy with the outcome of surgery, both in terms of cosmetic appearance and function
- only two patients had post operative complications in the form of infection which quickly cleared

On a Lickert ten point scale:

- the overall general satisfaction with life since the surgery as compared to before went from 3.7 to 7.8
- satisfaction with work went from 5.2 to 8.1
- satisfaction with leisure time went from 5.2 to 9.0
- relationships with family members went from 5.3-7.1
- relationships with friends went from 5.6 to 7.25
- no patient expressed any regret

#### Summary:

Transgendered individuals who are assessed and followed at the gender clinic at the Grey Nuns Hospital represent a cross section of society in terms of education, employment, and family background. Types of employment include medical, legal or teaching professionals, to civil servants, tradesmen, owners of businesses, and unskilled workers. Many usually try to change themselves by getting married and having children. When this is unsuccessful, this group comes for help in middle age with a spouse and children that complicate the situation. Younger individuals are now asking for help, either by themselves or accompanied by parents, many in their adolescence or late childhood.

Two satisfaction surveys have been completed since 1996, the second one done in 2006 and was more comprehensive in terms of questions asked as well as life satisfaction. Virtually all patients reported an improvement in life satisfaction and life circumstance following the surgery. Of importance none of the patients expressed any regret for having had the sex reassignment surgery. This is reassuring and suggests that the pre operative assessment including the one year real life test is being done adequately.

The weakness of the study is that only about 50% of patients returned the survey questionnaire completed, the remainder were returned because the individual had changed their address and could not be contacted.

A third survey will be conducted in 2008.

## Research Corner

### Upcoming Workshops & Events:

**June, 2007, 12:00-13:00 hrs** (details to be announced on website) - Luncheon Forum for Researchers w/Caritas Nurse Scientist, Donna Wilson, RN, PhD

**September 28<sup>th</sup>, 2007, Friday, 09:00-12:00 hrs** at GNCH - "Increasing your Chances of Getting Published", presented by Anthony Shardt, MD, MHSc & Luba Wolchuk, MD, MHSc, CCFP

**October 24<sup>th</sup>, 2007, Wednesday, 08:30-12:00 hrs** at MCH - "Demystifying HREB and the Research Application Process", presented by Judith Abbott and Donna Wilson, RN, PhD

## Caritas Research Centre

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