LITERATURE REVIEW – BEHAVIOURAL GUIDELINES FOR ADJUSTING TO MEDICAL CONDITIONS

PREPARED FOR
THE ONTARIO WOMEN’S HEALTH COUNCIL
BY THE UNIVERSITY HEALTH NETWORK
PROGRAM IN MEDICAL PSYCHIATRY & WOMEN’S HEALTH PROGRAM
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The purpose of this project was to review the literature and make recommendations about behavioural guidelines to foster adaptation to chronic medical conditions that are relevant to Ontario women.

There is increasing recognition that adequate adjustment to chronic medical conditions is associated with improved quality of life and lower health care utilization and costs. Despite a growing literature on behavioural interventions in chronic medical conditions, there is a major problem in knowledge translation into the clinical setting. Many health care professionals see themselves as ill prepared to collaborate with individuals with chronic medical conditions in these approaches.

To fulfil the terms of reference, the published and unpublished literature relevant to behavioural interventions in chronic medical conditions was reviewed using information from key informants, health databases and health websites. Interventions reviewed included education, stress management, cognitive-behavioural approaches, behavioural approaches, exercise, nutrition, mind-body approaches, and multimodal or integrative approaches. The data obtained through the literature review was graded in terms of its scientific quality. Recommendations were made in terms of the areas of clinical care, health care professional education, public education, areas for further research and policy initiatives.

This report consists of an overview of issues relevant to quality of life in chronic medical conditions and a review of the major categories of approaches to foster successful adaptation to chronic medical conditions. More detailed reviews are provided for eleven chronic medical conditions that negatively impact the quality of life of Ontario women. For each chronic medical condition, information is provided about its epidemiology, impairment in quality of life and associated psychosocial morbidity, sex and gender differences, a systematic review of behavioural interventions relevant to the condition and recommendations for clinical care, health professional and public education and areas for further research.
**General Recommendations**

**Clinical Care**

1. Optimal clinical care for Ontario women with chronic medical conditions includes behavioural interventions and these need to be available for women both in terms of providing women with guidance as to what they can do to foster their own adaptation to illness and providing direct clinical services.

2. Modify or develop interventions for those groups of women for whom current programs are inaccessible.

**Health Professional Education**

1. Advocate for the inclusion of formal exposure in the undergraduate and post-graduate curriculum for health professionals to behavioural interventions to foster adaptation to illness and the evidence basis for their use.

2. Develop continuing professional development activities for practicing health care professionals on how they can empower patients/clients in self-care, including introduction to the various types of behavioural interventions and training in motivational interviewing.

3. Develop directories of community and disease specific advocacy groups providing programming that fosters adaptation to chronic medical conditions. This information should be widely disseminated within the health care professions and to the public at large.

4. Educate health professionals about easy to use measures of quality of life to assess the outcomes of their interventions with patients/clients.

**Public Education**

1. Develop a catalogue of current sources of written, audiovisual and web-based materials which individual women can use to facilitate their adaptation to chronic medical conditions.

2. Disseminate directories of community and disease specific advocacy groups providing programming that fosters adaptation to chronic medical conditions.

**Development of New Resources**

1. Develop a series of concise, practical written materials on behavioural adjustment to chronic disease such as pamphlets for patients/clients. These should include generic information such as self-monitoring of symptoms, cognitive-behavioural approaches, and healthy lifestyle issues such as nutrition and exercise. Ensure that these materials are available in a linguistically and culturally appropriate format for Francophone, Aboriginal, and immigrant women.

2. Develop a series of disease-specific written materials such as pamphlets for the major chronic medical conditions that impact on Ontario women's quality of life.

3. Undertake pilot programs to assess the suitability of programs such as the Chronic Disease Self-Management Program (CDSMP) for the Ontario context and whether further modifications would make the program even more valuable to women.

4. Undertake pilot programs to assess the potential for peers successfully dealing with chronic medical conditions and other volunteers to facilitate intervention programs.
5. Encourage community health centers and hospitals to offer group and individual programs focusing on adaptation to illness which are based on approaches that have documented impact on quality of life and adjustment to illness.

6. Increase community-based programs in partnership with health care agencies and disease specific advocacy groups.

7. Collaborate with disease-specific agencies to develop resources for both patients and health care providers.

8. Develop culturally sensitive and linguistically appropriate resources, programs and educational materials for Aboriginal and immigrant communities.

9. Develop materials relevant to the needs of rural women.

10. Develop materials relevant to children and adolescents with chronic medical conditions, and their parents.

**Research**

1. Advocate for adequate funding from research granting bodies for randomized, controlled trials of behavioural interventions in women suffering from chronic disease.

2. Encourage the development of research programs to evaluate the economics of behavioural interventions.

3. Develop “stepped care” approaches for common chronic medical conditions that negatively impact on the quality of life of Ontario women. Such approaches begin with the least intensive and costly approaches for participants, health care professionals, and the health care system, and then offer more intensive and costly approaches for those who do not benefit.

4. Encourage the development of pilot projects to assess the value of incorporating quality of life assessments in routine clinical care.

**Policy**

1. Advocate for a group within the Ministry of Health to be responsible for behavioural interventions to foster adaptation to chronic medical conditions. At the present time, there is no clear focus for this area, which impedes service development.

2. Encourage accreditation bodies to include assessment of whether behavioural interventions are provided and what their quality is as part of accreditation activities.

3. Identify and fund several Ontario Centers of Excellence in behavioural management of chronic diseases and foster the provision of service within an ongoing evaluative context.
SPECIFIC RECOMMENDATIONS FOR CHRONIC MEDICAL CONDITIONS

Autoimmune Diseases

1. Clinical Care
   - Behavioural interventions need to be integrated into routine clinical care for those women with autoimmune diseases who need or want them.
   - Arthritis self-management programs should be available at least on a regional basis
   - Group therapy and individual therapy using cognitive-behavioural and self-management approaches should be available for women with autoimmune diseases.

2. Health Care Professional Education
   - Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain, fatigue, and psychosocial distress associated with Systemic Lupus Erythematosus (SLE), Multiple Sclerosis (MS), and Rheumatoid Arthritis (RA).

3. Public Education
   - Educational materials need to be developed which address behavioural interventions that may facilitate adaptation to autoimmune diseases. These need to be produced in culturally and linguistically appropriate formats for diverse populations of women including Francophone, Aboriginal, and immigrant women. These should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and strategies to deal with distressing thoughts related to the diagnosis.

4. Research
   - Develop appropriate and effective interventions for special populations including children, adolescents, and immigrant women.

Cancer

1. Clinical Care
   - Supportive-expressive and psychoeducational group therapy should be available for women who wish to access it both early in the course of their disease and at the time of metastatic disease.
   - Behavioural and psychosocial interventions need to be integrated into routine clinical care for those women who need or want them.

2. Health Care Professional Education
   - Health care professionals involved in delivering psychosocial interventions should be trained and competent in the supportive-expressive model of group therapy.
   - Health care professionals need to learn more about the potential value of behavioural and psychosocial interventions in women with breast cancer.
   - Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain and fatigue associated with breast cancer.

3. Public Education
   - Educational materials need to be developed which address basic aspects of breast cancer and the behavioural interventions that may facilitate adaptation to it. These materials need to be produced as well in linguistically and culturally appropriate editions for Francophone, Aboriginal, and immigrant women. These materials should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and weight management strategies.
4. Research
- Develop appropriate and effective interventions for women who have difficulty accessing behavioural interventions through health care settings.
- Research the value of mind-body approaches in terms of improvements in quality of life and psychological and psychosocial functioning. These interventions are increasingly being incorporated into programs but there is little evidence as to which are most clinically effective and most cost-effective.
- Investigate the experiences of lesbian women with breast cancer in order to foster greater understanding of their needs within the health care community and tailor interventions for their special needs.

Cardiovascular Disease in Women

1. Clinical Care
- Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.
- Cardiac rehabilitation programs with special modifications for women in high risk groups should be available on at least a regional basis.
- Smoking cessation programs tailored to the specific needs of women should be available on at least a regional basis.

2. Health Care Professional Education
- Knowledge translation is essential. Education about the importance of cardiovascular disease and rehabilitation as a women’s health issue needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.
- Education about smoking cessation strategies and motivational interviewing to promote smoking cessation need to be emphasized with both primary care practitioners and specialists.

3. Public Education
- Written materials on risk factor modification and, in particular, details about exercise regimens should be developed and then modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant populations.
- Education must be undertaken through diverse public media about the importance of women knowing what their blood pressure is and taking action if it is elevated.

4. Research
- Assess the needs of special populations and tailor interventions that would be appropriate for them.
- Research the financial and psychosocial costs of cardiovascular diseases in women.
- Evaluate cardiac rehabilitation programs with respect to what modifications would facilitate women’s participation.
- Translate knowledge when data is available from the cognitive-behaviour therapy trials currently underway.

Diabetes

1. Clinical Care
- Behavioural interventions need to be integrated into routine clinical care for those women with diabetes who need or want them.

2. Health Care Professional Education
- Health care professionals need to learn more about self-management strategies in special populations.

3. Public Education
- Educational materials need to be developed that are culturally and linguistically appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
- Develop appropriate and effective interventions for special populations including Francophone, Aboriginal, and immigrant women, and women with eating disorders.
## Fibromyalgia

### 1. Clinical Care
- Behavioural interventions must be integrated into routine clinical care and should be available both in health care settings and in the community for women with fibromyalgia.
- Cognitive approaches integrated with exercise training appear to be the optimal intervention.

### 2. Health Care Professional Education
- A variety of health care professionals need to be educated about fibromyalgia including those in primary care, general internal medicine, and rheumatology and orthopedic specialty settings. Education needs to focus on how to work most effectively with individuals with fibromyalgia and how to encourage their participation in behavioural interventions.
- Health care professionals caring for individuals with fibromyalgia need to understand basic principles of exercise training and cognitive approaches and how to operationalize these in the context of the individual.

### 3. Public Education
- Educational materials need to be developed which address basic approaches to the behavioural management of fibromyalgia. As well, these materials need to be modified so that they are linguistically and culturally appropriate for minority communities.

### 4. Research
- Develop a “stepped care” approach to fibromyalgia.
- Translate knowledge into the clinical setting.
- Explore ways of fostering participation in behavioural interventions.

## Gastrointestinal Disorders

### 1. Clinical Care
- Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.
- Group-based cognitive therapy and self-management programs for Irritable Bowel Syndrome (IBS) should be available on at least a regional basis.

### 2. Health Care Professional Education
- Knowledge translation is essential. Education about contemporary perspectives on IBS and the role of self-management and behavioural interventions needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.

### 3. Public Education
- Educational materials need to be developed that address basic aspects of IBS and common misconceptions about IBS and these need to be modified to be linguistically and culturally appropriate for Francophone, immigrant, and Aboriginal women.

### 4. Research
- Conduct further research into the educational needs of individuals with IBS and Inflammatory Bowel Disease (IBD).
- Assess the value of group-based cognitive-behaviour therapy in IBD.

## Headaches

### 1. Clinical Care
- Self-management and behavioural interventions need to be integrated into routine clinical care for those women who need or want them.

### 2. Health Care Professional Education
- Education about the importance of headaches as a women's health problem and the range of behavioural interventions that may be of value needs to be communicated to both primary care practitioners and health care providers in specialty settings.
3. Public Education

- Educational and self-management materials need to be developed that address basic aspects of headache management and provide information about rebound headaches associated with analgesic use. These materials must also be presented in a linguistically and culturally appropriate manner for Francophone, immigrant, and Aboriginal women.

4. Research

- Research the most cost-effective self-management and behavioural interventions and how they might be manualized for delivery in primary care and community settings.

HIV & AIDS

1. Clinical Care

- Behavioural interventions need to be integrated into routine clinical care for those women with HIV and AIDS who need or want them.

2. Health Care Professional Education

- Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain, fatigue, and medication side-effects associated with HIV and AIDS.

3. Public Education

- Educational materials need to be developed which address behavioural interventions that may facilitate adaptation to HIV and AIDS. These materials need to be produced in culturally and linguistically appropriate formats for Francophone, Aboriginal, and immigrant women. They should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and strategies to deal with distressing thoughts related to the diagnosis.

4. Research

- Develop appropriate and effective interventions for special populations including Francophone, Aboriginal, and immigrant women.
- Research the value of mind-body approaches in terms of improvements in quality of life and psychological and psychosocial functioning. These interventions are increasingly being incorporated into programs but there is little evidence as to which of them may be most clinically effective and most cost-effective.

Mental Health

1. Clinical Care

- There needs to be greater availability of cognitive-behavioural and self-management therapies for a wide range of mental health problems.
- There needs to be greater availability of interpersonal psychotherapy for depression and bulimia nervosa.

2. Health Care Professional Education

- Knowledge translation is essential. Education about cognitive-behavioural therapies needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula. There needs to be a focus on both brief and more complex interventions. Education about interpersonal psychotherapy needs to be included in all three curricula.
- Education about eating disorders needs to be directed to primary health care providers.
- Education about self-help strategies and available resources needs to be included in continuing professional development events for primary care and mental health practitioners.

3. Public Education

- The public needs to be informed about non-pharmacological interventions for mental health problems as well as the advantages and disadvantages of pharmacologic therapy for women.
• Information about self-help strategies needs to be more widely disseminated.
• Educational materials need to be developed and modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
• There needs to be greater research in “stepped care” approaches to depression and anxiety.
• Mindfulness-meditation coupled with cognitive-behavioural therapy appears to be a fruitful area for further research.
• Innovative cost-effective strategies to prevent or decrease the burden of postpartum depression need to be evaluated.

Pelvic Pain

1. Clinical Care
• Chronic Pelvic Pain (CPP) requires a comprehensive assessment including access to mental health care professionals.
• Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.

2. Health Care Professional Education
• Education about CPP and the potential value of behavioural interventions needs to be communicated to both primary care practitioners and health care providers in specialty settings.

3. Public Education
• Educational materials need to be developed that address basic aspects of CPP and these need to be modified to be linguistically and culturally appropriate for Francophone, immigrant, and Aboriginal women.

4. Research
• Research needs to be done into the value of a “stepped care” approach with CPP and the most cost-effective way of assisting individuals coping with it.

Respiratory Disorders

1. Clinical Care
• Asthma self-management programs should be available on at least a regional basis.
• Pulmonary rehabilitation programs should be available on at least a regional basis.
• Smoking cessation programs tailored to the specific needs of women should be available on at least a regional basis.

2. Health Care Professional Education
• Knowledge translation is essential. Education about self-management of asthma needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.
• Education about self-help strategies and available resources needs to be included in continuing professional development events for primary care and specialists.
• Education about smoking cessation strategies and motivational interviewing to promote smoking cessation need to be emphasized with both primary care practitioners and specialists.

3. Public Education
• The public needs to be informed about self-management strategies for asthma and Chronic Obstructive Pulmonary Disease (COPD).
• Educational materials need to be developed and modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
• Research needs to address the question of how best to deliver education about asthma.
• The unique needs of women with respect to pulmonary rehabilitation programs needs to be better understood.
• Nutritional approaches to COPD need to be better understood.
To fulfill the terms of reference the following research activities were undertaken:

- Review of published peer-reviewed literature on behavioural interventions fostering adaptation to chronic medical conditions using a strategy that included searching electronic health databases (e.g. MEDLINE, CINAHL, HEALTH STAR, PSYCHINFO, PSYCH LIT), hand search of major journals, and identification of further relevant references cited in papers obtained through the first two activities.

Data was gathered for the following classes of interventions:

- Education
- Multi-modal/Integrative Programs
- Stress Management
- Cognitive-Behavioural Approaches
- Behavioural Approaches
- Other Psychotherapies
- Social Support
- Exercise
- Nutrition
- Mind-Body Approaches

Given the scope of the project, representative chronic medical conditions were chosen to highlight the relevant issues. Chronic medical conditions were chosen for inclusion in this report based upon the degree to which they are women’s health problems and to which there is a literature which discusses behavioural interventions in fostering adaptation to the condition.

Data was evaluated using the criteria of the Canadian Periodic Health Examination Taskforce (1979) with an additional two levels added as well as the use of superscript “M” for interventions that have been primarily or completely tested on men.

I evidence obtained from at least one properly randomized controlled trial

I\textsuperscript{M} evidence obtained from at least one properly randomized controlled trial but limited to male participants

II-1 evidence obtained from well-designed controlled trials without randomization

II-2 evidence obtained from well-designed cohort or case-control analytic studies, preferably from more than one centre or research group

II-3 evidence obtained from comparisons between times or places with or without the intervention

III opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees

IV insufficient evidence in peer-reviewed literature to adequately evaluate

V evidence against this intervention
**BEHAVIOURAL ADJUSTMENT TO CHRONIC MEDICAL CONDITIONS**

Chronic medical conditions constitute significant burdens for the individuals with the disease, their family and friends, and society. There is increasing research and clinical attention to the optimization of the management of chronic medical conditions in the hopes of decreasing their negative impact on quality of life (QoL) and controlling health care costs. There has been increasing recognition of the high economic costs associated with these disorders. The per capita cost for individuals with chronic medical disorders is three times that of individuals without chronic disorders and the 17% of the population with chronic medical conditions account for 47% of health care costs (Hoffman et al., 1996). These costs will increase over the next 20–30 years with the aging of the baby boom generation, as aging is associated with increased risk of chronic medical conditions.

**The Burden of Chronic Medical Conditions**

A large number of investigators have documented the burdens associated with chronic medical conditions. Lorig et al. (1996) described focus group research on the range of concerns of individuals with chronic medical conditions. The impact of disease included: physical limitations; lack of control over symptoms and one’s life; body awareness and concerns about body image; challenges in dealing with depression, anxiety, and anger secondary to health concerns; altered relationships with family and friends; disturbed sleep; pain; and fatigue. Individuals with chronic medical conditions describe concerns about the future including disability, loss of independence and medical complications, altered social relationships, economic uncertainty, the need to modify housing arrangements, and fear of death and dying. Current and future worries about the social stigma and bias associated with chronic medical conditions and disability are a source of significant concern. Many individuals wish to take an active role in managing their illness and yet did not know how they might contribute to their own care.

Beyond the individual and familial burden of chronic medical conditions are the socioeconomic costs which include lost wages, decreased contributions to the tax base, and increased direct and indirect health care costs. Over the past decade, interest in behavioural adjustment to chronic medical conditions and self-management of symptoms has increased in tandem with the growing sophistication of consumers of health care and the realization on the part of the health care system and health care providers that poorer adjustment to illness is associated with higher health care costs including higher physician fees, hospital and emergency room utilization, ambulatory care utilization, and laboratory investigations (Lorig et al., 1996).

**Quality of Life & Chronic Medical Conditions**

Chronic medical conditions are often associated with illness intrusiveness (illness-induced disruptions to valued activities and interests) (Devins et al., 1983) in which illness interferes with valued life domains and results in poorer health-related quality of life. The QoL literature is complex. “A confusing plethora of definitions and terms abounds in the QoL literature” (Heinemann, 2000), but there is agreement that relevant domains include physical status and function, emotional functioning, and social functioning. Some conceptualizations also include economic and vocational status and religious and spiritual status (Heinemann, 2000). Quality of life reflects “the net consequences of disease and its treatment on the patient’s perception of his ability to live a useful and fulfilling life” (Schipper et al., 1990).

There has been a marked increase in attention to the issue of how best to measure QoL in individuals with chronic medical conditions (Heinemann, 2000; Spilker, 1997). This has followed on the recognition in the late 1980s that patients with chronic medical conditions account for the majority of health care expenditures and that maximizing function in everyday life and QoL might be associated with reduced health care costs (Stewart et al., 1989).
In the landmark Medical Outcomes Study, health status and QoL (in terms of daily functioning and well-being) were assessed in adults. The focus was on nine common medical conditions – hypertension, diabetes, myocardial infarction within the prior 12 months, congestive heart failure, arthritis, chronic lung problems, back problems, chronic gastrointestinal conditions and angina (Stewart et al., 1989). Of the sample, 54% had at least one of the nine conditions. Comorbidities among the nine conditions were common with 29% of the sample having two or more conditions. Unique profiles of functioning (e.g., physical functioning, role functioning and social functioning) and well-being (mental health, health perceptions and bodily pain) were obtained for each condition. Decrements in all measures were reported in arthritis, gastrointestinal disorders, angina and lung problems. Impairments in functioning and health perceptions were reported for diabetes, myocardial infarction, and congestive heart failure. Back problems were associated with decrements in physical and role functioning, health perceptions and pain, while social functioning and mental health were not affected. Hypertension was only associated with a decrement in health perceptions. The study also documented “substantial variability in health among patients within each chronic medical condition group” (Stewart et al., 1989). This study was so significant because it clearly demonstrated the impact of chronic medical conditions on functioning and well-being. More importantly, it raised the issue of why there is such variability in functioning and well-being within each chronic medical condition and what characteristics contribute to better or poorer functioning and well-being amongst individuals with the same chronic medical condition. The authors concluded, “More direct approaches to improve functioning and well-being may also be possible, although little is actually known about optimal strategies that physicians might take to accomplish this goal. Interventions that directly target functional limitations may be beneficial. The challenge is to identify the more effective interventions.” (Stewart et al., 1989).

Since this landmark paper, there has been increasing attention to issues of both assessment of health-related QoL and development of interventions to optimize it in individuals with chronic medical conditions. More recently, attention has turned to the problem of assessment of health-related QoL in culturally diverse populations (Stewart & Napoles-Springer, 2000).

The Process of Behavioural Adaptation to Chronic Medical Conditions

Adaptation to chronic medical conditions is not a linear process that is identical across individuals. Rather, it reflects the individual’s life experiences, characteristics of their chronic medical condition and its biomedical treatment which bring “a complex set of ever-changing stressors” (Maes et al., 1996), their social worlds, and the attitude and approaches of their health care providers (Maes et al., 1996). There have been a variety of different models of adaptation to chronic medical illness (see reviews in Maes et al., 1996) but most emphasize the initial uncertainty and disruption of lifestyle that occurs with diagnosis of the disorder, followed by attempts to gain control over illness. Understanding adaptation as a series of stages integrates well with the Prochaska et al. (1992) model of behavioural change which emphasizes that change involves a series of stages and that interventions may be valuable in promoting movement through these changes. In the Prochaska model, making behavioural change involves a series of stages that begin prior to the individual considering the need for change (precontemplation) and move through contemplation, preparation, taking action, relapse and maintenance of change. This model is increasingly being used to promote management and effective behavioural change in the context of adaptation to chronic illness. Coincident with this model is the technique of motivational interviewing that focuses on promoting movement along the stages of change (Miller & Rollnick, 1991).
Self-Management of Chronic Medical Conditions

There is a new emphasis on self-management of symptoms because it promotes empowerment, mastery, and enhancement of personal control (Devins & Shnek, 2000). The overall aim of self-management is “to help affected individuals compensate for deficits that can be addressed directly and accommodate to those that cannot with the goal of minimizing illness intrusiveness and maximizing quality of life” (Devins & Shnek, 2000).

There are three fundamental principles underlying self-management of chronic medical conditions (Devins & Binik, 1996b; Devins & Shnek, 2000): (1) individuals must accept responsibility for managing their condition to the extent that this is possible and to do so they must acquire knowledge about their disease and its management; (2) individuals collaborate with health care providers rather than act as the subservient objects of health care providers actions; and (3) effective self-management requires implementation of knowledge through effective behaviour and coping. Clark and colleagues (1991) identified twelve key components of self-management of chronic disease that are common across diseases: (1) appropriate identification of symptoms and response to them, including identification of symptom triggers and developing strategies for their control; (2) effectively managing acute episodes and emergencies; (3) optimal use of medications; (4) optimizing nutritional status, including compliance with dietary restrictions if relevant; (5) optimizing physical activity and appropriate exercise; (6) not smoking; (7) managing the stress associated with chronic medical conditions through stress management and relaxation techniques; (8) managing the emotional response to illness and the negative emotions which may accompany chronic disease states; (9) optimizing interactions with physicians, nurses, and other health care providers; (10) effectively communicating with family and friends; (11) using community resources as required; and (12) dealing with changes in ability to fulfill social role functions (e.g., work or school, role as partner/parent).

Self-Efficacy & Chronic Disease

“Self-efficacy in dealing with chronic disease is not simply a matter of knowing what to do. Rather, it reflects a capability to organize and integrate cognitive, social and behavioral skills to meet a variety of purposes” (Lorig et al., 1996).

Enhancing self-efficacy in self-management of chronic medical conditions is a goal of many interventions designed to enhance adjustment to illness. Interest in self-efficacy derives from the social psychology literature that posits that the strength of one’s belief in one’s capacity to accomplish a specific task or achieve a goal is a good predictor of motivation and behaviour (Bandura, 1986). Self-efficacy beliefs can be enhanced through mastery of knowledge and skills and modeling of effective behaviours and attitudes (Lorig et al., 1996). An enhanced sense of self-efficacy leads to more effective behaviour, more adaptive thinking, heightened motivation, and enhanced emotional wellbeing (Bandura, 1986; Lorig et al., 1996). Many individuals with chronic medical conditions have experienced a drop in their sense of self-efficacy and interventions often help restore it.

Evaluating Adjustment to Chronic Medical Disorders and Outcome of Interventions

There is a growing body of knowledge directed towards assessing illness intrusiveness and QoL and measuring outcomes (Devins et al., 1983; Heinemann, 2000; Lorig et al., 1996; McDowell & Newell, 1996; Spilker, 1997; Stewart & Naples-Springer, 2000). In particular, there is increasing awareness that the evaluation of the impact of interventions to optimize behavioural adjustment to chronic medical conditions is essential in clinical trials. There is developing recognition in the clinical context that measuring QoL would bring important benefits to health care professionals in their work with individual patients/clients and their evaluation of the impact of their treatments.
Barriers to Effective Behavioural Adjustment to Chronic Medical Conditions

There are many barriers preventing effective behavioural adjustment to chronic medical conditions. While the tendency is to focus on the individual with the chronic medical condition and their difficulties in adjustment, it is clear that there are larger systemic barriers which must be addressed. There have been significant deficits in translating knowledge from research and behavioural science literature about how to foster more effective adaptation to chronic medical conditions into the daily work of healthcare professionals in hospital and community settings and into the hands of individuals with chronic medical conditions and their families.

Our earlier focus group research has demonstrated that female nurses and physicians have significant difficulties empowering their patients/clients in this area. They report having had no formal education in their undergraduate degrees and no opportunities for continuing professional development which would build knowledge and skills in these areas. While these health care professionals described interest in promoting self-care, they also felt that they did not know enough about the various approaches to fostering self-care and were unaware of educational resources in the community and in print and electronic form. They did not have a clear sense of how they might go about addressing their learning needs in this area given the lack of attention to these themes in most continuing professional development events. They had particular concerns about lack of skills in enhancing patients'/clients' motivation to change and none were familiar with motivational interviewing (Miller & Rollnick, 1991), developed in the context of substance abuse treatment and now applied in a variety of health care settings (Nolan, 1995). Motivational interviewing is a powerful tool to assist individuals in making changes that would promote behavioural adjustment to chronic medical illness; however, it has been poorly disseminated amongst front-line health care providers.

There is a paucity of health psychologists in hospital and community clinic settings and the numbers have dropped in conjunction with the cutbacks in health care. Health psychologists have an essential role to play in developing, delivering, and disseminating interventions. Psychiatrists specializing in the care of the medically ill are also in short supply and are often focused on crisis intervention and the more severe end of the spectrum of adjustment difficulties. There is no distinct voice in the Ministry of Health or central group with responsibility for behavioural adjustment to major medical illness.

There is a clear and pressing need for greater attention to QoL issues in routine clinical care and developing cost-effective strategies to deliver behavioural interventions to those in need of them.
A wide range of approaches has been advocated for fostering behavioural adjustment to chronic medical conditions. The nomenclature with respect to various approaches and techniques may be confusing at times, as well as controversial. For example, it is often difficult to sort out cognitive strategies from the behavioural outcomes associated with them (Keefe et al., 1992). This chapter provides an overview of these approaches. The chapters devoted to the specific chronic medical conditions will specify their use in different contexts.

**Education**

In addition to specific information about disease states and coping with the physical and psychosocial aspects of disease, educational programs provide information about community resources for both instrumental and emotional support which enhances adaptation to illness. Education may focus on building skills in communicating with health care professionals and is delivered via a wide range of formats, including individual and group sessions, written materials, audio and videotapes, and the internet. Bibliotherapy, or the reading of educational materials, is an important educational strategy as individuals can read at their own speed, return to materials as needed, and share them with family and friends. Education about self-management approaches to chronic medical disorders, which individuals can pursue on their own, are increasingly available directly to the public through popular self-help books (e.g., Fortman & Breitrose, 2001; Greenberger & Padesky, 1995; Lorig et al., 2000; Milchovich & Dunn-Long, 1999; Moore et al., 1999) and through disease specific advocacy groups. Unfortunately, most health care providers are either unaware of these materials or are unsure how to support individuals in using them effectively.

**Self-Monitoring of Symptoms**

Self-monitoring of symptoms takes a variety of forms, all of which involve keeping track of some aspect of symptoms - frequency, intensity, severity, physiological measures, precipitants to acute exacerbations, response to various interventions, etc. Individuals with chronic medical conditions may complete charts or tables to assist in their self-monitoring activities. In some chronic medical conditions, it may be helpful for individuals to institute treatment modifications based on symptoms so that they can then tailor their treatment to their current disease burden.

**Cognitive Approaches to Symptom Management**

Cognitive approaches to symptom management and behavioural adjustment to chronic disease emphasize identifying and evaluating the thoughts that individuals have about their disease and its impact upon their life. Cognitive approaches emphasize the active participation of the individual and aim for an egalitarian relationship between the therapist and the client. These approaches lead to reduced emotional distress, and may enhance psychological wellbeing. They may also improve coping with chronic medical conditions through fostering the development of new skills as well as reducing attitudes and beliefs that are unhelpful, maladaptive, or irrational and which limit functioning (Devins & Binik, 1996a). Note, however, that the nomenclature in this area is confusing because many times these cognitive approaches are labeled cognitive-behavioural as they also assess the impact of thoughts on behaviour.

Cognitive symptom management is derived from cognitive therapy, initially developed to treat major depression (Beck, 1976) and now being extended to facilitate coping with chronic medical illness (see review in Devins & Binik, 1996a). The cognitive
symptom model posits that thoughts about symptoms or lifestyle limitations produce emotional and physiological responses that further complicate successful adaptation. This approach encourages the individual to identify and describe their thoughts and then evaluate how adaptive/helpful/appropriate they are. Cognitive symptom management may also be learned through books (e.g., Greenberger & Padesky, 1995).

Cognitive restructuring seeks to replace unhelpful thoughts with more adaptive ones. If the thought contributes to distress rather than successful coping, the individual is encouraged to consider alternative thoughts that may be more adaptive/helpful/appropriate/accurate. For example, an older woman with end-stage lung disease isolates herself in her home because she is ashamed of wearing nasal prongs and carrying an oxygen tank. When she works on identifying her thoughts, she realizes that she thinks, “I can’t go out like this because I’m not looking my best, public image is everything”. This is a longstanding thought that has always spurred her to carefully groom herself before being seen in public and to which she credits her success in her personal and professional life. With support, she is able to challenge the usefulness of the thought at this point in her life as it precludes her from engaging in any social activity. She comes to see the thought as limiting and unhelpful as it connects her personal value solely with her appearance and interprets a life-saving therapy as “ugly” and stigmatizing. She substitutes the thought with “I may not like wearing the oxygen but it keeps me alive and that is important. People love me for who I am on the inside rather than on the outside”.

Earlier formulations of cognitive therapy used language describing cognitive “distortions” and “irrational thoughts”. However, feminist critiques have noted that many of the unhelpful thoughts which women have about their experiences are not in fact “distortions” but rather reflect the social realities that they have been raised with.

In addition to cognitive restructuring, there are a diverse range of cognitive techniques which are employed by individuals in managing their symptoms but which have received less systematic study. These include coping self-statements, distraction, counting, self-reassurance, and rationalization.

Problem solving encourages individuals to identify problems, get to the bottom of them, and actively seek solutions to them (D’Zurilla, 1986). Its use has been extended into work with individuals with chronic medical conditions. For example, a woman with a medical debilitation has difficulties using stairs. Her difficulties may be related to physical problems such as weakness, decreased cardiovascular status, and problems with balance; or they may be related to emotional concerns such as fear of falling and not being able to obtain help. Being clear about whether the problem is physical or emotional opens the door to finding an appropriate solution. Problem solving encourages individuals to generate a series of solutions to their problems and to canvas family, friends, and care-givers for suggested solutions. Once solutions have been generated, they are evaluated in terms of their pros and cons and one of the solutions is chosen to be implemented. The results are evaluated and, if unsuccessful, another solution may be instituted. If the problem cannot be solved, then the focus becomes accepting that reality and adapting to it as best as possible.

Cognitive approaches have been very helpful in a wide range of chronic medical conditions in managing pain and fatigue.
**Behavioural Symptom Management**

While the term “behavioural” is sometimes used in connection with cognitive-behavioural, it can also be used to describe a range of interventions derived from the principles of operant and respondent conditioning. Examples of such techniques are biofeedback, various forms of relaxation training, autogenic training, progressive muscle relaxation, and hypnosis. Biofeedback involves moment-to-moment information about some aspect of an individual’s biology (e.g., muscle tension, skin temperature) which is provided to allow assessment of interventions such as relaxation. Relaxation therapies come in a wide variety of forms but they all share the capacity to calm the mind and the body. Two of the most commonly used relaxation therapies are progressive muscle relaxation and relaxation response. Progressive muscle relaxation involves tensing and relaxing muscles throughout the body (Bernstein & Carlson, 1993). The “relaxation response”, popularized by Benson (1975, 1979, 1984), is a form of concentrative meditation. Autogenic training refers to the use of suggestion and deep breathing to reduce autonomic arousal, thus producing a sense of relaxation (Linden, 1993).

Meditation has been included in behavioural symptom management by some, while others include it in mind-body approaches. Meditation approaches can be clustered into three basic classes: (1) concentrative forms of meditation; (2) mindfulness meditation; and (3) imagery. Concentrative forms of meditation involve focusing the mind on a stimulus (e.g., breath, mantra, candle flame) and disregarding other mental contents. The most widely known forms of concentrative meditation are transcendental meditation and Benson’s relaxation response. Concentrative meditation is associated with significant physiological calming and has been demonstrated to reduce heart rate, respiratory rate, and blood pressure. Derived from Buddhist vipassana meditation, it calms the mind and induces a sense of relaxation, and has been championed for use in chronic medical disease (Kabat-Zinn, 1990; Santorelli, 1999). Mindfulness meditation anchors awareness in the breath; physical sensations, emotions, and thoughts that occur are recognized in a non-judgemental way, thereby changing one’s relationship with symptoms. Meditation based in imagery has been used in a variety of different ways to promote healing, but has received less systematic attention.

**Social Support Interventions**

Social support facilitates coping with and adjustment to illness. Social support may be informal, through the individual’s own social network (i.e., family and friends and contacts with other individuals with the same chronic medical condition) or through mutual aid and self-help groups where there is no leader. It may also be formal, through groups run by a leader who may be an individual successfully coping with an illness or a professional health care provider. The literature on social support interventions in facilitating coping with chronic physical illness is largely positive, although there are exceptions (see review by Devins & Binik, 1996a).

**Exercise**

Exercises valuable in fostering behavioural adjustment to chronic illness fall into three broad categories: (1) stretching for flexibility; (2) strengthening; and (3) aerobic. Exercise confers a variety of health benefits for individuals with chronic medical conditions, including better functioning and a greater sense of wellbeing (Stewart et al., 1994). While exercise may be important for optimizing physical status, it is also essential for limiting the functional decline associated with the downward cycle of deconditioning which imposes added burdens to the primary chronic medical condition. Physical deconditioning further limits activity and makes any activity that is done more taxing and exhausting. Low mood and feelings of helplessness and hopelessness typically accompany physical deconditioning. Stretching exercises promote flexibility which in turn can reduce pain, reduce the risk of injury, and make muscles work more efficiently (Lorig et al., 2001). Increasing muscle strength counteracts the muscular
weakness that follows inactivity and physical deconditioning; as noted by Lorig and colleagues (2000) in their popular book, “Much of the disability and lack of mobility for people with chronic illness is due to muscle weakness”. Aerobic exercise brings a wide range of benefits including improved cardiovascular fitness, muscular conditioning, a sense of well-being, improved sleep, and decreased depression and anxiety (Durstine et al., 2000; Vuori, 1998).

**Stress Management**

Stress management refers to a broad range of approaches that may incorporate many of the techniques previously described as well as other approaches, including time management, priority setting, and value clarification.

**Mind-Body Medicine**

Mind-body medicine is a phrase that has been used in a variety of different ways. Some definitions include all cognitive and behavioural interventions, while others focus on complementary approaches. Meditation is frequently included in mind-body medicine although it may also be classified within the cognitive-behavioural or behavioural spectrum.

**Integrative/Multi-Modal Programs**

Many programs bring together a number of different approaches in an integrated package. Some of these are disease specific and others target a range of diseases. Two examples of more generic integrative programs will be briefly described.

The Chronic Disease Self-Management Program (CDSMP), developed by Lorig and colleagues, is an well-researched, highly respected program. It is an extension of their earlier work in the Arthritis Self-Mangement Program. CDSMP uses pairs of trained lay leaders with chronic diseases (which offers positive role modeling) to teach a 7-week series of 2.5 hour sessions with the following content: how to develop an exercise program; cognitive symptom management; breathing exercises for relaxation; problem solving techniques; skills to communicate with health care providers, family, and friends; optimal use of medication; and dealing with the negative emotions associated with chronic illness (Lorig et al., 1994). A randomized trial at community-based sites demonstrated that seven weekly 2.5 hour sessions led by trained lay leaders resulted at 6 month follow-up in improvements in multiple domains of chronic disease self-management (e.g., weekly minutes of exercise, frequency of cognitive symptom management, communication with doctors, self-reported health, decreased limitations in social activities and roles, less health distress, disability and fatigue and fewer hospitalizations) as well as fewer hospitalizations and fewer days in hospital (Lorig et al., 1999).

Mindfulness-based stress reduction (Kabat-Zinn, 1990) incorporates relaxation breathing, mindfulness meditation, gentle yoga stretching, cognitive-behavioural approaches, including identifying and evaluating thoughts and the emotional impact of experiences, and psychoeducation. It is delivered in a 9-week series of 2 – 3 hour sessions to 15 – 30 participants by an instructor with extensive experience in mindfulness meditation.
Autoimmune diseases are characterized by their self-destructive nature that causes the body’s immune system to attack its own healthy tissue (Miller & Eoyang, 1992). Antibodies may attack specific organs, such as the thyroid in Hashimoto’s disease, or initiate a more general attack on non-specific tissue, as in Systemic Lupus Erythematosus (SLE).

Numerous autoimmune disorders exist and each differs with respect to symptoms, disease severity, incidence, remission, and other factors. Three of the most common autoimmune disorders are Rheumatoid Arthritis (RA), Multiple Sclerosis (MS), and SLE. What appears to be common among these illnesses, and of particular interest to the focus of this report, is that men and women present and respond differently to autoimmune disorders. Approximately 79% of the 8.5 million individuals diagnosed with an autoimmune disease are women. In comparison to men, two to three times as many women are diagnosed with MS and RA, and women with SLE outnumber men nine to one (Whitacre, 1999). A limitation of the published research in this area is the failure to specify the number of male and female participants. However, due to the high percentage of women diagnosed with autoimmune diseases, it can be assumed that many research initiatives utilize a high proportion of women as participants.

Sex & Gender Specific Issues

A US national task force recently reviewed more than 75 scientific papers and published an agenda to guide future research in autoimmune disease (Whitacre, 1999). Their work focused extensively on men’s and women’s varied experience of autoimmune diseases and the researchers reported that sex differences, such as specific sex hormones – estrogen, progesterone, testosterone, prolactin, growth hormone, and insulin-like growth factor 1 – may influence the immune system response. For example, during pregnancy, women with MS and RA experience decreased symptom severity, in contrast to pregnant women with SLE who experience increased symptom severity. They also reported that disease course may be influenced by one’s sex and that in comparison to men, women have a more aggressive immune response (Whitacre, 1999). These findings give substantial credence to the suggestion that future research in the area of autoimmune disease must consider the independent effect of gender.

The US national task force report suggested that gender differences in disease course are of critical importance. For example, MS progresses faster in women than men and, in comparison, women experience symptoms earlier than men. In addition, women tend to be diagnosed with SLE during their childbearing years, while men develop the disease later (Whitacre, 1999). Health care providers must be aware of patients’ specific disease experiences and have access to guidelines that are founded on credible research in order to design individual treatment programs.

Systemic Lupus Erythematosus

SLE is a chronic, inflammatory disease, often febrile, characterized by injury to the skin, joints, kidneys, nervous system, and mucous membranes (Miller & Eoyang, 1992). It is an autoimmune disease that can affect any organ of the body and often follows a pattern of remission and flares. Symptom severity can range from mild to life threatening and the disease commonly presents with fatigue, fever, arthritis, and various types of skin rashes (Bremer, 2000). Mood disturbance and psychosis are reported in approximately 20 and 15 percent of patients, respectively (Bremer, 2000).
Epidemiology
The prevalence of SLE is approximately one case per 800 people (Miller & Eoyang, 1992), with the highest occurrence in Afro-Caribbeans and Asians. It is diagnosed 13 times more frequently in women than men, with peak incidence occurring between 30 and 40 years of age (Bremer, 2000). The etiology of SLE is thought to be multifactorial, including exposure to sunlight or UV radiation from sunlamps, a genetic predisposition to the disease, certain drugs, viral infections, and hormonal influences (Miller & Eoyang, 1992).

Impairment in Quality of Life & Psychosocial Morbidity
Ward and colleagues (1999) have repeatedly studied the association between various factors and morbidity in women with SLE. Their most recent study found that psychosocial factors are associated with SLE morbidity; however, the specific relationship is dependent on the measure of morbidity examined (Ward et al., 1999). For example, it was concluded that greater SLE activity was associated with less adequate social support and that greater cumulative organ damage was associated with lower self-esteem and a time orientation focused on the future versus the present. In addition, greater physical disability was associated with increased depression. The clinical implications of these findings are considerable since they suggest that interventions targeting a specific psychosocial factor may not decrease all aspects of morbidity in patients with SLE (Ward et al., 1999). Furthermore, an assessment of the current literature in this area can provide the framework for determining the most important psychosocial factors to address in treatment intervention programs. Ward et al. (1999) do provide a general overview of recent studies and suggest that longitudinal research designs are required to establish causal connections between specific psychosocial factors and morbidity in women with SLE.

Sex & Gender Specific Issues
Sex and gender have received little attention as of yet.

Interventions Fostering Adaptation to Illness
The use of behavioural interventions to lessen or treat the associated symptomatology of SLE has not been widely studied. In fact, no double blind crossover studies have been done to test the effectiveness of psychosocial and adjuvant treatments in SLE and most reports of treatments used in addition to drug therapy programs are anecdotal and observational in nature (Bremer, 2000).

Education
Level of Evidence - IV
There has been no systematic study of the use of educational interventions in SLE.

Multimodal/Integrative Programs
Level of Evidence - IV
There has been no systematic study of the use of multimodal/integrative programs in SLE.

Stress Management
Level of Evidence - IV
There has been no systematic study of the use of stress management interventions in SLE.

Cognitive-Behavioural Approaches
Level of Evidence - IV
There has been no systematic study of the use of cognitive-behavioural approaches in SLE.

Behavioural Approaches
Level of Evidence - IV
There has been no systematic study of the use of behavioural approaches in SLE.

Other Psychotherapies
Level of Evidence - IV
There has been no systematic study of the use of other psychotherapies in SLE.
Social Support
Level of Evidence - IV
There has been no systematic study of the role of social support in adaptation to SLE.

Exercise
Level of Evidence - III
An eight-week pilot study showed that an exercise program could have beneficial effects for patients with SLE. Luang (1999) examined the effects of aerobic conditioning on lupus fatigue found that an aerobic conditioning program increased the aerobic capacity of the experimental group by 19% versus 8% in the control group. Furthermore, the exercise program did not appear to exacerbate the disease and only 2 of 16 experimental subjects reported transient joint symptoms during the exercise protocol (Luang, 1989). Research on the impact of behavioural interventions on autoimmune disease has been much more progressive in conditions such as MS and RA. Higher priority needs to be placed on the study of behavioural interventions and less common autoimmune diseases, such as SLE.

Nutrition
Level of Evidence - IV
There has been no systematic study of the role of nutrition in adaptation to SLE.

Mind-Body Approaches
Level of Evidence - IV
There has been no systematic study of the role of mind-body approaches in adaptation to SLE.

Interventions in Special Populations
Since SLE most commonly affects young women, pregnancy is also an important topic to address. All expectant women with SLE are classified as high-risk pregnancies, since 25% of these pregnancies result in premature births and 25% in fetal loss; thus only 50% of lupus pregnancies have normal terms and deliveries (Bremer, 2000). The mother’s health also presents concern since symptom flares are known to occur during the first or second trimester of pregnancy. Educational counseling is an important intervention for women of childbearing years diagnosed with SLE to enable them to make informed decisions regarding family planning.

Despite ethnoracial variations in prevalence, there has been no attention to ethnoracial issues in adaptation to disease.

Multiple Sclerosis
Multiple Sclerosis (M S) is an autoimmune disease characterized by scattered patches of demelination on the nerves of the central nervous system (Miller & Eoyang, 1992). These lesions cause a disruption in nerve impulse conduction and are the cause of the varied nature and severity of disease symptoms. The most common symptoms are difficulty walking, fatigue, numbness and tingling of varied body parts, reduced vision, slurred speech, bladder dysfunction, spasticity, and tremors. Psychosocial manifestations of M S are partly an adaptive response mechanism to the many physical symptoms; however, cognitive changes also occur that can cause intellectual, emotional, and functional disturbances. Depression and anxiety are common in patients with M S and although psychosis is rare among this group, bipolar disorder is observed more frequently than in the general population (Mahler, 1992).
The course of MS has a similar pattern to other autoimmune disorders, characterized by a pattern of remissions and relapses over an extended period of time. It has been speculated that viral exposure and genetics may contribute to the overactive immune reaction of the central nervous system and stress appears to be an aggravating factor responsible for many relapses in MS (Miller & Eoyang, 1992).

**Epidemiology**

The prevalence of MS is difficult to estimate since it is highly underreported and misdiagnosed (Miller & Eoyang, 1992). However, the increased availability of medical care and the use of magnetic resonance imaging (MRI) has enabled early diagnosis in many individuals. It is estimated that approximately 50,000 individuals in Canada have MS with prevalence ranging from 1 in 500 to 1 in 1000 across the country (Multiple Sclerosis Society of Canada, 2001a). Approximately twice as many women are diagnosed with MS as men, and similar ratios are reported for blacks and whites (Ghadirian et al., 1998). MS is also more common in countries of the temperate zone than in tropical and subtropical regions (Miller & Eoyang, 1992) and has been highly reported in areas where goiter is endemic, in regions with low selenium and iodine concentration and high exposure to heavy metals, and in areas of higher latitude (Ghardirian et al., 1998). It is reported that Canada has one of the highest rates of MS in the world (Multiple Sclerosis Society of Canada, 2001b). In addition to geographical factors, increased risk for developing MS has been associated with viral infections, higher socioeconomic status, and certain nutritional profiles.

The peak incidence of MS occurs in individuals between the ages of 20 - 40. This is particularly concerning to women because diagnosis during this period has great implications for family planning and pregnancy. The New England Journal of Medicine published a study by leading neurologists from 12 European countries that participated in the Pregnancy in Multiple Sclerosis (PRIMS) study. Confavreux et al. (1998) investigated women with MS during their pregnancies and up to 12 months post delivery to determine the rate of relapse per trimester. The relapse rate in each trimester was compared to the rate of relapse the year prior to pregnancy. The researchers concluded that the rate of relapse declines during pregnancy, mostly in the third trimester, and increases during the first three months postpartum before the rate of relapse returns to the prepregnancy baseline (Confavreux et al., 1998).

**Impairment in Quality of Life & Psychosocial Morbidity**

MS is obviously associated with significant impairments in multiple domains of quality of life and psychosocial functioning; however only in the past five years has there been an attempt to systematically document these (Fischer et al., 1999; Meyers et al., 2000). In addition to measuring impairment in those areas covered by disease-generic measures, MS quality of life measures need to assess symptoms which are common in the disease including fatigue, pain, bladder and bowel dysfunction, perceived cognitive function, visual dysfunction, and sexual satisfaction. Subcortical dementia develops in some patients (Brassington & Marsh, 1998). Depression occurs in 50% of individuals diagnosed with MS and may contribute to increased mortality via suicide (Feinstein et al., 2000). There are questions as to whether some of the disease modifying treatments for MS may further increase the likelihood of depression, although the data is inconclusive (Feinstein et al., 2000).
Sex & Gender Specific Issues

There has been little systematic attention to these issues in MS.

Interventions Fostering Adaptation to Illness

Researchers studying the psychosocial aspects of MS suggest that proper disease management should include neurologic care, cognitive rehabilitation, counseling, group support, and pharmacotherapy (Mahler, 1992; Murray, 1995). Furthermore, McLaughlin (1998) has suggested that a key role of the health care practitioner is to educate the patient with MS about how to self-advocate in order to facilitate coping by accessing appropriate resources and services.

Research has explored various behavioural interventions for the treatment of MS, including cognitive behavioural therapy, diet interventions, and exercise programs. In general, research supports the use of treatment programs that emphasize the rehabilitation of functional losses, stress management, social support, and adopting healthy lifestyle practices. One review of the literature looked at the following treatment interventions: social support, cognitive-behavioural therapy, meditation, placebo effect, imagery, visualization, spiritual/energy healing, music therapy, hypnosis, yoga, t'ai chi, and qigong (Luskin et al., 2000). The researchers concluded that these alternative interventions are effective primarily for musculoskeletal disease and related disorders and that further research is required to establish mechanisms of action and appropriate guidelines for the recommended protocol of their use (Luskin et al., 2000).

Education

Level of Evidence - IV

There have been no systematic investigations of the role of education in adaptation to MS.

Multimodal/Integrative Programs

Level of Evidence - II-I

The Rehabilitation Research and Training Centre for Multiple Sclerosis has implemented a rehabilitative model that emphasizes a proactive approach to treatment that includes many of the components recommended above (National Rehabilitation Information Centre, 1994). Preliminary findings evaluating cognitive-retraining of individuals with MS show that even a few treatment sessions can yield significant reduction in psychological distress and increased problem-focused coping (National Rehabilitation Information Centre, 1994).

Stress Management

Level of Evidence - IV

There have been no systematic studies of stress management in MS.

Cognitive-Behavioural Approaches

Level of Evidence - II-I

Researchers have specifically examined the effectiveness of cognitive behavioural therapy (CBT) for the treatment of depression in MS and have reported positive findings (Larcombe, 1984; Mohr & Goodkin, 1999; Mohr et al., 2000). This relationship may be partly facilitated by the improvement of measures that have been correlated with depression symptoms in patients with MS, such as learned helplessness and low self-efficacy (Shnek et al., 1997). Rodgers et al. (1996) found that CBT also resulted in significant improvements in verbal learning, verbal abstraction, and some measures of grip strength and tactile sensitivity. It is evident that CBT can have positive outcomes on the psychological, cognitive, and functional health of individuals with MS. Future research initiatives should study its potential benefit on various measures within these different dimensions of health.

The study by Mohr et al. (2000) deserves particular mention since the CBT was administered by telephone. In an eight-week treatment program of depressive symptomatology in MS patients, researchers reported a decrease in depression, as well as improved adherence to disease-modifying medication (Mohr et al., 2000). The researchers also found that the patient’s level of neurologic impairment was positively related to depressive symptoms. These findings provide support for the provision of telephone-administered mental health services for
people with MS since more impaired patients, who will also have more difficulty accessing services may be at greater risk for depression (Mohr et al., 2000). Further study on telephone-administered services could benefit patients with MS who are not able to access other treatment programs due to mobility problems or geographic location (Mohr et al., 2000).

**Behavioural Approaches**

**Level of Evidence - III**

There is a limited literature that includes a discussion of biofeedback in the management of the fecal incontinence which can occur in some patients with MS (Cooper & Rose, 2000). Hypnosis has been used for pain and neuromuscular rehabilitation in small case series (Dane, 1996).

**Other Psychotherapies**

**Level of Evidence - IV**

There has not been systematic investigation of the use of other psychotherapies in MS patients.

**Group Therapy**

**Level of Evidence - II-I**

In addition to cognitive-behavioural therapy, other types of psychotherapeutic interventions have been successful at reducing the psychological distress associated with MS. Group psychotherapy has demonstrated multiple benefits specific to improving the relationships and support among family members and friends (Landoni et al., 2000; Langenmayr & Schottes, 2000). Langenmayr and Schottes (2000) implemented a one-year group psychotherapy intervention with MS patients and observed significant changes between the therapy and control group with respect to relationships with family and friends, activities, and certain physical functioning abilities. The value of this psychotherapy intervention also exhibited long-term potential. At two-year follow-up, Langenmayr and Schottes (2000) found that the therapy group experienced additional physical improvements and a greater optimism toward life than the control group. These findings will need to be confirmed by future investigations; however, they provide support for the use of long-term psychotherapeutic intervention strategies to improve certain life qualities of patients with MS. In addition, the degree of value placed in the social relationships of women is widely acknowledged, and psychotherapeutic interventions may provide a means to strengthen these sources of social support for women with MS.

**Social Support**

**Level of Evidence - IV**

There have been no systematic studies of the role of social support in adapting to MS.

**Exercise**

**Level of Evidence - III**

According to Ponichtera-Mulcare and Glaser (1993), the literature supports the use of regular exercise for patients with MS to minimize the deconditioning process and maintain a maximal level of physical function. Broadening this field of research, Ponichtera-Mulcare and Glaser (1993) examined the specific exercise responses of persons with MS and concluded that exercise response is indirectly influenced by the level of physical impairment. This finding has important clinical implication for health professionals since it stresses the importance of establishing individualized exercise programs for MS patients who have varied levels of impairment. Leg cycling exercises and arm cycling for neurologically-impaired individuals were suitable for determining maximal aerobic power in individuals with MS (Ponichtera-Mulcare & Glaser, 1993). Establishing a patient’s baseline aerobic capacity is essential for developing an individualized exercise plan (NARIC, 1994) and could be the first step to introducing MS patients to the multiple benefits of physical activity.
Exercise as a treatment modality for improved psychological health of individuals with MS has not been adequately studied. Research has shown that depression and anxiety levels can be significantly decreased by exercise intervention (Leith, 1994); however, future research is required to examine the psychological benefits of exercise for people with MS.

**Nutrition**

**Level of Evidence - III**

Controlled research studies of dietary interventions for individuals with MS have focussed primarily on the recommendations of the popular “Swank diet” and the nutritional supplementation of fatty acids. These interventions are similar with respect to their underlying premise that the type of fat eaten may correlate with the development of MS and also disease outcome for diagnosed individuals. Although the link between MS and diet remains poorly understood, there are several studies that suggest that diets low in fat, particularly saturated fats, and high in polyunsaturated and monounsaturated fats, lessen one's risk for developing or dying from MS (Esparza et al., 1995; Ghadirian et al., 1998). Ghadirian et al. (1998) surveyed over 400 individuals (half with MS) and found that people who ate a diet high in fish, vitamin C, thiamin, riboflavin, calcium, and potassium and low in saturated fats and sugar had a decreased risk for developing MS. This finding supports the suggestion that diet may be related to the onset of MS. Thus, future research should explore dietary factors involved in the development and relapse occurrences of MS.

Research demonstrating that nutritional supplementation has beneficial effects on MS symptomatology involve dietary intake of fish oil (Cendrowski, 1986), cod liver oil fortified with Vitamin D in combination with calcium and magnesium supplementation (Goldberg et al., 1986), and evening primrose oil as a source of omega-6 fatty acids (Dworkin et al., 1984). Many of these studies have methodological limitations. One extensive double-blind controlled study looked at the effect of fish oil on over 300 people with MS and found no significant improvements (Bates et al., 1989). However, this study was criticized as the researchers used significantly reduced amounts of fish oil in the experimental group than has been found to be effective in the past. Based on the limited number of controlled research studies, as well as the lack of more recent research initiatives, conclusive guidelines regarding dietary interventions for MS treatment programs remain unsubstantiated. However, preliminary research in this area supports the role of healthy fats in the diets of MS patients and nutritional intervention may significantly influence the course of disease for some individuals. Research should continue to investigate the role of dietary interventions for individuals with MS.

**Mind-Body Interventions**

**Level of Evidence - IV**

There is little systematic data on mind-body approaches in MS.

**Interventions in Special Populations**

There has been little attention in the literature to tailoring interventions to specific populations.

**Rheumatoid Arthritis**

Rheumatoid arthritis (RA) is a chronic, inflammatory, systemic disease that affects the body’s connective tissue and can cause debilitating changes in joint structures, as well as lesions in the collagen of the lungs, heart, blood vessels, and pleura (Miller & Eoyang, 1992). The precise etiology of RA is unknown; however, it is classified as an autoimmune disease since high levels of certain immunoglobulins are in the blood of people with the disease. Similar to other autoimmune diseases, viral exposure, genetics, and stress are thought to contribute to the development of RA (Miller & Eoyang, 1992).
Epidemiology
RA is estimated to affect 1% of the adult population worldwide (Alarcon, 1995); however, three times as many women as men develop symptoms severe enough to require medical attention (Miller & Eoyang, 1992). Peak incidence of RA occurs between ages 40 and 50. Prevalence rates are greatest in the elderly; however, juvenile RA is also diagnosed in childhood (Miller & Eoyang, 1992).

Impairment in Quality of Life & Psychosocial Impairment
The disease course of RA presents mild symptoms at onset in 75% of patients, including malaise, fever, weight loss, and morning stiffness of the joints (Miller & Eoyang, 1992). If left untreated, the disease prognosis can worsen and increased damage is evident by crippled joints showing signs of pain and inflammation (Miller & Eoyang, 1992). As the disease advances, there is greater pain, immobility, and functional limitation in physical, emotional, social, and role functioning. Zautra et al. (1997) studied women with RA over 12 weeks and found that interpersonal stress was associated with increases in disease activity. Since RA can follow a disease pattern of relapse and remittance, it is essential that patients make appropriate lifestyle changes, such as stress reduction, to positively influence disease progression. Further research is needed to explore these themes, identify key sources of stress by gender, and incorporate findings into stress-management programs.

Sex & Gender Specific Issues
The current literature examines other aspects of the disease experience unique to women. In a retrospective case-control study, researchers from the Mayo Clinic compared men and women with RA for whom there was a minimum of 10 years of follow-up data available; women comprised 67% of the sample. The investigators found that men with RA had a higher risk of poor prognosis and that women had surgical procedures more frequently (as cited in Boers, 1998). Katz and Criswell (1996) analyzed the difference in symptom reports between men and women with RA and concluded that the observation that women report more severe symptoms may be due to greater disease severity rather than a tendency by women to over-report symptoms or over-rate symptom severity. The observed discrepancy in disease experience between men and women with RA indicates that further research is needed to establish the difference in disease experience relative to gender.

One possible explanation for the difference in symptom reporting observed by Katz and Criswell (1996) may be offered by a recent study by Affleck et al. (1999) examining the effects of RA and gender on daily pain, mood, and coping. The investigators found that women with RA experienced average daily pain 72% greater than men and observed that women used more emotion-focused strategies each day. However, an unexpected finding showed that RA patients who sought emotional support experienced increased pain the next day, suggesting that expressing distressing emotions and redefining the pain experience may not be effective strategies for pain reduction in RA (Affleck et al., 1999). Clinical applications of these results involve utilizing cognitive-behavioural therapy to help women make more positive cognitive appraisals regarding their pain experience.

Given that women of childbearing years are frequently diagnosed with RA, it is not surprising that this disease has tremendous impact on their ability to participate fully in family activities and commitments. Katz and Yelin (1995) analyzed data from a longitudinal panel study of women with RA and found that the aspect of functional decline in RA precipitating depressive symptoms is not only functional impairment, but also the loss of valued activities.

Interventions Fostering Adaptation to Illness
Treatment interventions for RA are primarily developed to decrease the pain, immobility, stress, and discomfort experienced by arthritic patients (Miller & Eoyang, 1992). In addition to drug therapy, many behavioural interventions are targeted at achieving these same outcomes. Furthermore, research supports the assertion that cognitive factors...
are stronger predictors of arthritis pain and disability than actual disease activity (Flor & Turk, 1988). For example, Lambert et al. (1990) demonstrated a positive correlation between the duration of morning stiffness and clinical measures of psychological well-being and depression in women. These observations provide statistical evidence to support the use of various cognitive-behavioural approaches to lessen the symptom experience of RA.

In comparison to MS and SLE, there is an extensive body of research examining cognitive-behavioural approaches and self-care treatment programs to facilitate adaptation to RA. Furthermore, research has focused on specific sub-populations and has reported successful behavioural intervention programs for both women (Sinclair et al., 1998) and children (Lavigne, 1992) with RA.

**Education**

**Level of Evidence - IV**

Education about RA has primarily occurred within the context of the self-management approach described in the next section. No studies could be identified in the past 15 years which used education as a sole modality.

**Multimodal/Integrative Programs**

**Level of Evidence - I**

Lorig and Holman (1993) wrote an extensive review on the Arthritis Self-Management Program (ASMP), an intervention that has been developed and studied for over 12 years. Three conclusions drawn from this collection of studies are important to outline: 1) the ASMP in randomized trials improves behaviours, self-efficacy, and aspects of health status; 2) the mechanism by which the ASMP affects health status appears to be more closely linked to changes in self-efficacy than to changes in behaviours; and 3) the ASMP is an intervention that can be and has been disseminated widely (Lorig & Holman, 1993). Outcomes of this 12-hour intervention, which incorporates a variety of behavioural techniques, including exercise, pain management, and problem-solving, show a 19% reduction in pain and a lower than average disease progression among participants (Centre for the Advancement of Health, 1999). Furthermore, these same individuals report 43% fewer physician visits, which translates into reduced health care costs (Centre for the Advancement of Health, 1999). In a separate study, Lorig and colleagues established that this program gave RA patients 20 - 40% more pain relief and decreased disability than non-steroidal anti-inflammatory drugs (NSAIDs) alone, and 60 - 80% more relief from tender joints (Superio-Cabuslay et al., 1996). Collectively, these findings suggest that physicians and arthritis health professionals should incorporate formal multimodal interventions in the treatment of individuals with RA.

Recent research has made important contributions to Lorig and Holman's (1995) original research in the area of self-management education programs for patients with RA. For example, Bath et al. (1999) examined patient perceptions of RA to identify key categories of importance to patients and to apply these findings to the development of tailored self-management programs. Their findings supported Lorig and Holman’s (1993) research that identified the following key areas of importance for patients with arthritis pain management, fitness and mobility, understanding medications, dealing with depression, and doctor/patient relationships. Their findings also indicated that “social support” and “issues relating to work” were key areas for intervention and that individual categories of importance can have dynamic interactions (Bath et al., 1999). Patient perception of disease experience should be strongly considered in the development of self-management treatment interventions and future research in this area is needed to explore patient perceptions of RA relative to specific sub-groups, such as women and children.

**Stress Management**

**Level of Evidence - IV**

Stress management has been included in multi-modal programs but has not been evaluated independently.
Cognitive-Behavioural Approaches
Level of Evidence - I
The success achieved by cognitive behavioural therapy to improve functional abilities, quality of life, and enhance pain relief is attributed to the development of self-efficacy in intervention participants (Lefebvre et al., 1999). Self-efficacy is defined as the confidence that one has the ability to perform a specific behaviour or change a specific cognitive state (Lorig & Holman, 1993). Self-efficacy differs from other constructs, such as stress and coping, because it is behaviour specific. Therefore, a patient's level of self-efficacy depends on her perceived ability to successfully achieve a particular behaviour, such as pain reduction (Lorig & Holman, 1993). A large, randomized, treatment outcome study, with predominantly women subjects, found that patients who initially rated their arthritis self-efficacy high reported lower levels of pain and negative mood and higher levels of positive mood (Lefebvre et al., 1999). The clinical implication for this finding lies in the development of self-management programs to teach patients with RA skills to enhance their daily coping abilities for disease associated stressors.

Behavioural Approaches
Level of Evidence - III
Behavioural approaches were studied in the 1970s and early 1980s but have not formed a prominent part of current approaches to adaptation to illness. They may be used to target pain management.

More recently, our group has become interested in the role of mindfulness-based stress reduction in facilitating adaptation to RA.

Other Psychotherapies
Level of Evidence - IV
There have been no systematic studies of other forms of psychotherapy in adaptation to RA.

Social Support
Level of Evidence - IV
There have been no systematic studies of other forms of psychotherapy in adaptation to RA.

Nutrition
Level of Evidence - II-1
It has been observed that individuals with RA frequently have nutritional deficiencies, including folic acid, vitamin C, vitamin D, vitamin B6, vitamin B12, vitamin E, calcium, magnesium, zinc, and selenium (see review by Koch, 2001). Consequently, researchers have recommended treatment interventions focused on various dietary approaches to reduce arthritic symptoms and slow the disease course. Three areas of nutritional medicine have been studied in relation to RA: vegetarian diets, elimination diets, and fish oil supplementation.

An intensive study conducted in Norway examined experimental subjects who completed a one-week juice fast, followed by a 3-5 month vegan diet. The control subjects ate a mixed food diet (Kjeldson-Kragh et al., 1991). Significant improvements on measures of inflammation and disease activity were observed in the experimental group. Follow-up comparisons were made between diet responders, non-responders and omnivorous controls at two years following the vegetarian diet intervention. All diet responders, and 50% of the non-responders were on a form of modified diet, excluding foods that aggravated symptoms. Commonly avoided foods were refined sugar, coffee, white flour, and sugar. Overall, there was significant improvement at two-year follow-up in disease symptoms for the diet responders, compared to both non-responders and omnivorous controls (Kjeldson-Kragh et al., 1991). Although this study has been criticized for non-random selection of subjects, it is of interest to note that 85% of participants were women. This suggests that vegetarian diets may significantly reduce RA symptoms in women, an observation warranting further study.
Elimination diets have been recommended by some researchers based on the observation that specific food sensitivities appear to exacerbate disease symptoms in many individuals with RA (Koch, 2001). The most common aggravating foods reported are dairy protein, corn, wheat, grains, citrus fruits, eggs, red meat, sugar, fats, salt, caffeine, and nightshade plants such as potatoes and eggplant. Darlington et al. (1986) conducted a blind, placebo-controlled study to examine if particular foods triggered symptoms following an elimination diet protocol. Significant reduction in RA symptoms was observed, including shorter duration of morning stiffness and fewer painful joints. In more recent studies (Kjeldsen-Kragh et al., 1991; Panush, 1991), researchers have supported the observation that dietary elimination and modification may be associated with significant improvement in RA symptoms. However, improvements are only temporary unless diet modifications are strictly maintained. It appears that there is a positive correlation between food sensitivities and RA symptoms; however, recommendations should be made with caution until larger, controlled, and randomized studies are completed (Koch, 2001).

Since nutritional deficiencies are associated with RA, patients should only attempt the suggested dietary changes required by these interventions under the supervision of a health care professional. Expectant women should not adopt a restrictive diet during their pregnancy term. In addition, women with RA face an increased risk of osteoporosis as a consequence of menopausal changes and arthritis drug therapy interventions. Nutritional counseling should be provided regarding the role of calcium and vitamin D, as well as weight-bearing exercise, for the prevention and treatment of osteoporosis.

Recently, researchers have examined the role of dietary fatty acids in modulating immune system response. Multiple studies have shown that dietary supplementation with fish oil can offer significant symptomatic relief for individuals with RA (Cleland et al., 2000; Fortin et al., 1995). It has also been demonstrated through double-blind, randomized, controlled studies that improvement in some patients may be significant enough to enable patients to reduce or discontinue their use of NSAIDs (Geusens et al., 1994; Kremer, 2000; Kremer et al., 1995). It is important to note that these studies have included both male and female participants and that benefits have generally been observed after 12 weeks of supplement intervention and appear to increase with continued use (Koch, 2001). Despite the encouraging benefits of fish oil supplementation, one researcher cautions that their use may interfere with blood clotting and increase the risk for stroke, particularly if taken in combination with aspirin or NSAIDs (Koch, 2001). Increased consumption of fish rich in omega-3 fatty acids, such as salmon, tuna, and mackerel may be a safer alternative (Koch, 2001). Navarro et al. (2000) examined female and male participants, in comparison to controls, and found that RA patients have an abnormal fatty acid profile and a significant deficiency in certain essential fatty acids. Women who follow strict low-fat diets may be at particular risk of fatty-acid deficiencies, and therefore, future studies to substantiate intervention guidelines, particularly for women with RA, should be prioritized.

**Mind-Body Approaches**

**Level of Evidence - IV**

Although many individuals use mind-body approaches, there has been little systematic study.

**Interventions in Special Populations**

**Children & Adolescents**

There has been surprisingly little written from the perspective of quality of life in children and adolescents with RA. Ten years ago, Singsen (1991) called for the development of health status measures for children with RA, but little has been done. Unmet service needs have been identified for children with rheumatic diseases and their parents in a metropolitan area (Lineker et al., 1996) and one can only presume that things are more difficult in rural settings. Children and parents both describe the need for further information (Barlow et al., 1999; Lineker et al., 1996) as well as formal and informal support groups and guidance around schooling. Sturge et al.
(1997) noted that problems with school attendance were associated with noncompliance with physiotherapy and “child psychological deviance”. Little is known about gender differences, although Lineker et al. (1996) report that parents of boys request more services. There is a pressing need for research and interventions for this age group.

Little has been written about behavioural interventions in other special populations.

**Recommendations**

1. **Clinical Care**
   - Behavioural interventions need to be integrated into routine clinical care for those women with autoimmune diseases who need or want them.
   - Arthritis self-management programs should be available at least on a regional basis
   - Group therapy and individual therapy using cognitive-behavioural and self-management approaches should be available for women with autoimmune diseases.

2. **Health Care Professional Education**
   - Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain, fatigue, and psychosocial distress associated with Systemic Lupus Erythematosus (SLE), Multiple Sclerosis (M S), and Rheumatoid Arthritis (R A).

3. **Public Education**
   - Educational materials need to be developed which address behavioural interventions that may facilitate adaptation to autoimmune diseases. These need to be produced in culturally and linguistically appropriate formats for diverse populations of women including Francophone, Aboriginal, and immigrant women. These should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and strategies to deal with distressing thoughts related to the diagnosis.

4. **Research**
   - Develop and evaluate an Arthritis Self-Management Program and Chronic Disease Management Program based on the work of Lorig and colleagues and modified for the Ontario health care context.
   - Develop appropriate and effective interventions for special populations including children, adolescents, and immigrant women.
There is a growing interest in the use of non-pharmacological interventions to improve the quality of life of individuals with cancer. Unfortunately, systematic literature validating the use of these interventions has not kept pace with the popular enthusiasm for them.

The field of cancer is very wide and the systematic study of behavioural interventions has been limited to specific tumour sites. Nonetheless, behavioural interventions are used on a daily basis in most cancer treatment centres, although the translation of research knowledge gained from randomized controlled trials about the most effective interventions into practice has been slow.

This review will focus on breast cancer as it is the tumour site with the largest empirical literature addressing the role of interventions to foster adaptation to illness.

**Breast Cancer**

Breast cancer is the most common form of cancer among Canadian women. Advances in diagnosis and treatment have increased the disease-free survival for many women diagnosed with breast cancer and this has heightened concerns about quality of life. As Rowland and Massie (1998) have observed “...unlike treatment for other chronic diseases such as diabetes and heart disease, the treatments for cancer are both more toxic and intensive. The result is increasing demands not only on patients’ physical reserves, but also on their psychological and social resources to survive and manage illness”. They have also commented on the growing demand by women and their families for health care professionals to address the psychosocial impact of breast cancer and to promote quality of life in individuals with breast cancer.

**Epidemiology**

Davidson (2001) reviewed the epidemiology of breast cancer and noted that the incidence of breast cancer increases with advancing age. Approximately 75% of breast cancers are diagnosed in women over the age of 50. Risk factors include early menarche, late menopause, late first pregnancy, nulliparity, prolonged use of hormone replacement therapy, ionizing radiation during adolescence, ongoing use of oral contraceptives, and consumption of alcohol. Approximately 5 – 8% of breast cancers occur in high risk families. The incidence of breast cancer in men is approximately 1% that of women.

**Impairment in Quality of Life & Psychosocial Morbidity**

The psychosocial morbidity and impact on quality of life (QoL) varies across individuals with the disease and depends on a host of factors, including the stage of life, psychological functioning, availability of practical and emotional support, medical factors (i.e., type of tumour, extent of disease, and treatment regimen), socioeconomic status, and the sociocultural context of the disease both within the broader culture and their own social worlds (Rowland & Massie, 1998). Chemotherapy and radiation therapy are often associated with significant fatigue, pain, and lifestyle disruption as well as disturbance in body image which is even greater when surgical resection of tumour has occurred. Psychological distress tends to be highest at points of change in the disease trajectory (e.g., diagnosis, initiation and termination of courses of treatment, diagnosis of metastatic disease, transition to palliative care). Sexual functioning is often compromised. Age or point in the life cycle is important in terms of which social and emotional roles are disrupted and there is evidence that women at both ends of the age continuum experience heightened difficulties in adapting to breast cancer (Rowland & Massie, 1998). A large study of women undergoing mastectomy found that women who were well adjusted before the surgery and whose disease was early had a QoL one year post-operatively which was equal to unaffected peers (Hughson et al., 1988). However, up to 25% of women may have problems in adapting to illness and lowered QoL which extends beyond two years post-treatment (Irvine et al., 1991).
Sex & Gender Specific Issues
The vast majority of the literature focuses on women. A recent review on male breast cancer noted that the epidemiology and clinical features generally parallel those of breast cancer in women but that men tend to be older, have subareolar tumours and present in more advanced stages of disease (Donegan, 2000).

Interventions Fostering Adaptation to Illness
Consumer activism on the part of women has fueled the development of interventions to promote successful adaptation to the disease and fostered study of the psychosocial aspects of breast cancer. While this has been positive, there have been concerns that a “blame the victim” mentality might be inappropriately used to explain further disease activity.

In reviewing the rapid growth in psychosocial interventions over the past decade, it has been observed that utilization of these services is increasing, that individuals who take part in interventions do better than those who do not take part in some additional form of care, and that there may be special advantages to group treatments in this setting (Rowland & Massie, 1998).

Consumer participation in the development of psychosocial clinical practice guidelines for breast cancer has emphasized the importance of psychosocial care (Rankin et al., 2000). At least 50% of women rated 28 of 52 items related to psychosocial care as “essential”. The most important priorities were providing information and choice, and doctor-patient communication. Counselling and support group services were rated as very important or important.

Education
Level of Evidence - I
While there have been studies of educational and psychoeducational interventions specific to breast cancer (Spiegel et al., 1989; Spiegel et al., 1981; Vachon et al., 1982), breast cancer patients more often form parts of mixed cohorts of cancer patients (Fawzy & Fawzy, 1998). Psychoeducational interventions have included some combination of information about cancer, health education about promoting healthy lifestyles while living with cancer, coping skills (e.g., problem-solving techniques, stress management), behavioural training to enhance pain management, and adaptation to the demands of the medical regimen. The literature suggests that education and psychoeducation has its greatest potential benefit early within the disease course. It has been suggested that it may be most effective if it is short-term and structured and focuses on learning to live with cancer; there should be separate longer-term groups for individuals with ongoing difficulties in adjusting to cancer or who are dealing with metastatic disease (Fawzy & Fawzy, 1998).

Helgeson et al. (1999) compared the effectiveness of a peer discussion-based group intervention with an education-based group intervention using a randomized controlled design. Education-based groups improved adjustment both immediately following the groups and at six months follow-up, whereas peer discussion group members showed no benefits of participation and some trend to adverse effects.

“The Healing Journey” is a brief psychoeducational program for cancer patients which provides a four session lecture-style introduction to basic coping skills including stress management, relaxation training, thought monitoring and changing, mental imagery, and goal setting (Cunningham et al., 1999). It is associated with improvement in mood in nonrandomized studies and is cost-effective as 40 – 80 individuals can be serviced at a time.

Multimodal/Integrative Programs
Level of Evidence - III
Breast clinics providing multidisciplinary care are increasing popular and there is clinical evidence to suggest that these programs are helpful in reducing stress, improving access to information, and facilitating decision-making.
Stress Management
Level of Evidence - IV

There have been no evaluations of stress management as a unimodal intervention. It has been incorporated into educational and psychoeducational interventions as noted earlier.

Cognitive-Behaviour Approaches
Level of Evidence - I

Cognitive-behavioural therapy (CBT) was first studied in a controlled randomized trial in breast cancer for the management of pain by Spiegel and Bloom (1983) who taught women with metastatic disease to use hypnosis in pain management. Women receiving group therapy and hypnosis reported less severe pain and less suffering than those receiving group therapy alone and both groups had substantially less pain than a control group. The study was limited by the non-random assignment of women to hypnosis and a high death rate within the one year study period.

A study of cognitive-behavioral stress management which included a variety of different components (stress management; cognitive restructuring; coping skills training; anger management; social support utilization skills; and relaxation modalities including progressive muscle relaxation, meditation, abdominal breathing, and guided imagery) delivered over 10 weeks in a group format found that participants showed perceived positive personal growth which the investigators called “benefit finding” as well as significant decreases in serum cortisol (Cruess et al., 2000). A five month, 11-session CBT intervention for women with metastatic breast cancer reduced mood disturbance and improved self-esteem, but these improvements were not maintained at three and six month follow-up (Edelman et al., 1999).

Cognitive-behavioural homework assignments were coupled with a supportive-expressive group therapy in a randomized clinical trial with positive benefits for mood, quality of life, and adjustment to cancer (Edmonds et al., 1999).

CBT to enhance coping with pain and fatigue are in wide clinical use.

Behavioural Approaches Level of Evidence - IV

Behavioural therapy with a particular emphasis on relaxation has been studied in mixed tumour site populations and has been found to reduce aversive reactions to chemotherapy and anticipatory nausea and vomiting (Jacobsen & Hann, 1998).

Our group is presently evaluating mindfulness-based stress reduction in women with cancer.

Other Psychotherapies
Level of Evidence - I

Group psychotherapy is an excellent modality for improving QoL and reducing psychological distress in women with breast cancer and there is also a possibility that participation in it extends the duration of life. Group therapy has become of great clinical and theoretical interest following the results of Spiegel et al.’s (1989) 10-year follow-up of women with metastatic breast cancer who had participated in a randomized trial of supportive expressive group therapy. They found that survival time was twice as long among women who had participated in the group compared to controls (36.3 months vs. 18.9 months). Canadian researchers are currently doing a replication trial; data is pending. Spiegel’s group (Classen et al., 2001) reported on a randomized clinical intervention trial which compared women receiving an intervention consisting of one-year of weekly supportive-expressive group therapy and educational materials with controls who received educational material only. The intervention has been described as follows: “The supportive-expressive therapy model involved the creation of a supportive environment in which participants were encouraged to confront their problems, strengthen their relationships, and find enhanced meaning in their lives. The intervention was unstructured with the therapists trained to facilitate discussion of the following themes as the material emerged and in an emotionally expressive rather than a didactic format: (1) fears of dying and death, including dealing with the deaths of group members; (2) reordering life priorities; (3) improving support from and communication with family and friends; (4) integrating a
changed self and body image; and (5) improving communication with physicians. The groups also included psychoeducation and discussion of coping skills, but this always arose out of participants' spontaneous reports rather than being presented in a didactic fashion. The intervention group, compared to the control group, demonstrated a significantly greater decline in total mood disturbance and traumatic stress symptoms.

Spiegel and colleagues (1999) have recently demonstrated the feasibility of undertaking supportive-expressive group psychotherapy in recently diagnosed breast cancer patients in community settings. In another study, women with metastatic breast cancer treated with supportive-expressive group psychotherapy showed a significant decline in traumatic stress symptoms and depression (Classen et al., 2001).

Cunningham and colleagues (2000) have conducted a number of studies looking at the value of group psychotherapy in women with breast cancer in terms of improving QoL (Edmonds et al., 1999) and potentially extending survival (Cunningham et al., 2000a; Cunningham et al., 2000b). Cunningham (2000) has argued that adjuvant psychological therapy must be put on the same footing as adjunctive medical therapies.

Interpersonal psychotherapy has recently been adapted for use in a telephone intervention for breast cancer patients and their partners (Donnelly et al., 2000). A pilot study of patients and partners found high participant satisfaction and improvement in psychosocial functioning.

**Social Support**

**Level of Evidence - IV**

Social support is one of the presumed mechanisms involved in the positive outcomes with supportive-expressive group therapy described above. There have been no interventions of social support as a unimodal intervention. There is an extensive and complicated literature on whether and how social support might protect people from adverse QoL in cancer (see review in Helgeson et al., 1999).

**Exercise**

**Level of Evidence - II-1**

Exercise has been recommended in the physical rehabilitation of breast cancer patients. Recently published Canadian clinical practice guidelines for the management of lymphedema noted that clinical experience supports the use of exercise (Harris et al., 1998; McVicar & Winningham 1986; McVicar et al., 1989; Mock et al., 1994; Mock et al., 1997; Winningham et al., 1989) and a further study with the majority of participants having breast cancer and being post-treatment (Berglund et al., 1993; Berglund et al., 1994). Not all studies have used randomized controlled designs, and many have been plagued by small sample sizes and issues of selection bias. As well, prior history of exercise has not been adequately evaluated (see review in Pinto & Maruyama, 1999) and studies have not comprehensively assessed the impact on QoL.

**Nutrition**

**Level of Evidence - I**

Recent attention has focused on the importance of low fat diet and weight loss in obese women with breast cancer because of evidence that factors related to metabolic overload (e.g., energy density of food, obesity) are associated with increased risk of breast cancer recurrence and death (Hibbert, 1998). Hibbert et al. (2001) conducted a randomized clinical trial of a 15-session group-based and dietician-led nutrition education program and found that women randomized to this intervention had lower fat consumption and lost an average of 1.3 kg (although weight loss was not a goal) compared to those in a mindfulness-based stress reduction clinic program or usual supportive care. Research on the feasibility of using volunteer research staff to deliver and evaluate a low-fat dietary intervention found that volunteers could deliver a complex and intensive dietary intervention (Kristal et al., 1997).
Mind-Body Approaches
Level of Evidence - IV

Mind-body approaches are an integral part of many community and hospital-based interventions for women with breast cancer and yet have not been adequately evaluated in terms of their impact on QoL (Tagliaferri et al., 2001).

Interventions in Special Populations

Rural Women
Rural women have come under study. In focus groups with rural Washington breast cancer survivors, woman reported problems with the medical system and the need for increased support and educational services (Wilson et al., 2000). They revealed that the diagnosis of breast cancer is among the most stressful life events they have ever experienced and described themselves as distressed, although this was not reflected in the Profile of Mood States (Koopman et al., 2001). There was considerable variation in which kind of social group provided them with the most effective support - the two most frequently mentioned sources were church/spiritual groups and family members. The matching of interventions to individual woman requires further study (Koopman et al., 2001).

Lesbian Women
Lesbian women have begun to receive greater attention with the recognition of risk factors contributing to their incidence of breast cancer (Roberts et al., 1998). When compared with heterosexual women enrolled in an early intervention trial to facilitate adaptation to early (12 – 18 months post-diagnosis) breast cancer, lesbian woman reported fewer problems with body image; greater social support from friends and less from family members; and did not differ in terms of level of emotional distress, relational issues, or sexual satisfaction. They reported being less satisfied with their physician’s care and a different profile on cancer related coping measures with greater anger, less fighting spirit but also less fatalism and cognitive avoidance (Fobair et al., 2001). Data on their experience within the intervention has not yet been reported.

Aboriginal Women
Aboriginal women may be at decreased risk of breast cancer compared to the total Canadian population, although they are at increased risk for cervical cancer (Gaudette et al., 1993). There has been no systematic attention to developing interventions targeting these women and they share many of the problems of rural women in terms of accessing both information and psychosocial interventions.

Women At Risk for Familial Breast Cancer
With the advent of genetic screening for breast cancer, there has been a concomitant rise in the numbers of women seeking out this testing. Not surprisingly, there is often significant psychological distress associated with such testing and subsequent decision-making based upon results. The intervention literature is developing in this area and it shows that interventions can decrease the psychological distress and psychosocial morbidity associated with genetic testing in high risk women (Esplen et al., 2000; Esplen et al., 1998; Lerman et al., 1997).

Recommendations

1. Clinical Care
   - Supportive-expressive and psychoeducational group therapy should be available for women who wish to access it both early in the course of their disease and at the time of metastatic disease.
   - Behavioural and psychosocial interventions need to be integrated into routine clinical care for those women who need or want them.

2. Health Care Professional Education
   - Health care professionals involved in delivering psychosocial interventions should be trained and competent in the supportive-expressive model of group therapy.
   - Health care professionals need to learn more about the potential value of behavioural and psychosocial interventions in women with breast cancer.
   - Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain and fatigue associated with breast cancer.
3. Public Education

- Educational materials need to be developed which address basic aspects of breast cancer and the behavioural interventions that may facilitate adaptation to it. These materials need to be produced as well in linguistically and culturally appropriate editions for Francophone, Aboriginal, and immigrant women. These materials should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and weight management strategies.

4. Research

- Develop appropriate and effective interventions for women who have difficulty accessing behavioural interventions through health care settings.
- Research the value of mind-body approaches in terms of improvements in quality of life and psychological and psychosocial functioning. These interventions are increasingly being incorporated into programs but there is little evidence as to which are most clinically effective and most cost-effective.
- Investigate the experiences of lesbian women with breast cancer in order to foster greater understanding of their needs within the healthcare community and tailor interventions for their special needs.
Cardiovascular disease (CVD) is defined as any abnormal condition characterized by dysfunction of the heart and blood vessels. It is therefore a broad term and includes conditions such as hypertension, atherosclerosis, coronary heart disease, myocardial infarction (MI), and stroke (cerebrovascular accident).

**Coronary Heart Disease**

Coronary heart disease (CHD) is also known as coronary artery disease (CAD) and ischemic heart disease (IHD). It occurs when the coronary artery circulation is unable to supply sufficient blood flow to meet the demands of the heart muscle in response to the work the heart is required to do.

**Epidemiology**

CVD is the leading cause of death in Canada and the third leading cause of premature death in women under the age of 75. There is a paucity of evidence regarding women's psychological response to CHD as most studies in this area have been conducted with male subjects. Research that has examined CHD in women has tended to focus on how physiologic rather than psychosocial factors affect the diagnosis and management of the disease (Arnold, 1997). CHD may determine the quality of life (QoL) and independence experienced by women of older ages more than any other disease. Arnold (1997) asserts that psychosocial factors are major influences on the cardiac health care of women and are significant factors with regard to primary, secondary, and tertiary prevention strategies. Depression and lower socioeconomic status (SES) are positively associated with higher CHD morbidity and mortality rates in women (Arnold, 1997).

Women who live alone and who are socially isolated are at the highest risk for mortality from CHD. One study demonstrated that socially isolated women who live alone and have high stress levels have four times the risk of CHD mortality compared to women with low stress levels and less limited social networks (Arnold, 1997).

**Impairment in Quality of Life & Psychosocial Morbidity**

CHD has an enormous impact on QoL and is associated with significant psychosocial morbidity. The Medical Outcome Study demonstrated the worst QoL across nine chronic medical conditions in individuals with a myocardial infarction in the prior 12 months or with congestive heart failure which is an end-stage of CHD (Stewart et al., 1989). Functioning was impaired in all aspects of life—physical, role, and social functioning, mental health, bodily pain, and health perceptions. While there has not been sufficient study of women, a number of studies with men and with mixed samples have shown elevated rates of depression, which appears to be an independent predictor of mortality following myocardial infarction (see review in Lesperance & Frasure-Smith, 2000).

**Sex & Gender Specific Issues**

Despite the fact that CHD is a major killer of women, it is still conceptualized as a man's disease (Arnold, 1997). Current diagnostic procedures and treatments are based on research that was carried out largely on men. “Although further research is badly needed, enough solid data has been collected to indicate that gender differences exist in coronary heart disease, requiring different approaches to prevention, detection, and management” (American Medical Women's Association, 2001).

Women on average develop CHD when they are 10 years older than men and are more likely to have unrecognized infarctions and atypical presentation of their cardiac symptoms (Cole, 1993; Flavel, 1994). “The primacy of the male perspective on a feminine experience of CHD can lead to minimizing potentially fatal cardiac symptoms in a woman or a psychiatric diagnosis when a physical one would be more appropriate” (Arnold, 1997). Early, treatable cardiac pathology in women may be missed because screening procedures do not recognize significant gender-based variations in presentation of symptoms.
The role of “knowledge deficit” may therefore be important in determining a woman’s CHD outcome (Arnold, 1997). Dempsey et al. (1995) found that when women did not recognize cardiac symptoms or when they tended to minimize them due to misinformation or denial, they turned to lay people for advice or used self-treatment rather than consulting a physician. Because women diagnosed with CHD are often older than men who have been similarly diagnosed, treatment of women must take into account the co-morbidities often associated with aging (Brechue & Pollock, 1996).

We have recently reviewed the literature on gender differences in the psychological and psychosomatic aspects of CHD (Abbey & Stewart, 2000).

Emotional distress can aggravate physical symptoms and cause delays in recovery. Research suggests that women experience more psychological stress associated with CHD than men and that this stress negatively affects their outcomes. Studies conducted by Conn et al. (1991), Low (1993), Schuster et al. (1991) and Wenger (1994) have shown that after an MI, women experience greater emotional pain and lower self-esteem, have more subjective complaints, make more visits to physicians, experience a decline in sexual functioning, complain of sleep disturbances, and experience more social isolation than men.

Women are less likely than men to return to work or to participate in cardiac rehabilitation programs after experiencing an MI (Chirikos & Nickel, 1984; Downing & Litman, 1991; McGee, 1992). Women are also more likely than men to leave the workforce within two years following an MI. Women who do participate in rehabilitation programs have a significantly higher dropout rate than men (Ginzel, 1996). King (NIH publication #94-3009) has written that the lower participation and higher dropout rates of women may indicate that the schedules of such programs are not appropriate for women with caregiving or family responsibilities. Women may need to approach the rehabilitation process differently than men because they appear to have a greater need to receive interpersonal support by talking to others about their illness and required lifestyle changes.

**Interventions Fostering Adaptations to Illness**

Given the importance of CHD for impairment in QoL, psychosocial morbidity, and medical morbidity and mortality, it is surprising that there is a dearth of literature on effective behavioural interventions to foster adaptation to illness and promote secondary prevention. Most of the literature is on men or mixed samples with small percentages of women. Existing literature is also characterized by methodological limitations and insufficient detail in reporting of results, such as analyses for sex and gender differences (Toobert et al., 1998). The importance of interventions aimed at behaviour change has been emphasized given that most of the risk factors responsible for the development and progression of CHD are associated with lifestyle factors (Sebregts et al., 2000; Wielgosz & Nolan, 2000). Yet most internists and cardiologists are not appropriately trained and remunerated for their efforts in this area and most psychologists and psychiatrists who do not have experience with this population are fearful about working with them (Scheidt, 2000).

**Education**

**Level of Evidence - I**

There have been two meta-analyses of education and psychoeducational programs for CHD patients (Dusseldorp et al., 1999; Mullen et al., 1992) which unfortunately did not pay much attention to the issue of gender. They did show that education and psychoeducation (i.e., health education and stress management) have positive effects on mortality, recurrence of MI, blood pressure, cholesterol, body weight, diet, exercise, and smoking behaviour.
Multimodal/Integrative Programs
Level of Evidence - I

A national survey in the US found that following an MI, 7% of women enrolled in a cardiac rehabilitation program compared to 13% of men and suggested these gender differences may be related, in part, to the degree of encouragement a woman receives from her physician (Mosca et al., 1997).

The most effective cardiac rehabilitation uses a multi-interventional approach, which should include patient education, lifestyle change, diet and lipid management, smoking cessation, and an exercise program (Brechue & Pollock, 1996). The objectives are to restore physical function and health, to decrease risk of cardiovascular morbidity, and to decrease all-cause mortality. Exercise programs typically include both endurance and resistance exercises in order to reduce CAD risk factors; restore bone mineral density, muscle mass, and overall fitness; and assist in the control of hypertension and the reduction of body fat. Endurance and resistance exercise are both effective in improving insulin sensitivity and glucose tolerance. Increased bone mineral density and muscle mass are important in that they enhance an individual’s ability to complete an endurance program and may decrease risk of injury (Brechue & Pollock, 1996).

Modified cardiac rehabilitation programs are of benefit to elderly cardiac patients (Brechue & Pollock, 1996). Exercise regimens for elderly cardiac patients should be specifically tailored to each patient’s age, fitness level, and health status. Low-impact exercises such as cycling, walking, swimming, stair-climbing, and cross-country skiing are all suitable exercise prescriptions. Avoiding high-intensity or high-impact activities decreases the risk of injury or a cardiac event and increases compliance with an exercise program (Brechue and Pollock, 1996). Although further study is required, cardiac rehabilitation exercise appears to be of equal benefit to young and old patients. While the women in this population tend to be less fit than their male counterparts and less likely to be referred to a cardiac rehabilitation program, their response to the exercise has been found to be similar to that of men (Ades et al., 1987).

The Lifestyle Heart Trial, described by Ornish et al. (1998), was a randomized trial of patients with moderate to severe CHD that entailed the following rigorous lifestyle program for its experimental subjects: (1) vegetarian diet with a maximum of 10% fat; (2) moderate aerobic exercise; (3) stress management training; (4) smoking cessation; and (5) group psychosocial support. Control subjects received usual care. The main outcome measures were adherence to intensive lifestyle changes, changes in coronary artery percent diameter stenosis (atherosclerosis), and cardiac events. Adherence to all aspects of the lifestyle changes required by the program for the experimental group was determined to be excellent during the first year and good after five years. In the experimental group, subjects experienced a regression of coronary atherosclerosis. After the first year, average percent diameter stenosis underwent a 5% improvement relative to baseline among the experimental group and an 8% improvement over five years. Among the control group, the stenosis underwent a 5% worsening at one year in the control group (2.25 per patient) than in the experimental group (0.89 per patient). A limitation of the study was its near exclusion of women – none (compared with 20 men) in the experimental group and three (compared with 12 men) in the control group – and the difficulty in generalizing such an intensive intervention to the general CHD population.

Rutledge et al. (1999) describe a study that assessed the effects of a two-year intensive lifestyle modification program on clinical outcomes in patients with coronary atherosclerosis (28% women). Serum lipids, body weight and consumption of fat were reduced and physical fitness was improved in the 60% of patients who completed the two-year program (Rutledge et al., 1999). The attrition rate, at 40%, was high. It was particularly high for the women, among whom 45% dropped out compared with 37% for the men. The authors state that the high dropout rate warrants investigation and suggest that a more flexible program may be required to enhance adherence.
**Stress Management**  
**Level of Evidence - III**

There are have been few systematic studies of stress management as a unimodal therapy despite the importance of heightened cardiovascular reactivity to stress (Wielgosz & Nolan, 2000). Trzcieniecka-Green and Steptoe (1994) showed improvements in psychological well-being, activities of daily living, social activity, satisfaction with sexual relationships, and decreased anxiety and depression in participants in a 12-week stress management program. Bundy et al., (as cited in Johnston, 1997) compared stress management offered in a group setting with regular care and found that the former intervention was associated with decreased duration of pain and decreased medication usage. Lewin et al. (1992) also found that, compared with regular care, stress management decreased pain and medication use, as well as the extent of disability as measured through a questionnaire.

**Cognitive-Behavioural Approaches**  
**Level of Evidence - III**

Cognitive-behavioural therapy (CBT) has been targeted at a number of salient aspects of adaptation to CHD, including facilitating lifestyle risk factor modification and coping with anxiety and depression. CBT appears to increase self-efficacy in individuals recovering from an MI (Z. Shnek, personal communication). Several large trials of CBT in CHD by North American investigators are currently underway.

**Behavioural Approaches**  
**Level of Evidence - III**

There have been no meta-analyses of behavioural approaches but expert opinion endorses positive effects for progressive muscular relaxation, autohypnosis, transcendental meditation, and biofeedback training (Sotile, 1999). Behavioural approaches may be incorporated into smoking cessation strategies.

**Other Psychotherapies**  
**Level of Evidence - IV**

There is interest in the use of interpersonal psychotherapy in the depressed cardiac patient. A Canadian pilot study, in which our group is participating, of interpersonal psychotherapy in depressed cardiac patients is underway and a protocol for a comparison of interpersonal psychotherapy and pharmacotherapy has been submitted for funding. Pilot data suggest that interpersonal psychotherapy is well accepted and effective in decreasing depressive symptoms (F. Lesperance, personal communication).

**Social Support**  
**Level of Evidence - IV**

Social support interventions have received relatively little study given the evidence that social support decreases cardiovascular reactivity (Gerin et al., 1995).

**Exercise**  
**Level of Evidence - I**

While the literature clearly shows the value of exercise in improving cardiac function, there has been less attention to its impact on QoL and psychological status in terms of depression and anxiety. While it is a reasonable inference that improved cardiac function would translate into improved QoL, only a handful of studies directly assess these issues and there are methodological complexities which sometimes make it hard to isolate the effect of exercise.

A Cochrane review (Jolliffe et al., 2001) of more than 8,000 patients with CHD concluded that exercise-based cardiac rehabilitation is effective in lowering mortality. However, it was not possible to ascertain whether exercise alone or in combination with other interventions was most effective. Exercise-only interventions resulted in a 31% decrease in cardiac mortality and a 27% decrease in all-cause mortality. Comprehensive cardiac rehabilitation resulted in a 26% decrease in cardiac mortality and a 13% reduction in all-cause mortality. Neither of
the interventions affected the occurrence of non-fatal MI. There was a significant reduction in cholesterol in subjects who participated in comprehensive cardiac rehabilitation programs. The reviewers noted that the population included in the review was predominantly male, middle-aged, low-risk, and of unreported ethnicity. The reviewers also stated that individuals who may have benefited most from the intervention could have been excluded from trials due to gender, age or co-morbidities.

Miller et al. (1997) report on clinical trials that have evaluated effects of exercise on clinical symptoms, exercise-induced ischemia, and anatomical progression of disease in individuals with confirmed CAD. Eight of the 12 trials demonstrated statistically significant improvement in symptoms of angina or heart failure. The degree of exercise-induced ischemia was also reduced through cardiac rehabilitation programs.

The exercise component of cardiac rehabilitation programs does not significantly decrease psychological distress on its own (Kugler et al., 1994). Lewin and colleagues found that a comprehensive manual with relaxation tapes and periodic telephone calls from a cardiac nurse are more effective than routine care in decreasing anxiety and depression in patients during the one-year period post-MI (as cited in Johnston, 1997).

In order to improve aerobic capacity, duration of an activity should be between 20 to 60 minutes and the intensity should be between 60% to 90% maximum heart rate for healthy young and middle-aged individuals. If intensity is in the 50% to 70% maximum heart rate range, duration should be between 40 to 60 minutes. The activity should require a total energy expenditure of 250 to 300 kcal per session (Brechue & Pollock, 1996). An individual may judge the intensity of exercise through ratings of perceived exertion that have been found to correlate well with heart rate. Among the elderly, a longer warm-up period is required prior to the initiation of more vigorous exercise. Also, the intensity of an activity should be lowered to 30% to 75% maximum heart rate and duration increased (Brechue & Pollock, 1996). Low-impact activities/exercises should be used for individuals over 50 as injuries are more common among this age group. This is particularly true for women, for whom the injury rate is four to five times greater than for men (Brechue & Pollock, 1996).

Nutrition

Level of Evidence - III

Evaluation of nutrition strategies to facilitate adaptation are troubled by the same issue as with exercise - i.e., there has been little attention in the literature to the impact of these interventions on QoL. Instead, the major focus has been on cardiovascular mortality and recurrent cardiac events, although one might infer improved quality of life if recurrent cardiac events are reduced.

A Cochrane review (Hooper et al., 2001) evaluated the effect of reduction or modification of dietary fats on total and cardiovascular mortality and morbidity, using 27 eligible randomized clinical trials. Only trials that included a control group and that had an intervention of at least six months' duration were considered. Trials with multiple interventions or those that looked specifically at omega-3 fats were excluded. The reviewers found a trend towards decreased cardiovascular mortality and a significant reduction in risk of cardiovascular events. Total mortality was not affected. The reviewers note a “small but potentially important” decrease in cardiovascular risk in subjects who participated in trials for longer than two years. They recommend that dietary advice for individuals at low and high risk for CVD should continue to emphasize the need to reduce saturated fat and to partially replace these with unsaturated fats.

Research reported by Sackett and Snow (1979) has shown that patients often find it difficult to incorporate dietary changes into their lives. There has been little research, however, to examine potential gender differences in successful implementation of dietary changes among individuals with CVD.
In an intervention study by Aish (1996), patients (44% women) who had experienced an MI were randomly assigned to a control group or a nursing intervention that entailed a home visit and three follow-up phone calls to assist the patient in making dietary changes. After seven weeks, the intervention group was found to have healthier eating habits than the control group. The average daily consumption of total fat and saturated fat was lower in the treatment group, but there was no significant difference in cholesterol intake between the groups. Women in the treatment group were found to have a lower intake of cholesterol and healthier eating habits than the men. Measures of self-care agency and self-efficacy for healthy eating were comparable between women and men; however, women perceived lower levels of social support for healthy eating.

Hatton et al. (1996) assessed the effects of prepackaged and self-selected meals on QoL for individuals with CVD. The prepackaged meals were developed to ensure that current dietary recommendations for CVD risk reduction were met. As well, providing meals in this manner was seen as a way to circumvent the problems individuals frequently have adopting new diets. Patient acceptance of the diet was assessed through measures of QoL. The study design was a randomized, parallel-design, multicentre clinical trial in which individuals with hypertension, diabetes mellitus, dyslipidemia, or a combination of these conditions were assigned to either a prepared meal plan or a comparable self-selected diet and followed for 10 weeks. Analysis of subjects’ responses on a battery of instruments revealed that those eating the prepackaged meals underwent a greater improvement in quality of life.

**Mind-Body Approaches**

**Level of Evidence – IV**

While there is clearly interest in this area, there is little systematic data.

**Interventions in Special Populations**

There has been little attention to the needs of special populations in intervention studies. Clinical experience and anecdotal evidence highlight the importance of better understanding the need for and tailoring of interventions for pre-menopausal women, women of diverse ethnoracial backgrounds, and impoverished women.

**Hypertension**

Hypertension, or high blood pressure, is a major public health problem because of its association with an increased risk of CVD. Blood pressure (BP) is distributed normally in the population, making the choice of a cut-off point to identify hypertension arbitrary. The classification of BP for adults is based on a systolic blood pressure (SBP) at or above 140 mm Hg or a diastolic blood pressure (DBP) at or above 90 mm Hg or both (National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure, 1997).

**Epidemiology**

Hypertension affects more than 20% of Canadian adults (McAllister et al., 2001). It is an important modifiable risk factor for CHD and stroke and can cause end-organ damage in the kidneys, eyes, and brain.

**Impairment in Quality of Life & Psychosocial Morbidity**

In the Medical Outcome Study, the only statistically significant difference from normative data was in health perceptions (i.e., overall self-rating of current health in general; Stewart et al., 1989). Often QoL issues are more of a concern with pharmacological treatment than without it because of the side-effects associated with medications, as hypertension is often a disease without symptoms until end-organ damage occurs. Drug treatment of hypertension is commonly associated with changes in QoL (Cote et al., 2000) and pharmaceutical companies use QoL data as part of their marketing campaigns.

**Sex & Gender Specific Issues**

Recent reviews have considered sex and gender differences in the physiology, genetics, and treatment of women compared with men with hypertension (August & Oparil, 1999; Hayes & Taler, 1998; Reckelhoff, 2001). Wielgosz (1996) has reviewed the impact of social environment on women and suggests that there may be important gender differences in the way that socioenvironmental factors...
affect blood pressure. He concludes that these gender differences argue for the importance of developing intervention strategies directed specifically to women.

Interventions Fostering Adaptation to Illness

Interventions in hypertension focus primarily on decreasing BP through addressing factors associated with it. In a meta-analysis evaluating the effectiveness of a variety of treatments for hypertension (Linden & Chambers, 1994), it was found that weight reduction/physical exercise, and individualized cognitive-behavioural psychotherapy were especially effective and did not differ from pharmacological treatments in effect size for decreases in SBP. It was also found, however, that drug treatments tend to be more effective than non-pharmacological options in lowering DBP. The authors note that this meta-analysis compared pre- and post-treatment blood pressures, which produces larger effect sizes than a comparison of treatment versus placebo. The average decreases in SBP and DBP were: weight reduction 10.8/7.8 mm Hg; physical exercise 13.4/9.0 mm Hg; individualized psychotherapy 15.2/9.2 mm Hg; diuretics 14.3/7.9 mm Hg; beta blockers 17.5/12.3 mm Hg; calcium-channel blockers 15.6/12.0 mm Hg. Sodium-restricted diets were also effective, lowering BP 15.5/7.5 mm Hg (Linden & Chambers, 1994). The authors caution that while drug therapies for BP have been proven to be of benefit to patients in the long term, this has not yet been conclusively demonstrated for non-drug treatments. As well, it is not clear whether office-measured decreases in BP are maintained in an ambulatory setting. Further, the length of the baseline period in the reviewed studies may be an important factor since BP may decrease over this period. The authors abandoned their initial desire to control for this variable due to the unreliability of baseline reporting in the reviewed studies. Finally, the authors allude to the principle of regression to the mean, stating the clinical outcomes are greater when a treatment is started at high initial BP levels. Concern given the potential differences in hypertension in men and women is the lack of attention to sex and gender in assessments of these approaches.

Education
Level of Evidence - I

A meta-analysis of 102 studies of education and psychoeducation in adults with hypertension showed small to medium sized beneficial effects on BP, and large treatment effects on knowledge, medication compliance, and compliance with health care (Devine & Rieischneider, 1995).

Multimodal/Integrative Programs
Level of Evidence - III

A wide variety of multimodal programs, primarily delivered at worksites, have been developed and evaluations have been positive in terms of identification of hypertension and risk factor modification (Ellis et al., 1994; Erfurt et al., 1991) but no studies have assessed impact on QoL.

Stress Management
Level of Evidence - III

The stress management literature has primarily focused on changes in BP and has not systematically assessed QoL and impact on psychosocial morbidity. Johnston (1997) reviewed research related to psychological stress and hypertension and found that the stress management programs that have shown some success in the treatment of hypertension have been based on live, rather than pre-recorded, relaxation training that included regular home practice and some form of counselling and advised patients to apply relaxation in stressful situations. Such programs are usually administered on an individual basis over approximately eight sessions. However, Johnston also found that the data from trials over a 25-year period have provided contradictory results regarding the ability of stress management to lower high BP. The majority have been positive; however, more recent research has found little associated benefit to stress management compared with controls (Johnston, 1997). Johnston (1997) states: “On balance, the effect of stress management on blood pressure is disappointing as the effect appears weak, variable, temporary, and limited to a subset of patients who may not be at great risk from their elevated pressure.”
Cognitive-Behavioural Approaches  
Level of Evidence - IV

Cognitive-behavioural approaches have been used as adjunctive interventions in addition to medication. In a randomized trial of a six-week cognitive-behavioural group intervention, Shapiro et al. (1997) found that at 12 month follow-up, 73% of the treatment group were at lower levels of medication than at the time of randomization compared to 35% in the control group. Further, 55% of the treatment group were completely free of medication compared to 30% of the control group. They concluded that the addition of this standardized and inexpensive intervention reduced costs and potential side effects of antihypertensive medications but did not directly measure impact on QoL and psychosocial morbidity.

Behavioural Approaches  
Level of Evidence - IV

There was greater interest in behavioural approaches (e.g., relaxation, transcendental meditation, biofeedback) in the 1980s and early 1990s. A review in 1993 concluded that only 26 of 800 published studies were of sufficient rigour to include in the analysis (Eisenberg et al., 1993). It was concluded that these interventions for essential hypertension were superior to no therapy but not superior to credible sham techniques or to self-monitoring alone in decreasing BP and there were no measures of impact on QoL.

Other Psychotherapies  
Level of Evidence - IV

There have been no systematic studies of other psychotherapies in facilitating adaptation to hypertension.

Social Support  
Level of Evidence - IV

There have been no systematic studies of the role of social support in adapting to hypertension.

Exercise  
Level of Evidence - I

Exercise intervention studies have focused on decrements in BP and have not attended to questions of impact on QoL. The literature demonstrates that regular aerobic exercise of mild-to-moderate intensity decreases BP in patients with essential hypertension (Kokkins & Papademetriou, 2000). Decreases in BP brought about by exercise are independent of changes in body weight or body composition (Kokkins & Papademetriou, 2000).

Exercise regimens most effective in decreasing BP are performed 20 to 30 minutes, three times per week, at approximately 70% to 75% maximum heart rate, using an easy aerobic activity such as brisk walking (Blanchard et al., 1988). Moderately intense exercise at 40% to 60% of maximum oxygen consumption, (i.e., 30 to 45 minutes of brisk walking on 4 – 5 days a week) has also been found to lower BP (Anand, 1999). The decreases in BP in women seen in another study assessing the effects of exercise (Kokkins & Papademetriou, 2000) were comparable to those of men, suggesting there are no gender differences in the response of BP to exercise training.

Nutrition  
Level of Evidence - I

Adults with hypertension are, on average, approximately 30% above ideal weight. Although not every overweight individual develops hypertension, there is a strong positive association between weight and hypertension. Many studies have confirmed that a large proportion of individuals with hypertension who undergo weight loss also undergo a reduction in BP (Blanchard et al., 1988). M ulrow et al. (2001) reviewed 18 randomized controlled trials to determine whether weight-loss diets are more effective than antihypertensive medication in assisting hypertensive individuals to lose weight and control BP. Subjects in the former group generally lost weight compared to control groups. Comparison of weight-loss diets with antihypertensive medication revealed that a
“stepped care” approach with antihypertensive medication may bring about greater BP declines (6 mm Hg systolic BP and 5 mm Hg diastolic BP) than a weight-loss diet alone. The reviewers concluded that overweight individuals with hypertension can experience weight loss of 3% to 9% body weight and decreases in SBP and DBP of approximately 3 mm Hg through the use of weight-loss diets. They also concluded that weight-loss diets may allow hypertensive individuals to decrease the dosages of antihypertensive medications.

**Mind-Body Approaches**

**Level of Evidence** - IV

There is interest in these approaches but little systematic research.

**Interventions in Special Populations**

There has been little attention to the needs of special populations in intervention studies. Clinical experience and anecdotal evidence highlight the importance of better understanding the need and tailoring of interventions for children and adolescents, pregnant women, pre-menopausal women, Aboriginal women, women of diverse ethnoracial backgrounds, and impoverished women. The recent Canadian Coalition for High Blood Pressure and Control has called for particular focus on children, pregnant women, and Aboriginal women (Chockalingam et al., 2000).

**Recommendations**

1. **Clinical Care**
   - Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.
   - Cardiac rehabilitation programs with special modifications for women in high risk groups should be available on at least a regional basis.
   - Smoking cessation programs tailored to the specific needs of women should be available on at least a regional basis.

2. **Health Care Professional Education**
   - Knowledge translation is essential. Education about the importance of cardiovascular disease and rehabilitation as a women’s health issue needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.
   - Education about smoking cessation strategies and motivational interviewing to promote smoking cessation need to be emphasized with both primary care practitioners and specialists.

3. **Public Education**
   - Written materials on risk factor modification and, in particular, details about exercise regimens should be developed and then modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant populations.
   - Education must be undertaken through diverse public media about the importance of women knowing what their blood pressure is and taking action if it is elevated.

4. **Research**
   - Assess the needs of special populations and tailor interventions that would be appropriate for them.
   - Research the financial and psychosocial costs of cardiovascular diseases in women.
   - Evaluate cardiac rehabilitation programs with respect to what modifications would facilitate women’s participation.
   - Translate knowledge when data is available from the cognitive-behaviour therapy trials currently underway.
Diabetes is a metabolic disorder characterized by the body’s inability to regulate blood glucose levels as a result of insufficient insulin secretion and/or action (Canadian Medical Association, 1998). The physiological effects in chronic hyperglycemia include long-term complications such as retinopathy, nephropathy, neuropathy, cardiovascular disease, and foot problems due to insufficient circulation (Canadian Medical Association, 1998). It is estimated that long-term complications associated with diabetes can remove ten years from the female lifespan. Various types of diabetes exist and clinical diagnosis for each is based predominantly on fasting plasma glucose levels (Canadian Medical Association, 1998). The physiological complications and risks are similar for all forms of diabetes; however, each type is differentiated by its age of onset and/or the cause and degree of insufficient insulin release.

Type 1 diabetes is defined as an autoimmune disorder, characterized by self-destruction of the insulin-producing cells of the pancreas (Redmond, 1996). Environmental and genetic factors predisposing individuals to Type 1 diabetes have been identified but are not highly predictive (Redmond, 1996). Treatment of Type 1 diabetes must include exogenous insulin administration in addition to the modification of lifestyle factors. Type 2 diabetes often develops during middle age and presents as insulin insensitivity and insufficiency due to an overexhausted pancreas (Redmond, 1996). It is the most common form of diabetes and its main causal factor is obesity (Berkowitz, 1998). The risk of genetic susceptibility to Type 2 diabetes is also greatly increased if there is a familial history of obesity.

When diabetes is diagnosed during childhood, it is termed juvenile diabetes and it presents most similarly to Type 1 diabetes (Brown et al., 1997). The development of Type 2 diabetes in childhood is rare; however, the risk is becoming increasingly common as a result of the poor diets and diminishing activity levels observed in children. Finally, diabetes can develop during women’s pregnancy term. This form is appropriately labeled gestational diabetes and is partially attributed to the fluctuating hormone levels associated with pregnancy (Redmond, 1996). In addition, the increased strain on the pancreas to facilitate glucose regulation during pregnancy contributes to pancreatic exhaustion and creates a physiological condition similar to Type 2 diabetes (Canadian Medical Association, 1998).

**Epidemiology**

Epidemiological studies estimate that 5% of Canadians, or 1.5 million people, are currently diagnosed with diabetes (Tan & MacLean, 1995). This statistic was expected to reach 2.2 million by the year 2000 and has been projected to 3 million by the year 2010 (Tan & MacLean, 1995). Within Canada, particular attention needs to address the growing incidence of Type 2 diabetes in Aboriginal people. Recent age-adjusted prevalence rates, reported in population-based epidemiological studies, cite the alarming statistics that 19% to 26% of Aboriginals are clinically diagnosed with diabetes (Canadian Medical Association, 1998). These numbers represent some of the highest prevalence rates in the world and emphasize the need for culturally based treatment interventions (Canadian Medical Association, 1998). Aboriginal children and women of childbearing age have been identified as high-risk populations in Aboriginal communities and particular attention to their individual needs is highly warranted (Canadian Medical Association, 1998).

US studies have also showed an increased prevalence of Type 2 diabetes in populations of specific ethnic origin including Hispanic Americans, African Americans, American Indians and Alaska Natives, as well as Pacific and Asian Islander Americans (National Institute of Diabetes and Kidney Diseases, 1998; 1999a; 1999b; 1999c). The development of diabetes is a particular concern in African American women (National Institute of Diabetes and Kidney Diseases, 1998). Furthermore, a nine-year longitudinal study at Johns Hopkins Medical Institution in Baltimore found that almost half of the increased risk for African American women was explained by “potentially modifiable” lifestyle factors (Mayo Clinic, May 4, 2000). These findings continue to confirm the significant role of self-managed health
behaviours in the treatment of diabetes and provide empirical support for increased intervention intensity in at-risk female populations.

**Impairment in Quality of Life & Psychosocial Morbidity**

Diabetes impacts negatively on multiple life domains. Managing diabetes requires a significant degree of structure and organization with respect to blood sugar monitoring, tailoring insulin and other medication dosing, timing of meals, and timing of exercise. Pain and fatigue are common. End-organ failure that occurs secondary to diabetes can further adversely impact on quality of life (e.g., blindness, renal failure requiring dialysis). Similar to other chronic medical conditions, physiological complications of diabetes can be coupled with increased psychological distress. The co-morbidity of depression in diabetes is estimated between 15% – 20% and is associated with poor adherence to diabetes treatment, poor glycemic control, and an increased risk for physical complications, specifically coronary heart disease and retinopathy (Lustman et al., 1998).

**Sex & Gender Differences**

There has been relatively little attention to issues of sex and gender in diabetes. There is increasing recognition that diabetes is an important cause of death and morbidity in women and that it needs to join the women's health agenda (Wishner, 1996). There are several papers examining gender differences in adolescence – adolescent women report more mismanagement of their diabetes than adolescent men (Hanna & Guthrie, 1999) and are more likely to require hospitalization (Cohn et al., 1997).

**Interventions Fostering Adaptation to Illness**

Due to the severity of complications associated with diabetes, the goal of treatment intervention is the stabilization of blood glucose levels through self-management and pharmacological therapy and adaptation to illness. Early, intensive interventions have demonstrated to be the most effective in preventing associated complications and, in regards to individual and social health costs, are reputed to be the most economically viable (Canadian Medical Association, 1998).

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**Education**

**Level of Evidence - I**

Diabetes self-management education has been defined by Clement (1995) as “the process of providing the person with diabetes with the knowledge and skills needed to perform self-care, manage crises, and make lifestyle changes required to successfully manage this disease”.

Current literature guiding the treatment protocol for Type 1 and Type 2 diabetes has focused predominantly on the use of specific interventions such as diet and exercise, and on the use of education programs to promote self-management skills. In this regard, the literature uses the terms self-management education and diabetes education synonymously (Clement, 1995). Brown (1999) provides a comprehensive descriptive analysis of the diabetes self-management studies currently funded by the National Institutes of Health and notes that greater emphasis has been placed on longer, simpler, and more practical approaches to diabetes self-management. Diabetes research has not often assessed the use of interventions on exclusive populations such as women or various ethnic groups, although the subject cohorts of recent studies are most often represented by an equal, if not greater, proportion of female participants to male.

Several current literature reviews provide considerable evidence to support the effectiveness of diabetes education programs in improving health outcomes in diabetics (Brown, 1999; Clement, 1995; Funnel & Haas, 1995; Maldonato et al., 1995). Clement (1995) also concluded that diabetes self-management education is associated with reduced diabetes healthcare related costs, including reduced hospitalizations for diabetes-related problems. These meta-analytic reviews of self-management diabetes education programs identify the goal of self-management as empowering an individual with diabetes to become the most active and most knowledgeable participant in the care of her condition. This process-orientated approach emphasizes the importance of self-responsibility and acknowledges that the management of diabetes has moved beyond the single required task of self-blood-glucose-monitoring.
In 1993, The National Diabetes Advisory Board reviewed its standards for diabetes self-management education programs to ensure consistency and credibility in the provision of diabetes education across various regions of the U.S. In an extensive report, Funnell and Haa (1995) identify the core 15 content areas of self-management education programs and provide empirical evidence for their inclusion. Recommended content areas include: diabetes overview; stress and psychosocial adjustment; family involvement and social support; nutrition; exercise and activity; medications; monitoring and use of results; relationship among nutrition, exercise, medication, and blood glucose levels; prevention, detection, and treatment of acute and chronic complications; foot, skin, and dental care; behaviour change strategies; options for improving glucose control; preconception and pregnancy care; and use of health care systems and community resources (Funnel & Haas, 1995). Although similar standards have not been developed in Canada, the Canadian Medical Association (1998) has established clinical practice guidelines to provide leadership and recommendations for the care and management of diabetes in Canada. To date, no studies have been completed to compare the effectiveness of standardized and non-standardized intervention programs; however, Funnell and Haas (1995) suggest a future evaluation of each recommended standard for both its independent and contributing effects on the intervention program as a whole.

Since self-management education programs have repeatedly been shown to improve health outcomes in diabetics, researchers continue their attempts to isolate the variables determining successful intervention strategies. Based on a review of 114 studies, Clement (1995) has concluded that diabetes self-management education is most effective when: a) behaviour change strategies are extensively used; b) coupled with expert adjustment of medication and reinforcement of learned behaviours by the healthcare provider; and, c) instruction in the use of self-monitoring of blood glucose data is used to optimize the insulin regime for optimal glucose control. Additional research has emphasized the physician's role as a health educator as one of the essential elements in the provision of successful diabetes education (Maldonato et al., 1995).

Individualization of a self-management program is key to increasing a patient's motivation to participate. Specific interventions are not equally beneficial for all patients and factors such as preference for group or individual therapy or mode of education must be considered (Maldonato et al., 1995). For example, research suggests that individual teaching may be more effective initially and that group interaction can provide the advantage of additional social support (Maldonato et al., 1995). Haynal and Schulz (1983) demonstrated that non-compliance is directly related to the amount of behavioural change required by the therapeutic regime, which suggests a need to prioritize and preferentially select essential program components. Different modes of education delivery have been explored and both computer-based interaction and voice-based electronic systems have been used successfully as cost-effective means to deliver diabetes education instruction (Albisser et al., 1996; Wise et al., 1986). In a prospective case study, researchers completed an evaluation on the voice-interactive physician-directed system and demonstrated the effectiveness of the intervention to significantly improve metabolic control (Albisser et al., 1996). This finding enhances the credibility and benefits of alternative modes to promote diabetes education. Clement (1995) affirms that future research must identify determinants to predict which education programs will most benefit various populations of diabetic patients, such as women and Aboriginals.

Unfortunately, statistics repeatedly show that people with diabetes have limited access to participate in self-management education programs. In a U.S. nationwide survey, 41% of people with Type 1 diabetes, 51% of people with insulin-treated Type 2 diabetes, and 76% of people with non-insulin-treated Type 2 diabetes reported having never attended a diabetes education class, course, or other diabetes education program (Coonrod et al., 1994). The negative health effect suggested by these statistics is startling. For example, one research team determined that patients who never received diabetes education “showed a striking fourfold increased risk of a major complication” (Nicolucci et al., 1996). Barriers that have been identified as limiting program attendance include the cost and scheduling of education.
programs, limited physician referrals, and patients who felt additional knowledge was unnecessary (Funnell & Haas, 1995). There is no evidence in the literature to suggest that the provision of self-management education in Canada is any better received in comparison to our US counterparts.

Anderson et al. (1995) describe the ideal patient education program to include equal attention to blood glucose management and the psychosocial challenges of living with diabetes. It has been suggested by Rubin (1992) that these daily challenges may include “psychosocial sequelae of medical crisis, psychopathology in diabetes, stress and hassles in living with diabetes, and family dysfunctions”. The need to incorporate psychological outcome measures, such as self-efficacy and self-confidence, in the future assessment of self-management education programs has been justified by current literature (Funnell & Haas, 1995). This revision will help researchers to accurately establish the interacting role of psychosocial variables on the provision of treatment intervention programs for diabetics.

Multimodal/Integrative Programs
Level of Evidence - I

Self-management is the key to the successful control of a diabetic condition and inherently requires a personalized treatment protocol. Self-management training must address relevant demographic variables such as age, sex, socioeconomic status, and culture, as well as individual psychosocial issues such as self-esteem and familial support. Since successful diabetes management is dependent on an individual's self-responsibility for health behaviours, the treatment of diabetes is highly contingent on the patient's motivation to follow a tailored treatment program. Key topics of concern in the diabetes literature, such as motivation, adherence, compliance, and empowerment, are greater issues in the scope of health psychology. As a result, current research in the area of diabetes management provides a foundation for the successful administration of self-management interventions used in the treatment of other chronic medical conditions, such as arthritis and asthma (Brown, 1999).

The core foundation of a diabetes intervention program is a supportive interdisciplinary team of health care professionals who are experts in the field of diabetes care. This team has been identified as the diabetes health care (DHC) team (Canadian Medical Association, 1998). Ongoing education and comprehensive care can be provided by collaborative communication and participation among all team members: the individual diagnosed with diabetes and her family members; the primary physician; the diabetes medical specialist/endocrinologist/internist; and diabetes educators such as nurses and dietitians (Canadian Medical Association, 1998). Other health professionals may be included as required, such as a cardiologist, social worker, psychologist, or an obstetrician. Research shows that diabetes care is most effective when provided in the structured manner represented by the DHC team. In addition, the individual and flexible nature of the DHC organization has enabled the provision of diabetes health care to urban, rural, and remote locations (Canadian Medical Association 1998).

Stress Management
Level of Evidence - IV

There have been few studies of stress management as a unimodal therapy.

Cognitive-Behavioural Approaches
Level of Evidence - I

Recent studies encourage the use of cognitive-behavioural therapies (CBT) for decreasing psychological distress in Type 2 diabetics and indicate their potential to co-currently improve glycemic control (Henry et al., 1997; Lustman et al., 1998). Jacobson and Weigner (1998) provide a condensed review of the current literature on the efficacy of CBT and discuss its clinical relevance, such as reducing patients' negative distortions about accomplishing daily goals and tasks. Furthermore, the results of CBT studies that examine glycemic control emphasize the importance of initiating CBT to reduce depression in diabetics. These findings have suggested that the difference in glycemic control between depressed and non-depressed patients is equivalent to the glycemic differences observed between the intensive and standard treatment groups of the Diabetes
Control and Complications Trial (Jacobson & Weigner, 1998). This would imply that the presence of depression would be a significant limiting factor in achieving optimal glycemic control.

**Behavioural Approaches**

**Level of Evidence - IV**

There have been few systematic studies of behavioural approaches as unimodal interventions. Behavioural approaches are useful in facilitating compliance in a subset of individuals with difficulties in this area.

**Other Psychotherapies**

**Level of Evidence - IV**

There have been few systematic studies of other psychotherapies in diabetes interventions.

**Social Support**

**Level of Evidence - IV**

While social support is inherent in the multimodal interventions, there have been few systematic studies of social support as a single intervention.

**Exercise**

**Level of Evidence - I**

Exercise has been researched extensively for its health-enhancing benefits, including improved cardiovascular functioning and blood lipid profile, reduced body weight and body composition, as well as increased feelings of well-being (Berkowitz, 1998). Research on diabetic individuals has demonstrated comparative benefits, in addition to the most relevant advantage of increased insulin sensitivity and improved glucose utilization (Berkowitz, 1998). The majority of studies have focused on the efficacy of aerobic exercise to improve health outcomes in diabetics; however, recent initiatives are also exploring the positive role of resistance training in the management of diabetes (Dunstan et al., 1998). Long-term studies have not conclusively validated that reduced blood glucose levels are an independent effect of exercise (Berkowitz, 1998) or that exercise can effectively establish blood glucose control in Type 1 diabetics (Pierce, 1999). However, the inclusion of exercise in diabetic treatment programs has been empirically supported due to the physical and psychological benefits observed in diabetics of various ages (Pierce, 1999; American Diabetes Association, 1997).

Exercise is a complex variable affecting the stabilization of blood glucose levels since increased energy expenditure requires the provision of both glucose and insulin. Insulin is required in calculated amounts to facilitate glucose uptake by working muscles and to avoid states of hypo and hyperglycemia. Since diabetics have a faulty insulin regulation mechanism, they must self-regulate this physiological process in order to exercise without increased health risks or safety concerns (Pierce, 1999). Due to the complexity of metabolic interactions during exercise and the necessity to ensure precise blood glucose regulation, it is highly advised that an experienced exercise physiologist is a member of the DHC team (American Diabetes Association, 1997).

The current literature focuses heavily on addressing specific considerations in exercise prescription for both Type 1 and Type 2 diabetics, specifically in regard to contra-indications for associated medical complications (American Diabetes Association, 1997; Giacca et al., 1994; Pierce, 1999). For example, individuals with proliferative retinopathy should avoid exercises that raise blood pressure, such as heavy lifting, and individuals with peripheral neuropathy should avoid long periods of walking or jogging due to an increased risk of soft tissue and joint injuries (Berkowitz, 1998). Several reviews have described the health risks associated with various modes of exercise used by diabetics (American Diabetes Association, 1997; Berkowitz, 1998; Giacca et al., 1994) and health care providers should be well-educated on this topic before prescribing exercise regimes. Little research has specifically addressed exercise in diabetic women, yet it is essential that programs designed for this population consider co-existing health concerns. Relevant issues include the female athlete, eating disorders, osteoporosis, and menopause, as well as the importance of psychosocial factors pertinent to exercise adherence, such as social support and self-efficacy.
Nutrition

Level of Evidence - I

Holler and Pators (1997) identify several factors affecting meal planning for diabetics, including treatment goals, daily meal and lifestyle patterns, and the combination of ethnic, religious, and financial factors. For example, dietary self-management goals often vary between Type 1 and Type 2 diabetics. At the time of diagnosis, Type 1 diabetics frequently show significant weight loss and measures must be taken to ensure that proper nutrient levels are reestablished (Redmond, 1996). Type 2 diabetics often present as overweight and a key element to dietary intervention includes a weight loss program in order to aid in blood glucose regulation (Feuerstein & Weinstock, 1997). The importance of individualized nutritional therapy is also highlighted in consideration of a diabetic's age. For example, Rosett-Wyline and Edlen-Nezin (1991) identify key issues to address in the dietary management of elderly patients with diabetes and discuss the unique clinical and psychosocial needs of this population. Research has not addressed the specific dietary needs of women with diabetes, with the exception of gestational diabetes. However, increased attention should be given to the nutritional requirements particular to other changes affecting a woman's hormone profile, such as menopause.

The benefits to individualizing dietary interventions have been demonstrated by the use of an intervention labeled Medical Nutrition Therapy (MNT). Franz et al. (1995a) define MNT as a comprehensive, individualized approach to achieving metabolic regulation: “MNT is tailored to the person’s medical, psychosocial, and educational needs; treatment goals; and desired outcomes.” The implementation of the new principles and guidelines requires trained and experienced dietitians who can assess each person’s situation, develop an intervention plan, and act on the outcomes of the intervention”. Franz et al. (1995b) evaluated the use of MNT as it was applied to the administration of practice guidelines for nutrition care and basic nutrition care in individuals with Type 2 diabetes. The researchers observed significant improvements in medical and clinical outcomes in both groups; however, since glucose levels began to increase at three months post-intervention, they recommended that continued use of MNT by dietitians is critical for long-term metabolic control (Franz et al., 1995b).

An important indirect finding of this study was that patients who had Type 2 diabetes for a longer duration received greater benefit from the more intensive nutritional intervention (Franz et al., 1995b). Consequently, the researchers strongly emphasize the role of the dietitian to accurately determine the intensity of MNT most beneficial to the patient’s needs and treatment goals. Furthermore, the active involvement of dieticians in the provision of nutritional therapy was supported when researchers demonstrated that it enhanced the cost-effectiveness of MNT (Franz et al., 1995a).

Self-management skills for altering nutritional habits of diabetics focus primarily on food selection and meal planning. The food exchange system and carbohydrate-counting are two methods utilized by diabetics to account for their food choices and to achieve blood glucose regulation through dietary means (Wheeler, 1999). Current nutrition recommendations have been established by the American Diabetes Association and are outlined by Wheeler (1999). However, how these nutrients are best attained has not been adequately addressed by current research and remains undefined. One team of researchers assessed the use of a vegetarian diet in Type 2 diabetics and concluded that its implementation was associated with positive improvements in blood glucose control and that further investigation was warranted (Nicholson et al., 1999).

One established role of education programs is to provide information regarding the nutrient composition of food, which assists patients in food selection when used in combination with food label information. Research has previously shown that women with Type 2 diabetes use food label information in their food-selection decision-making process and that the nutrient content of food is a key factor in food purchases (Miller et al., 1997). Women’s need for more knowledge regarding the comprehension and application of food labels has also been indicated by past research (Miller et al., 1997). In a nine-week,
pre-test/post-test, control group design, Miller et al. (1999) studied the effectiveness of a food label education program in forty-three women with Type 2 diabetes. The researchers concluded that the effectiveness of their intervention was demonstrated by significant improvements in participant knowledge and perceived confidence in using food label information (Miller et al., 1999). However, one must use caution in generalizing these results since a difference in label-reading skills has been established between older and younger women (Bender & Derby, 1992). Miller et al. (1999) attribute the success of their program to the high intensity of the intervention and its focus on the application of knowledge acquired. Future research suggestions included assessing knowledge retention and the effect of the intervention on metabolic measures of diabetes management (Miller et al., 1999).

Mind-Body Approaches  
Level of Evidence - IV  

There has been little attention to mind-body approaches in diabetes.

Interventions in Special Populations

Childhood

Diabetes in childhood is a condition that can be successfully managed with the combined assistance of the young patient, her family, and a diabetes health care team that is sensitive to the needs and issues of children. On-going education must be provided to both the parent and the child to accommodate the patient's developmental level of self-care and to facilitate the acquisition of skills leading to self-sufficiency (Canadian Medical Association, 1998). Education may be provided effectively in combination with supportive training in self-management (Delamater et al., 1990) or presented in an alternative means, such as an educational video game (Brown et al., 1997).

Type 1 diabetes affects one in every 400 individuals under the age of 20; it is the most common metabolic disease of childhood (Grey et al., 1999). The etiology and physiological consequences of childhood-onset diabetes are similar to adult-onset Type 1 diabetes and early treatment intervention of exogenous insulin and lifestyle changes are required to achieve optimal glycemic control.

Type 2 diabetes is most prevalent in certain subgroups of children and currently afflicts 1% to 2% of children from Aboriginal, Hispanic, or black descent and approximately 4% of adolescent girls (Canadian Medical Association, 1998). Canadian researchers have observed Type 2 diabetes in Aboriginal children aged 7 and older, and considering the risk of early-onset complications, the suggestion has been made that Aboriginal children should have routine medical screening (Canadian Medical Association, 1998). Since the treatment of Type 2 diabetes involves dedication to lifestyle modification, successful interventions must address the cultural and lifestyle preferences of each at-risk population. For example, interventions have been successfully implemented in a summer camp setting that have met the specific needs of children, while co-currently providing an intensive treatment program (Canadian Medical Association, 1998). The possibility of providing camp sessions specific to particular subgroups of children, as determined by age, sex, or culture, should be considered.

The goal of a self-management treatment program for children is to enable healthy and normal growth, as well as to reduce the risk for developing later-onset medical conditions, such as cardiovascular disease. Inherent within this goal is the acknowledgement that both prevention and intervention are important components of treatment programs for children with diabetes. Current literature examining treatment intervention programs for diabetic children have rarely defined outcome differences between girls and boys. However, several studies have used a participant population that consists of a greater proportion of females to males (Boardway et al., 1993; Grey et al., 1999; Grey et al., 1998).

One key to successful interventions for children involves teaching effective coping skills to promote adherence to lifestyle management strategies. This element is particularly important during adolescence (Grey et al., 1999). Researchers have suggested that factors specific to teen culture, such as peer pressure,
smoking, and alcohol use, may have a negative effect on the management and prognosis of adolescent diabetes (Anderson et al., 1999). Coping skills training (CST) teaches skills such as social problem solving, social skills training, cognitive behaviour modification, and conflict resolution. The acquisition of these coping techniques may help adolescents adhere to their diabetes management program despite the pressures and temptations of teen culture (Grey et al., 1999). The Adolescents Benefit from Control (ABCs) of Diabetes Study is a prospective randomized controlled trial that assessed CST in combination with intensive diabetes management and demonstrated improved metabolic and psychosocial outcomes, such as self-efficacy and quality of life in participating adolescents (Grey et al., 1999). Furthermore, after CST intervention, teenagers found it less difficult and upsetting to cope with their diabetes (Grey et al., 1998) and reported fewer worries regarding their diabetic condition (Grey et al., 1999).

It has been suggested that teaching personal and social coping skills can improve youth’s management skills for dealing with daily stressful encounters (Forman, 1993). This finding may provide one explanation for the mediating role of coping skills training on diabetes management. Research has demonstrated a significant relationship between life stress and poor metabolic control in diabetic adolescents; however, it also suggests that stress reduction interventions may only reduce diabetes-specific stress and may not be associated with increased metabolic control or regimen adherence (Boardway et al., 1993). Although current research on the efficacy of stress-reduction programs on diabetic adolescents is inconclusive, the importance of including this element in their treatment program must not be discounted. It is acknowledged that the stress-blood glucose relationship is highly individual and stress-reduction interventions may prove to be particularly beneficial for a specific subgroup of individuals (Boardway et al., 1993). Future research must address this possibility and clarify the benefit of stress-reduction programs for diabetic adolescents.

Current literature strongly emphasizes the importance of family involvement in the self-management program of the diabetic adolescence. Studies show that a decrease in parental involvement is observed in adolescent years and that this trend imposes a cost to the diabetic child. Adolescents who assume early responsibility for self-management tasks are less adherent, have more mistakes in their self-care, and experience less glycemic control than those whose parents are actively involved (Anderson et al., 1999). However, although parental involvement in the adolescent’s diabetic care is highly recommended, the result of this initiative is often increased familial tension and conflict (Anderson et al., 1999).

Wysocki et al. (2000) designed a study founded on Robin and Foster’s behavioural family system’s model that views parent-adolescent conflict as a result of the “clash between the adolescent’s need for autonomy and parental needs to maintain stability”. In a randomized, controlled trial of Behavioural Family Systems Therapy (BFST), the researchers demonstrated that BFST resulted in more improvement in parent-adolescent relations and reduced diabetes-specific conflict than an education and support group or current therapy (Wysocki et al., 2000). Its effectiveness was attributed to its ability to enhance communication and conflict resolution skills (Wysocki et al., 2000). An interesting finding in this study concerns the intervention’s differing effects on psychological adjustment to diabetes and diabetic control as a function of the adolescent’s age and gender. For example, adolescent girls had lower scores on diabetes-specific outcomes, such as the Teen Adjustment to Diabetes Scale (TADS) and glycosylated hemoglobin in comparison to boys and younger girls who showed benefit on these measurements (Wysocki et al., 2000).

Anderson et al. (1999) designed an intervention to maintain parent-adolescent teamwork in diabetes management tasks without increasing diabetes-related family conflict. Within the constructs of this developmental theory, Anderson et al. (1999) studied patients aged 10 – 15 with Type 1 diabetes who were randomly assigned to study groups of either teamwork, attention control, or standard care. Parental involvement in insulin administration and
blood glucose monitoring was evaluated and showed not only that it could be strengthened through a low-intensity intervention, but that teamwork families had decreased diabetes-related family conflict, despite increased interaction between parents and teens on diabetes management tasks (Anderson et al., 1999). These findings suggest that interventions supporting positive family interactions centered on diabetes management may help to resolve existing familial conflicts and may also help to prevent the increased tension frequently observed in adolescent years (Anderson et al., 1999). However, before intervention guidelines can be established, the results of this study must be replicated using a larger sample size and lengthened intervention and follow-up time periods.

**Eating Disorders**

Young women with diabetes may be at increased risk of developing eating disorders (Rodin & Daneman, 1992) and if they do, have greater sequelae from their diabetes (Rydall et al., 1997). Further research on interventions is crucial.

**Pregnancy**

The co-occurrence of diabetes and pregnancy is an issue that requires particular attention from the diabetes health care team. Diabetes of Type 1 or Type 2 may be present prior to pregnancy, or Gestational Diabetes Mellitus (GDM), an alternate diabetic condition, may develop during the pregnancy term. GDM is defined as “any degree of glucose intolerance with onset or first recognition during pregnancy”. The etiology of GDM is attributed to the increased pancreatic demands on the mother due to fetal developments and the fluctuating hormone levels associated with pregnancy (Carr & Gabbe, 1998). The American Diabetes Association (2000) estimates that unplanned pregnancies occur in two-thirds of women with diabetes and, consequently, the recommendation for contraceptive and prepregnancy counseling is strongly encouraged for diabetic women of childbearing age.

GDM complicates 1% - 14% of all pregnancies depending on the population and criteria used for diagnosis (Carr & Gabbe, 1998). More general estimates suggest that 3% - 5% of all pregnancies are affected by GDM, acknowledging that the incidence of glucose intolerance is increased among women of certain ethnicities, such as Latino, African American, Asian, North American Aboriginal (Dixon et al., 1999), Australian Indigenous, Polynesian, South African, Middle Eastern, and other Asian groups (Hoffman et al., 1998). To address the need for accurate disease rates among Canadian Aboriginals, one research team estimated the prevalence of GDM among Swampy Cree women in Moose Factory, James Bay, Ontario (Godwin et al., 1999). Between 1987 and 1995, comparative information from pregnant women, with and without GDM, was obtained from the medical charts of patients from Weeneebeyko Hospital. It was established that GDM was diagnosed in 8.5% of 1298 case studies (Godwin et al., 1999).

Unfortunately, research has poorly addressed the benefit of particular diets to achieve glycemic control specifically in patients with GDM. In a current literature review on the use of dietary therapy for pregnant women with impaired glucose tolerance, Walkinshaw (2001) concluded that the present lack of empirical evidence limits the potential to make substantiated recommendations. Presently, guidelines regarding the dietary choices for expectant women with GDM are similar to pregnant women with preexisting diabetes mellitus, focusing on carbohydrate and caloric restriction (Carr & Gabbe, 1998) as well as the increased consumption of complex carbohydrates and high-fibre foods (Dixon et al., 1999). These dietary guidelines have shown to help achieve normoglycemia in various types of diabetic conditions (Dixon et al., 1999).

Neither severe restriction of carbohydrates or dietary calories are advised for pregnant women with GDM due to the risk that resulting ketonemia or ketonuria may present for the developing fetus (Carr & Gabbe, 1998). However, in some women with GDM, obesity may be a medical condition that requires continued treatment during pregnancy and moderate caloric restriction may be advised. Encouraging findings by Knopp, Magee, and Raisys (1991) stated that moderate caloric restriction (33%) appears to reduce macrosomia rates without adversely
affecting neonatal outcomes or causing ketonemia. Although research has suggested that sporadic ketonuria occurs spontaneously in most pregnancies, its potential to cause perinatal morbidity has led to the recommendation for daily or periodic ketone testing during pregnancy in diabetic women (Fagen et al., 1995).

One goal of dietary intervention for women with GDM is to ensure adequate nutrition to support both the mother and her developing fetus. Research has not conclusively determined the percent composition of carbohydrates, fats, and proteins most beneficial for pregnant women with GDM, and therefore, the need for individualized dietary regimes is essential (Fagen et al., 1995). The American Diabetes Association has recommended a diet of 2000 - 2500 kcal/day, with 50 - 60% carbohydrates, 10 - 20% protein, and 25 - 30% fat (Carr & Gabbe, 1998) with recent encouragement for increased flexibility in carbohydrate and fat intake (Gunderson, 1997).

Current literature has begun to more closely examine the nature and impact of fats in the diet of pregnant women with glucose intolerance. Wijendran et al.'s (1999) study was the first to show that variance exists in the metabolism of maternal plasma phospholipid polyunsaturated fatty acids (PUFAs) in pregnant women receiving dietary therapy for GDM. Awareness of these findings is important for the provision of future dietary guidelines since PUFAs are necessary for optimal fetal growth and nervous system development (Wijendran et al., 1999). Furthermore, Sivan et al. (1998) found that an elevation of plasma free fatty acids (FFA) can contribute to the peripheral insulin resistance frequently seen in late pregnancy. This result is suggestive that FFA may play a causal role in the pathogenesis of insulin resistance and gestational diabetes (Sivan et al., 1998). Although the precise mechanisms and implications of these research findings were inconclusively defined, they provide the premise for future research on the role of fatty acids in the dietary therapy of pregnant women with glucose intolerance.

Aboriginal Women

Diabetes rates are very high among First Nations peoples in Canada. For example, 40% of the Oji-Cree of northern Ontario have obesity-related type 2 diabetes. As well, the incidence of coronary heart disease among this population has tripled over the last 20 years (Hegele, 2001). First Nations women in the Sioux Lookout Zone of Ontario who have a previous history of GDM have a very high risk of developing non-insulin-dependent diabetes mellitus (Mohamed & Dooley, 1998). Dyck et al. (1998) describe a pilot project designed to assess whether exercise can reduce the incidence of gestational diabetes among First Nations women in Saskatoon, Saskatchewan. A low dietary intake of fibre has been associated with newly diagnosed diabetes among First Nations people (Wolever et al., 1997). Obesity has also been noted to be more prevalent among First Nations women than among other women. Current studies are underway to tailor interventions to the Aboriginal population (G. Devins, personal communication).

Recommendations

1. Clinical Care
   - Behavioural interventions need to be integrated into routine clinical care for those women with diabetes who need or want them.

2. Health Care Professional Education
   - Health care professionals need to learn more about self-management strategies in special populations.

3. Public Education
   - Educational materials need to be developed that are culturally and linguistically appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
   - Develop appropriate and effective interventions for special populations including Francophone, Aboriginal, and immigrant women, and women with eating disorders.
Chapter 5 Fibromyalgia

Fibromyalgia is a disorder characterized by widespread bodily pain (axial plus upper and lower segment plus left and right sided pain) and tenderness at 11 or more of the 18 specific tender point sites which are associated with the disorder on digital examination (Wolfe et al., 1990).

Epidemiology

Fibromyalgia (FM) occurs in 0.5% - 5% of the population (White & Harth, 2001). Females are at greater risk with a prevalence that is approximately six times that of males. Middle age seems to be the time of greatest risk. FM accounts for 15% of rheumatology consultations (Wolfe, 1989). FM may arise de novo or may occur in the context of musculoskeletal trauma or following an infection. FM shares many characteristics with chronic fatigue syndrome (Wessely et al., 1998). It is estimated that FM accounts for up to 16% of new consultations to rheumatologists - the only more common diagnosis is osteoarthritis (Marder et al., 1991).

As with many other disorders, there are questions as to how representative individuals with FM seen in specialty settings are. Investigations of community samples have shown that 11% of the UK population and 10% of the US population experience chronic widespread pain (Wessely et al., 1998). In a community sample, 3% of women and 0.5% of men met the full criteria for FM (Wolfe et al., 1995). The London Fibromyalgia Epidemiology Study found a prevalence of 5% of women and 2% of men in London, Ontario with a peak prevalence of 8% in women aged 55 – 64 (White & Harth, 1999). Factors associated with increased odds of having FM included female sex, middle age, less education, lower household income, being divorced, and being disabled (White & Harth, 1999). A number of researchers have suggested that there is no discrete diagnosis of FM but rather that it represents the extreme end of the spectrum of pain which is found in the community (Wessely, 1998).

Impairment in Quality of Life & Psychosocial Morbidity

FM is characterized by chronic generalized pain that affects the individual in a number of ways - physical and psychological distress, impaired social and occupational functioning, loss of work productivity, and overall decreased quality of life (QoL) (White & Harth, 1999). FM patients had the lowest QoL in terms of Medical Outcomes Study (MOS) SF-36 scores on pain and impaired vitality in comparison with six other disorders - urinary incontinence, prostate cancer, chronic obstructive lung disease, AIDS, and hyperlipidemia (Shlenk et al., 1998). A study using the Quality of Well-Being Scale found that FM patients had lower scores than patients with chronic obstructive pulmonary disease, rheumatoid arthritis, atrial fibrillation, advanced cancer, and several other chronic diseases (Kaplan et al., 2000). In another study, FM patients reported lower QoL than women with systemic lupus erythematosus (DaCosta et al., 2000). FM patients with high levels of anxiety and depression have further worsening in their QoL compared to those with low levels of mood symptoms (Kurtze et al., 1999). Negative impacts have been described on personal relationships and career and individuals with FM report lack of social support (Bernard et al., 2000). A longitudinal study of FM patients in tertiary care found that patients with established FM have markedly abnormal scores for pain, functional disability, fatigue, sleep disturbance, and psychological status and these values do not substantially change over time (Wolfe et al., 1997).

Sex & Gender Specific Issues

Women are over-represented in FM samples. The reasons for this are poorly understood. Attention has focused on both psychosocial factors and biomedical factors such as hormones (M eisler, 1999). Yunus (2001) reviewed data from two recent studies that have shown gender differences in various clinical characteristics of FM. In both community and clinic samples, women with FM endorsed more tender points on clinical examination and greater generalized...
pain, fatigue, total number of symptoms, and irritable bowel symptoms. They did not differ from men in terms of pain severity, global severity, and physical functioning. There has been little attention to sex and gender differences in FM in the intervention literature.

Interventions Fostering Adaptation to Illness

Behavioural interventions to foster adaptation to FM have been under study for the past decade. Despite the growing data base on successful interventions, there has been a slowness to adopt them in treatment settings. The most successful interventions focus on exercise and cognitive-behavioural approaches (Rossy et al., 1999) and both are difficult to engage individuals in. Part of the slowness of knowledge translation probably also relates to the ongoing stigmatization of FM within the medical community.

Education

Level of Evidence - III

Education has been incorporated into a number of multi-modal programs but has received little systematic investigation as a single intervention. A comparison of a six week educational/discussion intervention with an educational/cognitive intervention showed no additional improvement in QoL with the addition of the cognitive component. In fact, the addition of the cognitive component increased health care costs (Goosens et al., 1996).

Multimodal/Integrative Programs

Level of Evidence - II-1

Approaches emphasizing self-management of symptoms are gaining interest within the FM community (Sandstrom & Keefe, 1998). These programs typically include training in coping skills such as relaxation; activity pacing; problem-solving techniques; and exercise training for cardiovascular fitness, strength, and endurance.

A six month group program, including formal lectures, group sessions emphasizing behaviour modification, stress reduction techniques, strategies to improve flexibility, and fitness and support sessions for spouses/significant others resulted in improvements in patients compared to control. At the end of the six months, 70% of patients had less than 11 tender points and their scores on the Fibromyalgia Impact Questionnaire had improved by 25% (Bennett et al., 1996).

Stress Management

Level of Evidence - IV

While stress management has been included in multi-modal programs, it has received little systematic attention as a single intervention. A prospective, randomized, controlled study of 14 weeks of stress management compared to aerobic exercise and treatment as usual found short term improvements, but aerobic exercise was the most effective treatment (Wigers et al., 1996). Gains were not maintained at 4.5 years follow-up.

Cognitive-Behavioural Approaches

Level of Evidence - II-1

A recent meta-analysis of interventions in FM emphasized the importance of cognitive-behavioural therapy (CBT) and described it as the optimal intervention for FM when coupled with exercise training (Rossy et al., 1999). White and Nielsen (1995) demonstrated not only short-term benefits but enduring benefits at 30 month follow-up from a CBT program. A recent study showed that cognitive factors such as catastrophizing and depressive self-statements have a more pronounced role in the self-reported pain of patients with FM than with rheumatoid arthritis (Hassett et al., 2000). Catastrophizing as a measure of coping predicted pain perception better than age, duration of illness, and education. This is further evidence of the potential value of CBT in this population.

Behavioural Approaches

Level of Evidence - II-1

A number of behavioural approaches are commonly used in practice, although they have not been systematically studied. These include activity pacing, relaxation training, and biofeedback. Typically studies of these interventions combine several of them with
exercise, making it difficult to disentangle their individual contribution to adaptation. A recent study using biofeedback and relaxation training found that benefits were best maintained over two years when participants received both the behavioural intervention and exercise training (Buckelew et al., 1998). In a comparison of a behavioural intervention and an education/control condition, there was no difference and both groups improved (Nicassio et al., 1997).

Sleep hygiene may be helpful in promoting more restorative sleep. A nonrandomized, non-controlled study of mindfulness meditation based stress reduction showed that 51% of participants with FM showed a moderate to marked improvement in multiple domains of QoL and psychological and psychosocial functioning (Kaplan et al., 1993).

**Exercise**

**Level of Evidence - I**

Exercise is the best studied and most effective non-pharmacological intervention in FM. Many individuals with FM are sedentary and 64 – 80% are reported to have aerobic fitness levels well below average (Busch et al., 2001). A recent meta-analysis of FM treatment interventions demonstrated that exercise produced improvements in physical status, self-reported FM symptoms, and psychological status but not daily functioning (Rossy et al., 1999). Exercise coupled with CBT appears to be the optimal intervention for FM (Rossy et al., 1999). Since that review there have been further positive randomized trials (Gowans et al., in press; Mannerkorpi et al., 2000).

**Nutrition**

**Level of Evidence - IV**

There has been no attention to nutrition in FM.

**Mind-Body Approaches**

**Level of Evidence - IV**

A wide range of mind-body approaches have been used in FM including qigong training, yoga, and t’ai chi. In a manuscript based on a Cochrane Collaboration systematic review, Hadhazy et al. (2000) reviewed the evidence for mind-body therapies which included CBT, relaxation response, autogenic training, mindfulness meditation, progressive relaxation, education, and movement therapy. They found strong evidence that, compared to waiting list or treatment as usual controls, mind-body therapies increased self-efficacy. There was limited evidence for improvement in QoL and inconclusive evidence for all other outcomes. There was some evidence of synergistic effects of mind-body therapy with exercise and antidepressants.

**Interventions in Special Populations**

There has been little attention to special populations in the behavioural intervention literature.

**Recommendations**

1. **Clinical Care**
   - Behavioural interventions must be integrated into routine clinical care and should be available both in health care settings and in the community for women with fibromyalgia.
   - Cognitive approaches integrated with exercise training appear to be the optimal intervention.

2. **Health Care Professional Education**
   - A variety of health care professionals need to be educated about fibromyalgia including those in primary care, general internal medicine, and rheumatology and orthopedic specialty settings. Education needs to focus on how to work most effectively with individuals with fibromyalgia and how to encourage their participation in behavioural interventions.
• Health care professionals caring for individuals with fibromyalgia need to understand basic principles of exercise training and cognitive approaches and how to operationalize these in the context of the individual.

3. Public Education

• Educational materials need to be developed which address basic approaches to the behavioural management of fibromyalgia. As well, these materials need to be modified so that they are linguistically and culturally appropriate for minority communities.

4. Research

• Develop a “stepped care” approach to fibromyalgia.
• Translate knowledge into the clinical setting.
• Explore ways of fostering participation in behavioural interventions.
Gastrointestinal disorders are associated with marked impairment in health-related quality of life (QoL) (Creed et al., 2001). This chapter will review irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD).

**Irritable Bowel Syndrome**

IBS is a functional disorder of the lower gastrointestinal tract which is characterized by chronic or recurrent cramping abdominal pain, bloating, and alterations in bowel habits (e.g., constipation and/or diarrhea).

**Epidemiology**

IBS has been found in up to 18% of the US population (Thompson et al., 1992) and may account for as many as 50% of new visits to gastroenterologists (Mitchell & Drossman, 1987). Women outnumber men in both patient and community populations – 14 – 24% of women and 5 – 19% of men (Gralnek et al., 2000). Although only a minority of those with IBS consult physicians, those who do account annually for millions of physician visits and medication prescriptions (Gralnek et al., 2000).

**Impairment in Quality of Life & Psychosocial Morbidity**

While IBS was initially trivialized, current research has shown that it impacts significantly on QoL and is associated with significant psychosocial morbidity. As Gralnek et al. (2000) note, “Although there is no associated mortality, IBS greatly affects physical symptoms as well as emotional and social functioning of affected individuals”. Lowered QoL has been reported using disease-generic instruments such as the Medical Outcome Study - Short Form 36 (Creed et al., 2001; Drossman et al., 2000a; Gralnek et al., 2000) and the Sickness Impact Profile (Drossman et al., 2000a) in life domains such as bodily pain, general health perception, physical functioning, role limitations secondary to physical factors, emotional well-being, role limitations secondary to emotional factors, vitality, and social functioning. Creed et al. (2001) found that abdominal pain occurred on average 24 days per month and activities were restricted on 145 days of the previous 12 months. QoL was found to be lower than in patients with diabetes mellitus and end-stage renal disease (Gralnek et al., 2000). A disease-specific QoL measure has recently been developed (Drossman et al., 2000a). IBS is associated with increased disability days and days in bed and loss of time in the workforce as well as impaired social functioning, relationships, and recreation. Patients with severe IBS report greater depression and psychological distress, poorer physical functioning and health-related QoL, more maladaptive coping strategies, and greater health care utilization (Drossman et al., 2000b).

**Sex & Gender Specific Issues**

Gender specific issues in IBS have received considerable attention and have moved in the past decade from focus on studies of physical and psychological symptomatology to include study of abuse history, health seeking behaviour, and gender role (Toner & Akman, 2000). The role of abuse in vulnerability to or development of IBS has been explored (Reilly et al., 1999; Talley et al., 1998; Walker et al., 1995). Women with IBS compared to women with IBD report more emotional abuse, self-blame, and self-silencing (Ali et al., 2000).

**Interventions Fostering Adaptation to Illness**

The intervention literature has begun to develop over the past decade although there has been little attention to the issue of sex and gender differences in response to the interventions.

**Education**

**Level of Evidence - III**

Education about IBS is a component of many of the interventions described below. Education as a single modality has only recently come under systematic study. In a study of IBS patients, 77% reported requiring further information about their disease and 27% rated their knowledge as less than 25 out of 100 (O’Sullivan et al., 2000). Their primary issues
of concerns were bowel cancer risk and diet. Recent guidelines for primary care (Paterson et al., 1999) and specialty care (Jones et al., 2000) have recommended “stepped care” approaches and have emphasized the importance of patient education.

**Multimodal/Integrative Programs**

**Level of Evidence - I**

Programs integrating multiple components such as relaxation, thermal biofeedback, cognitive therapy (Blanchard et al., 1992), education, progressive muscle relaxation, training in cognitive coping strategies, problem-solving, and assertiveness (Heymann-Monnikes et al., 2000) have been shown to be beneficial in improving QoL in individuals with IBS.

**Stress Management**

**Level of Evidence - IV**

Stress management strategies have not been adequately evaluated in IBS. They may form part of multimodal interventions.

**Cognitive-Behavioural Approaches**

**Level of Evidence - I**

Cognitive-behavioural therapy (CBT), both individual and group, has received significant attention in the past decade (see review by Toner et al., 1998) and has been the subject of randomized individual (Payne & Blanchard, 1995), nonrandomized individual (Boyce et al., 2000), randomized group (Greene & Blanchard, 1994) and nonrandomized group (Van Dulmen et al., 1996) studies. All of the studies have been positive in terms of decreasing the distress and disability associated with IBS and may work by altering the cognitive response to visceral hypersensitivity. A CBT treatment manual for IBS has recently been published (Toner et al., 1999).

**Behavioural Approaches**

**Level of Evidence - IV**

Biofeedback has been described as useful in IBS (Whitehead, 1992) but the evidence for its value comes from multi-modal studies and it has not been independently investigated in adequate sized, appropriately controlled samples.

**Other Psychotherapies**

**Level of Evidence - I**

Individual psychotherapy assessed in a randomised controlled trial was found to be superior to a matched condition of “supportive listening” with improvement in both physical and psychological symptoms in women but not in men (Guthrie et al., 1993). Gains were maintained at 12 month follow-up whereas those who had dropped out of the trial and those from the supportive listening condition who subsequently declined psychotherapy were worse.

**Social Support**

**Level of Evidence - V**

Self-help social support was found to be inferior to cognitive therapy and no better than waiting list control in improving physical and psychological functioning in women with IBS (Payne & Blanchard, 1995). “Supportive listening” was inferior to psychotherapy in a randomized controlled trial of 12 weeks of psychotherapy (Guthrie et al., 1993).

**Exercise**

**Level of Evidence - IV**

Exercise has not been systematically investigated in IBS.

**Nutrition**

**Level of Evidence - III**

Recent guidelines for dietary management of IBS note the lack of randomized control trials in the literature, which primarily consists of observational trials (Burden, 2001). The guidelines note that there is a limited role for exclusion diets, a move away from a focus on high fibre diets towards the manipulation of fibre fractions in the diet, and a heightened awareness of the role of caffeine on gut function. The importance of individual assessment and recommendations was highlighted.

**Mind-Body Approaches**

**Level of Evidence - IV**

A variety of mind-body approaches have been suggested in the management of IBS and recent interest has focused on yoga, but there have been insufficient studies.
Interventions in Special Populations

Despite recognition of the importance of IBS in childhood (Rasquin-Weber et al., 1999) and adolescence (Hyams et al., 1996), there has been little attention to interventions to foster adaptation to illness or to ameliorate symptoms in children. A community-based study of 507 subjects found that IBS-type symptoms were reported by 17% of high school students and 8% of middle school students and were associated with missed education, anxiety, and depression (Hyams et al., 1996).

No literature was found addressing other special populations.

Inflammatory Bowel Disease

IBD includes Crohn’s disease and ulcerative colitis. Both of these disorders are chronic inflammatory diseases of the gastrointestinal tract that are associated with significant pain, diarrhea, bleeding, and other symptoms such as nausea and vomiting, fever, joint pain or swelling, skin disease, difficulty with gas, and dependence on medication for control of diarrhea or pain.

Epidemiology

Crohn’s disease has a prevalence of 20 – 40 per 100,000 in US samples (Mendeloff, 1975) with an onset in 56% of cases before the age of 22. Crohn’s disease is slightly more common in men. Ulcerative colitis has a prevalence between 36 and 70 per 100,000 in US samples (Mendeloff, 1975) with a peak age of onset in the 20 – 40 age range. There is little sex differential; women may be slightly more frequently diagnosed than men.

Impairment in Quality of Life & Psychosocial Morbidity

The pain and associated disability of IBD results in significant disruptions in multiple life spheres. In addition to the pain and suffering associated with the physical symptoms of the disorder, individuals with IBD report concerns about being a burden, feeling out of control, compromised sexual performance, feeling dirty or smelly, and being treated as different (Maunder et al., 1997). Other common concerns include easy fatigability, poor nutritional status, dealing with the uncertain nature of the illness, and loss of bowel control (Maunder et al., 1997). Current psychiatric disorders further reduce functional status and increase disability (Walker et al., 1996).

Sex & Gender Specific Issues

There has been little attention to the role of sex and gender in IBD. In a recent study of illness-related concerns in IBD, data from IBD patients was analyzed for gender differences (Maunder et al., 1999). Women reported higher levels of IBD symptom severity and overall concerns about IBD. They were also more concerned than men about feelings related to their bodies, personal attractiveness, loneliness, and their ability to have children.

Interventions Fostering Adaptation to Illness

The intervention literature in IBD has been slower to develop than in IBS. It is only in the past decade that significant attention has been paid to interventions other than pharmacological ones, although there were uncontrolled and semi-controlled studies of the use of supportive psychotherapy in IBD in the 1950s and 1960s (Schwarz & Blanchard, 1991). These studies reported improved outcome in ulcerative colitis patients with shorter and less severe exacerbations of their illnesses.

There is a new recognition that non-pharmacological interventions to enhance adaptation to illness and improve QoL in IBD are important (Maunder et al., 1995). However, this new perspective has not yet translated into published research.

Education Level of Evidence – III

IBD patients report wanting further information about their condition with particular concerns about medications, prognosis, and cancer risk (O’Sullivan et al., 2000). Only 10% of IBD patients rated their knowledge as less than 25 out of 100 in contrast to the 27% of IBS patients.
Multimodal/Integrative Programs  
**Level of Evidence - IV**

Concerning and contradictory results were obtained in a small-scale randomized controlled trial (Schwarz & Blanchard, 1991) comparing the effectiveness of a multi-component behavioural package (IBD education, progressive muscle relaxation, thermal biofeedback, and training in use of cognitive coping strategies) to a control condition of symptom monitoring. Both groups showed reduction in symptoms, but the treatment group perceived themselves as coping better with IBD, feeling less IBD-related stress, and experiencing less anxiety and depression. When the control group was then offered active treatment, all of their symptoms worsened and the group means were higher than either their pretreatment or end-wait-list means. At follow-up, all symptoms had worsened and in the treatment group four symptoms had actually increased above pre-treatment levels. In summary, there were concerns that the treatment was detrimental although post-hoc analyses investigated a potential confounding effect of mixing ulcerative colitis and Crohn’s disease patients.

Stress Management  
**Level of Evidence - IV**

A randomized control trial of stress management that included autogenic training, planning skills, and communication skill building was compared to a control group and showed significant decreases in disease activity and IBD related stress, although the treatment group had higher pre-treatment scores and their drop in score could have also reflected regression to the mean (Milne et al., 1986).

Cognitive-Behavioural Approaches  
**Level of Evidence - IV**

There are no reports of trials of cognitive-behavioural therapy in the literature although individual clinicians use these techniques and perspectives in helping individuals work with the pain and fatigue associated with IBD.

Biofeedback has been described as useful in IBD (Whitehead, 1992), but the evidence for its value comes from multi-modal studies and it has not been independently investigated in adequate sized, appropriately controlled samples.

Social Support  
**Level of Evidence - IV**

There has been no attention to social support in the literature.

Exercise  
**Level of Evidence - IV**

Exercise has not been systematically investigated in IBD. A pilot study demonstrated that sedentary patients with Crohn’s disease can tolerate low-intensity exercise (i.e., walking) of moderate duration without an exacerbation of their symptoms and with improvements in cardiorespiratory status and psychological functioning (Loudon et al., 1999).

Nutrition  
**Level of Evidence - III**

There is active interest in nutritional approaches because of the weight loss and poor energy of many patients. Two recent reviews have documented the importance of nutrition; one largely focused on enteral feeding in the acute setting (Griffiths, 1998) while the second noted the importance of manipulating micronutrient and essential fatty acid intake (Burke et al., 1998) and reviewed the range of approaches which are taken clinically.

Mind-Body Approaches  
**Level of Evidence - IV**

A recent study investigated the views of IBD patients with respect to their use of complementary therapies (Verhoef et al., 1998). All of the patients reported using them as they felt that conventional treatments did not help or were too toxic and they perceived the treatments as safe. They did not discuss the use of these therapies with their doctors.
Interventions in Special Populations
Interventions have not been studied in special populations.

Recommendations

1. Clinical Care
   • Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.
   • Group-based cognitive therapy and self-management programs for Irritable Bowel Syndrome (IBS) should be available on at least a regional basis.

2. Health Care Professional Education
   • Knowledge translation is essential. Education about contemporary perspectives on IBS and the role of self-management and behavioural interventions needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.

3. Public Education
   • Educational materials need to be developed that address basic aspects of IBS and common misconceptions about IBS and these need to be modified to be linguistically and culturally appropriate for Francophone, immigrant, and Aboriginal women.

4. Research
   • Conduct further research into the educational needs of individuals with IBS and Inflammatory Bowel Disease (IBD).
   • Assess the value of group-based cognitive-behaviour therapy in IBD.
CHAPTER 7 HEADACHES

The assessment of pain presents unique problems due to its subjective nature. Even when identifiable pathology is present, its relationship to pain is unpredictable. Pain is also a multidimensional experience. The intensity of pain may be less of a concern to an individual than the resulting impairment of function. All illness is experienced in cultural, social, and psychological contexts but when biological pathology is not understood, these variables assume greater importance (Stones et al., 2000). Pain can be a frightening and all-consuming experience. As well, in a health care system that is becoming increasingly systematized, a health problem that cannot be readily categorized by objective criteria is considered problematic (Stones et al., 2000).

The 1999 Norwegian Official Report (as cited in Rannestad et al., 2000) noted that, in general, women experience much pain and are heavy users of analgesics. Dworkin and Gitlin (1991) found that women with multiple pain symptoms are at an especially high risk for mood disturbance. The risk was increased sixfold among women with two pain complaints and eightfold among women with three pain complaints.

Fifteen different types of headache were identified by the Ad Hoc Committee on the Classification of Headache in 1962, the most prevalent being migraine, tension, and combined headaches (Steele McCarran & Andrasik, 1987). Individuals who suffer from combined headaches (also known as vascular headaches) experience features of both migraine and tension headaches. As many as one-third of all headache sufferers are plagued with combined headaches. This has led some researchers to question the validity of discrete headache categories such as migraine and tension type, but there is enough support for this typology for it to form the basis for this review.

Migraine Headaches

Migraine headaches may occur with or without auras. Migraine with aura lasts four to 72 hours; has at least two of the following characteristics unilateral, pulsating, moderate or severe intensity, aggravated by physical activity; and is associated with at least one of: nausea, vomiting, photophobia, or phonophobia. Migraine with aura is diagnosed when at least two headaches are preceded by aura; aura symptoms usually involve blurred vision, flashing lights, missing area of visual field; and aura symptoms are fully reversible, lasting less than one hour, with headache following the aura within one hour. Symptoms in migraine will sometimes change from those of an episodic nature to chronic headache. Chronic daily headache in migraine patients is often associated with dependence on simple analgesics or ergotamines and severe rebound headaches often occur when medication is withdrawn (Steele McCarran & Andrasik, 1987).

Epidemiology

Surveys have demonstrated that 50% to 70% of the general population have headaches at some time (Steele McCarran & Andrasik, 1987). The prevalence of migraine in the general population has been estimated at 3% to 19% (Steele McCarran & Andrasik, 1987).

Impairment in Quality of Life & Psychosocial Morbidity

Migraine often has a very negative impact on women’s quality of life (QoL). It can result in disruption to one’s family and social life, impairment of function and productivity, and loss of income (Solomon & Santanello, 2000). Juang et al. (2000) investigated the frequency of depressive and anxiety disorders in individuals who suffered from daily headaches and found that 57% migraine patients had major depression, 11% dysthymia, 30% panic disorder, and 8% generalized anxiety disorder. Depressive and anxiety disorders were significantly more frequent in women. Women as a group have lower incomes as a result of the disability and disruption in their lives caused by migraine headaches (Lipchik et al., 1998). Women are two to three times more likely than men to require time off work due to headaches and experience a 60% decrease in effectiveness when they work while...
suffering from a migraine (Lipchik et al., 1998). According to Kryst and Scherl (1994), almost half of all individuals who suffer from headaches experience strained family relations as a result. Kryst and Scherl (1994) and Lacroix and Barbaree (1990) note that among individuals who suffer from recurrent headaches, women are more than twice as likely as men to experience disruptions in their family relations, social life, and leisure activities as a result.

Sex & Gender Specific Issues

While slightly more than half the children under ten years of age who suffer from headaches are males, approximately 76% of adult tension and migraine headaches sufferers are women (McCarran & Andraski, 1987; Stewart et al., 2000). Stewart et al. (2000) report that migraine prevalence in the US is 18% among women and 6% among men. Hormone fluctuations are believed to play a role in the triggering of migraine in women. Stewart et al. (2000) found that the risk of migraine increased 80% during the two days prior to menstruation and doubled during the first two days of menstruation. Remission of migraine is common during pregnancy and menopause, but migraine may also occur for the first time during pregnancy or when a woman begins to use oral contraceptives (Sinclair, 1999).

Between the ages of seven and 10 years, migraine prevalence among girls and boys is fairly uniform while after the age of ten, there is a dramatic increase in prevalence among girls. By age 15, migraine prevalence is 8% among girls and 2% among boys. The increase in prevalence around the time of puberty suggests there is a hormonal role in migraine etiology (Andraski & Kabela, 1988).

Women, on average, are two to three times more likely to be disabled to some degree by migraine headaches than men (Lipchik et al., 1998). Women have more severe headaches than men. Their headaches are of longer duration and higher pain intensity (Celentano et al., 1990). They are also more likely to experience nausea and vomiting, scalp tenderness, and visual aura or parathesias. Women who suffer from recurrent headache are two times more likely than men to see a physician and also two times more likely than men to receive a prescription for their headaches. Women are therefore at increased risk of developing medication-related complications, such as drug-induced or rebound headache (Lipchik et al., 1998). Despite these facts, migraine is rarely recognized as a significant health problem for women (Lipchik et al., 1998).

Most women with headache disorders do not seek medical attention (Rapoport & Sheftev, 1996). This has been attributed to a lack of awareness of effective treatments, poor access to medical care, and the lack of general acceptance of headache disorders as legitimate medical disorders. However, up to 40% of women with headache disorders who do consult a physician are inaccurately diagnosed or receive ineffective treatment (Lipchik et al., 1998).

There appears to have been a high proportion of female subjects included in migraine research; however, migraine is rarely recognized as a significant health problem for women (Lipchik et al., 1998). Therefore, migraine (and recurrent headache disorders) should be included in women’s health research initiatives (Lipchik et al., 1998). The small number of men in migraine research makes it difficult to evaluate gender differences.

Interventions Fostering Adaptation to Illness

The most frequently used behavioural interventions to treat migraine and tension headaches are relaxation training, biofeedback training (often in conjunction with relaxation training), and stress management or cognitive-behavioural therapy (Holroyd & Penzien, 1994). These are most often used to prevent rather than alleviate headaches and successful results occur when there is a decrease in the frequency of headaches and the lifestyle disruptions associated with them.

Blanchard (1987) notes that approximately one-half to two-thirds of patients who use behavioural interventions to control migraine are able to maintain or improve positive results one to five
years after initial training. He suggests that improvements in headache activity continue over time despite the “almost universal cessation of regular home practice” of biofeedback techniques because “the self-perpetuating cycle of chronic headache has been broken” (Blanchard, 1987).

Education
Level of Evidence - IV

Education has not received systematic attention, although clinicians agree it is an important part of care of the migraine patient.

Multimodal/Integrative Programs
Level of Evidence - II-1

Blanchard et al. (1990) assessed the efficacy of a largely home-based treatment program for migraine that combined relaxation training with thermal biofeedback and cognitive stress-coping therapy, and involved minimal therapist contact. Patients with vascular headache (migraine or mixed migraine and tension headache) were randomly assigned to one of three groups: (1) thermal biofeedback and relaxation training carried out over an eight-week period in three office visits, supplemented by audio tapes and manuals; (2) thermal biofeedback and relaxation training with instruction in cognitive stress coping techniques, carried out over an eight-week period in five office visits; or (3) monitoring of headache activity over an eight-week period. Based on headache diaries maintained by the subjects, it was determined that both treatments led to significantly decreased headache activity and medication use. However, the addition of cognitive stress-coping therapy in the second treatment group did not increase the efficacy of treatment. The authors write that “while this study could be considered to represent a failure of limited cognitive therapy to add to a physiological treatment for vascular headache, a more reasonable interpretation might be that the method of delivering the therapy was a failure. Cognitive therapies are elegant and sophisticated and usually are seen as requiring detailed interaction between patients and therapist. In the present study, this was not possible because of the goal of reducing therapist contact to a minimum” (Blanchard et al., 1990).

The delivery format for a combined thermal biofeedback/progressive muscle relaxation (PMR) treatment was also assessed by Blanchard et al. (1992) in a comparison of a largely home-based, minimal contact treatment delivery with a clinic-based treatment. They demonstrated that limited contact (three sessions over an eight-week period) and intensive contact (16 sessions over an eight-week period) resulted in equivalent reduction in headache relief among vascular headache subjects who received combined thermal biofeedback/PMR treatment. Headache reductions among subjects in the minimal contact group were maintained over a two-year follow-up period.

Kohlenberg and Cahn (1981) investigated an approach requiring minimal subject-therapist contact. All subject-therapist contact was carried out over the telephone or by mail. After migraine patients were matched for headache frequency, they were randomly assigned to receive either a “treatment” book or a “control” book. The treatment book explained physiological and emotional factors related to migraine, relaxation procedures, and cognitive coping techniques for daily use, while the control book simply provided general information about headaches. The treatment book also included a liquid crystal finger temperature band with an explanation of the relationship between changing hand temperature and headache activity. Results demonstrated that subjects in the treatment group experienced a 62% decrease in headache frequency, while those in the control group experienced a 14% decrease. As well, there was a significantly greater reduction in mean headache duration and pain among subjects in the treatment group. At three-month follow-up, the differences between the two groups had increased.

Del Fante (1985) described a pilot project conducted by community health nurses which taught self-care skills to individuals who suffer from migraine and
tension headaches. The program was based on principles from behavioural medicine and humanistic psychology and was designed for the increasing number of individuals who wish to take an active role in their health care. The program was delivered to groups who met for an initial meeting, followed four weeks later by ten weekly sessions of one-and-a-half hours. This was followed up by a final session four weeks later. At the preliminary meeting, participants monitored their headaches, medication use, and time lost from work or leisure. During the weekly sessions, participants were provided with basic information about headaches and taught relaxation techniques and stress reduction methods such as assertiveness, cognitive restructuring, problem-solving skills, and effective communication skills. The program was provided in a group format to foster social support and encouragement among participants. There was a significant decrease in headache scores and medication use. As well, participants felt they acquired increased self-awareness, were able to integrate newly acquired skills into their lives, and better understood the relationship between stress and headaches. Many also appreciated the support and camaraderie of fellow headache sufferers.

**Stress Management**

**Level of Evidence - IV**

Stress management has not been studied as a single modality in adaptation to migraine.

**Cognitive-Behavioural Approaches**

**Level of Evidence - IV**

Cognitive-behavioural therapy (CBT) focuses on the cognitive and affective components of headaches by training individuals to identify stressful situations in their lives, develop effective ways to deal with stress, and cope more effectively with headache pain and disability (Holroyd & Penzien, 1994). The efficacy of CBT in migraine has been less well established because there have been fewer studies in this area (McGrath, 1999). Also, the CBT employed in studies was originally developed for the treatment of tension headaches rather than migraine (Holroyd & Penzien, 1994). Blanchard (1992) is skeptical about the effectiveness of CBT in the treatment of vascular headache. Nevertheless, he speculates that a “cognitive-attributional” model may explain the way in which behavioural treatments lead to decreased headache activity (Blanchard, 1987). The pain of headache is itself a stressor that increases the likelihood of ongoing headache. Hillhouse et al. (as cited in Blanchard, 1987) report that after experiencing headache relief as a result of successful treatment, a patient may redefine herself as a person who can cope with headache. Blanchard speculates that this “cognitive-attributional” model may explain the way in which behavioural treatments lead to decreased headache activity.

Steele McCarran and Andrasik (1987) report that CBT for migraine appears to be as effective as thermal and vasoconstriction biofeedback in providing a reduction in headache activity. The benefits also appear to be maintained over time. Blanchard (1992) on the other hand, has noted that CBT alone has not demonstrated greater effectiveness than biofeedback or relaxation training in the treatment of vascular headache (migraine or mixed headache). As well, the addition of CBT to biofeedback or relaxation has not resulted in a significant increment in headache relief (Blanchard, 1992). Blanchard and colleagues (as cited in Blanchard, 1992) demonstrated that the addition of cognitive stress-coping therapy to a combined thermal biofeedback/PMR treatment for vascular headache did not result in a significant increment in improvement. An absence of benefit was also demonstrated when they assessed the same treatments in a minimal contract, home-based intervention.

**Behavioural Approaches**

**Level of Evidence - II-1**

Meta-analyses and reviews have concluded that relaxation and thermal (finger temperature) biofeedback, either alone or in combination, are the most effective treatment for migraine (McGrath, 1999). After summarizing results of randomized trials with migraine subjects, Holroyd and Penzien (1994) found that a relaxation/thermal biofeedback combination resulted in a 56% decrease in
headaches, while relaxation training or biofeedback alone resulted in a 35% decrease. Holroyd and Penzien (1994) recommend relaxation training with optional thermal biofeedback training as the preferred non-pharmacological treatment for migraine.

Three types of relaxation training are used in migraine: (1) PMR, whereby muscles are alternately tensed and relaxed allowing for both the induction and recognition of relaxation by providing an immediate contrast with tension; (2) autogenic training, which involves the use of self-instructions of warmth and heaviness; and (3) meditation or passive relaxation, involving the use of a silently repeated word or sound (Holroyd & Penzien, 1994). McGrath (1999) describes the three main types of relaxation therapy as: (1) relaxation with tension; (2) relaxation using imagery and "suggestion; and (3) relaxation induced by breathing exercise. Relaxation induced by hypnosis can be considered as a fourth category.

Sorbi et al. (1989) report on follow-up data three years after migraine patients completed either relaxation training or stress-coping training. Almost 80% of subjects were female, average pre-training age was 35.6 years, and the average length of migraine history was 17.3 years. The authors found a significant decrease in migraine frequency of 30% to 40% in both groups. There was less improvement noted in intensity and duration of migraine, which decreased by 10% to 20% in both groups. Only the decrease in migraine intensity persisted over the three-year period. These results suggest that the benefits of relaxation training and stress-coping training are to be found in the area of prevention rather than amelioration of migraine headache. Subjects in both groups were also able to decrease the use of vasoconstrictive and analgesic medications by 50% (Sorbi et al., 1989).

In a study by Kropp et al. (1997), the sequence of two behavioural treatments for migraine was evaluated. Subjects who suffered from migraine without aura were randomly assigned to either blood-volume-pulse biofeedback followed by cognitive-behavioural therapy (Group 1) or cognitive-behavioural therapy followed by blood-volume-pulse biofeedback (Group 2). While the results demonstrated significant improvement among subjects in both groups, number of days with migraine and intensity of migraine were lower among subjects in Group 1. The authors concluded that biofeedback helps patients to understand the importance of thoughts and emotions on the body and, therefore, assists in preparing them for successful CBT.

While cognitive-behavioural treatment (stress-coping training) has been assumed to be superior to psychophysiological treatment (relaxation training) for migraine, Sorbi and colleagues' (1989) results do not support this position. Instead, they conclude that relaxation training and stress-coping training are equally effective in the treatment of migraine. However, because relaxation training is less complex and less costly, it may be the preferred choice. The authors also conclude that the evidence does not suggest that multimodal regimens or more complex psychological therapies are superior to single-method interventions, such as those they employed.

Follow-ups of at least five years in duration have demonstrated that vascular headache patients who received either blood-volume-pulse biofeedback, thermal biofeedback, or relaxation maintained good headache reduction over the follow-up period (Blanchard, 1992). Diamond and Montrose (1984) carried out a four-year retrospective analysis of comprehensive biofeedback training and found that only 40% of the men, compared to 56% of the women, reported moderate to excellent improvement. As well, 32% of the men had a worse or unchanged status at follow-up, compared to 20% of women. The researchers noted that the gender differential in improvement may have been due to the women practicing the biofeedback techniques more consistently than the men. There is little evidence to suggest that a particular type of relaxation therapy is more effective than other relaxation therapy types in the treatment of migraine; however, Sorbi et al. (1989) note that effectiveness may be increased in migraine patients by combining relaxation with biofeedback or CBT.
Hypnosis has received some study. Emmerson and Trexler (1999) investigated the effect of a single group session hypnotic intervention followed by the use of tapes at home on the duration, frequency, and severity of migraines. Three-quarters of subjects were female, their ages ranged from 36 – 68, and 60% suffered bilateral migraines. The results demonstrated significant differences between pre- and post-treatment headache activity and medication use. Barber (1996) presents case studies of migraine patients whom he taught to successfully prevent migraine attacks by using self-hypnosis techniques. His technique requires an individual to immediately begin the self-hypnotic procedure at the first warning sign of an impending migraine attack. He notes that the most frequent reason for self-hypnosis failure in migraine is that individuals postpone performing the procedure. Hypnosis is only effective in preventing, rather than ameliorating, migraine. Hypnotic intervention appears to be more effective in the treatment of migraine than other headache disorders (Barber, 1996).

Our group is presently analyzing data from a mindfulness-based stress reduction cohort with respect to impact on migraine headaches.

**Other Psychotherapies**

**Level of Evidence - IV**

There has been no systematic study of the role of other forms of psychotherapy in adaptation to and improvement in quality of life in individuals with migraine.

**Social Support**

**Level of Evidence - IV**

There has been no systematic study of the role of social support in adaptation to and improvement in quality of life in individuals with migraine.

**Exercise**

**Level of Evidence - III**

Exercise may prevent or alleviate migraine through different mechanisms, including decreased pain perception and/or alleviation of anxiety or depression, often associated with migraine (Darling, 1991). Exercise may also alleviate anxiety and depression, which are often associated with and may precipitate migraine attacks (Darling, 1991).

**Nutrition**

**Level of Evidence - II-1**

Food (e.g., wheat, citrus fruits, tea, coffee, pork, chocolate, milk, grapes, nuts, beef, corn, cane sugar, legumes, yeast, pineapple, coconut, and cola drinks) may trigger migraine through an allergic reaction (Perking & Hartje, 1983).

High-dose riboflavin has been shown to be effective in preventing migraine. In a randomized, placebo-controlled study conducted by Schoenen et al. (1998), migraine patients were given either 400 mg riboflavin or placebo and followed over a three-month period. Riboflavin was significantly more effective than placebo in reducing the frequency of migraine attacks and headache days. The proportion of subjects who improved by at least 50% was 59% in the riboflavin group and 15% in the placebo group.

Ramadan et al. (as cited in Sinclair, 1999) report on a study in which patients aged 18 to 65 years who suffered a mean of 3.6 migraine attacks per month, were given either oral magnesium (600 mg trimagnesium citrate) or placebo for 12 weeks. The physiological activities of magnesium include counteracting vasospasm, inhibiting platelet aggregation, and stabilizing cell membranes; these are important factors in the pathogenesis of migraine (Sinclair, 1999). Between the ninth and twelfth weeks of the study, a significant difference in reduction of migraine frequency became evident between the two groups: 41.6% in the magnesium group compared to 15.8% in the placebo group. There was also a significant reduction among
subjects in the magnesium group in the number of
days with migraine. Duration and intensity of
migraine attacks and consumption of medications
also tended to decline in subjects in the magnesium
group, but failed to reach statistical significance.
Adverse effects noted among subjects included
diarrhea (18.6%) and gastric irritation (4.7%).

Mind-Body Approaches

Level of Evidence - IV

There has been little systematic study of mind-body
describe a study of the efficacy of yoga in the
treatment of migraine and tension headaches.
The sample of patients aged 16 – 55, predominantly
“housewives,” was randomly assigned to either
training in yoga twice a week for four months or to
the control group, which received no physical or
relaxation training but continued to take their
prescribed medications. Following yoga training and
practice over four months, the subjects reported a
significant decrease in headache frequency, intensity
and duration, fewer accompanying somatic
complaints, decreased use of medication, decrease in
the perception of stresses, and development of more
adaptive coping responses. The control group, on
the other hand, increased their use of medications,
experienced increased somatic complaints, perceived
more stressful situations, and used maladaptive
coping responses. While the investigators report that
there was a significantly greater reduction in the
post-treatment perception of stresses among the
treatment group compared to the control group, the
two groups were not comparable in several areas of
this measure at baseline. As well, there was a huge
increase in stress perception among subjects in the
control group (from 4.2 to 44.1) that is not
explained and requires clarification.

Interventions in
Special Populations

Nonpharmacological treatments are also effective
in the treatment of migraine in adolescents and
the elderly (McGrath, 1999). Biofeedback and
relaxation therapy are more effective for the
treatment of migraine in children than in adults and
are especially effective in females (Andrask &
Kabela, 1988).

Children

Studies of children with migraine have demonstrated
that thermal biofeedback, usually in conjunction
with autogenic training, results in at least 67%
of patients experiencing clinical improvement
(Blanchard, 1992). As well, there is usually good
maintenance of results up to at least one year.
Thermal biofeedback is also effective for treating
children when it is delivered in a home-based,
minimal contact format. Relaxation training is
controversial. Some studies have found it effective in
the management of pediatric migraine (Andrask &
Kabela, 1988), though perhaps not as effective as
thermal biofeedback and no more effective than
psychotherapy or headache monitoring (McGrath,
1999).

Tension Headache

Tension headaches are usually characterized by
pain and stiffness in the neck, and a bandlike pain
bilaterally or around the head. The pain tends to be
dull and steady rather than sharp and intense. There
are many individuals who suffer from tension
headaches on a daily or near-daily basis.

Epidemiology

The one-year prevalence of regular (more than once
per month) tension headaches is between 20% and
30%, with 10% to 15% of these cases being chronic
(more than 180 days per year) tension headaches
(Holroyd & Penzien, 1994). An even higher estimate
that 40% of the population suffer from tension
headaches was reported by Steele McCarran and

Impairment in Quality of Life &
Psychosocial Morbidity

There has been little systematic study of QoL
amongst tension headache sufferers. Two recent
studies document significant impact on daily life
with pain, disruption in sleep, fatigue, and social
isolation secondary to headaches (Passchier et al.,
1996). Headache-related disability days were reported
by 74% of tension headache patients in a U S sample -
the mean was seven days in the previous six months (Holroyd et al., 2000). These patients also reported impairments ten or more days per month in sleep, energy level, and emotional well-being. As well, they were 3–15 times more likely than matched controls to receive a diagnosis of an anxiety or mood disorder and more than half had clinically significant levels of anxiety or depression.

Sex & Gender Specific Issues
There has been no attention in the literature to sex and gender differences.

Education Level of Evidence - IV
There has been no systematic attention in the literature to education in facilitating adaptation to tension headaches.

Multimodal/Integrative Programs
Level of Evidence - I
Holroyd et al. (2001) conducted a randomized placebo-controlled trial to evaluate the efficacy of behavioural and pharmacological treatments, alone and in combination, for chronic tension headaches. The subjects (76% women, mean age of 37 years) were randomly allocated to receive either the tricyclic antidepressant amitriptyline, placebo, stress management therapy, or stress management therapy plus the antidepressant. The stress management therapy entailed relaxation and cognitive coping taught over three sessions and two telephone contacts. The antidepressant and stress management therapy each resulted in greater reductions in headache activity, analgesic use, and headache-related disability than did the placebo; however, the antidepressant brought about more rapid improvement. The combined antidepressant/stress management therapy was more likely than the antidepressant alone, stress management alone, or placebo to result in headache index score reductions of at least 50%; the percentage of subjects who achieved this reduction were 64%, 38%, 35% and 29%, respectively. Combined therapy was therefore significantly more effective than either the antidepressant or stress management therapy on their own.

Stress Management
Level of Evidence - IV
Stress management has not been systematically evaluated as a single modality intervention in tension headache.

Cognitive-Behavioural Approaches
Level of Evidence - II-1
Holroyd and Andrasik (1978) conducted a study in which subjects were assigned to: (1) lessons in cognitive stress-coping techniques; (2) stress-coping technique lessons plus muscle relaxation training; (3) headache discussion in a group format; or (4) a symptom-monitoring control group. Subjects in both cognitive treatment groups and in the discussion group demonstrated significant reductions in headache activity, while subjects in the control group showed no improvement. Electromyographic (EMG) levels were not related to headache improvement. Post-treatment interviews revealed that all but one of the subjects in the discussion group intervention devised their own coping strategies, which were often quite similar to coping strategies taught in the two cognitive treatment groups. The one subject in the discussion group who did not employ a coping strategy showed only minimal improvement in headache activity.

In a study conducted by Figueroa, subjects were divided into three groups: (1) a cognitive-behavioural group that received training in recognizing stressful situations, recognizing their own tension responses, and developing skills to deal more effectively with these and with pain; (2) a psychotherapy group that discussed headaches and possible underlying conflicts subjects may be experiencing; and (3) a self-monitoring group that completed headache diaries. Only subjects in the cognitive-behavioural group demonstrated significant decreases in headache frequency and severity, amount of medication used, and the disability associated with pain.

Evidence to support the efficacy of CBT in the treatment of tension headaches has been reviewed by Holroyd and Penzien (1994) with the conclusion that CBT may enhance the effectiveness of relaxation training. CBT enhances relaxation and biofeedback therapies for select subgroups of
headaches sufferers. These are likely to be individuals with problems, such as chronic daily stress or depression, that aggravate headaches or interfere with one’s ability to apply skills learned during relaxation or biofeedback training (Holroyd & Penzien, 1994).

Blanchard (1992) demonstrated that the addition of cognitive stress-coping therapy to PMR brought about a significantly greater reduction in tension headache activity than PMR alone or a credible placebo.

In summary, studies appear to show that CBT for tension headache are superior to EMG biofeedback in bringing about reductions in headache activity. The success of the CBT may be related to cognitive changes that occur in subjects as a result of mastery of new techniques to control their headaches (SteeleMcCarran & Andrasik, 1987).

**Behavioural Approaches**

**Level of Evidence - II-1**

A meta-analysis conducted by Holroyd and Penzien (1994) evaluated 37 studies of relaxation or EMG biofeedback in the treatment of tension headaches. When the results were averaged across the studies, relaxation, EMG biofeedback, and a relaxation/EMG biofeedback combination were each found to result in an approximate 50% reduction in headache activity. This reduction was significantly greater than that found in control groups. There have been several studies which suggest that an important component of all of these approaches is learning to monitor symptoms and elicit active coping rather than simply changes in muscle tension as positive results are also obtained when inaccurate feedback on muscle tension is given (SteeleMcCarran & Andrasik, 1987).

The type of feedback most often employed in the treatment of tension headache is EMG biofeedback. It provides feedback regarding the electrical activity of one’s scalp, neck or upper body muscles and is focused on reducing tension in the trapezius muscle of the neck and the frontalis muscle of the forehead (Holroyd & Penzien, 1994). Through biofeedback, patients are provided with constant feedback about the level of tension in these muscles. Interestingly, treatment effectiveness is independent of the direction of change (i.e., increase or decrease) for the EMG levels (see review in SteeleMcCarran & Andrasik, 1987). Findings such as these have led some researchers to point to the importance of cognitive factors, such as expectation, motivation, coping, and perceived success, in the reduction of headache. Narduzzi et al. (1998) have shown that treatment responders change their beliefs about their illness and their ability to bring about change in their symptoms.

Blanchard et al. (1992) report that a five-year follow-up study demonstrated that tension headache patients who received relaxation and EMG biofeedback maintained good headache reduction over the follow-up period. In a study of factors that may influence maintenance of headache reduction, Andrasik et al. (as cited in Blanchard, 1992) found that monthly “booster” treatments did not improve maintenance of results.

Home-based and clinic-based relaxation training programs are equally effective in producing significant decreases in headache activity and significant reductions in analgesic medication use (Blanchard et al., 1992).

Holroyd and Penzien (1994) recommend relaxation training as the preferred non-pharmacological treatment for tension headaches for several reasons. First, they believe the effectiveness of relaxation training is equivalent to that of other behavioural interventions. Second, it does not require the equipment needed for EMG biofeedback training. Third, it is easier to train health professionals to administer relaxation training than either EMG biofeedback training or CBT. Fourth, relaxation
training may be administered either in-person by a health professional or through a minimal contact format.

Our group is presently analysing data from a mindfulness-based stress reduction cohort with respect to impact on tension headaches.

Other Psychotherapies
Level of Evidence - IV
There have been no studies of other psychotherapies in fostering adaptation to tension headaches.

Social Support
Level of Evidence - IV
There have been no studies of social support in fostering adaptation to tension headaches.

Exercise
Level of Evidence - IV
There have been no studies of exercise in fostering adaptation to tension headaches.

Nutrition
Level of Evidence - IV
There have been no studies of nutrition in fostering adaptation to tension headaches.

Mind-Body Approaches
Level of Evidence - IV
Latha and Kaliappan (1987, 1992) describe a study of the efficacy of yoga in the treatment of migraine and tension headaches which was reviewed earlier in the migraine section of this chapter.

Interventions in Special Populations

Adolescents
Larsson et al. (as cited in Blanchard, 1992) conducted a study of school-based treatment for adolescents, aged 16 to 18 years, who suffered from tension-type or mixed headaches. The researchers found that a primarily self-help relaxation regimen was as effective as a therapist-guided regimen and more effective than symptom monitoring. Passchier et al. (as cited in Blanchard, 1992) carried out a study of PMR delivered in a classroom setting for adolescents with tension headache, which was found to be ineffective.

The Elderly
Tension headaches are much more prevalent in older adults than migraine. Early research indicated that psychological treatments for headache were relatively ineffective in older adults but more recent research has indicated that if slight modifications to the delivery format are made, older adults can also benefit from psychological treatments for tension headache (e.g., lengthening the time to explain instructions).

Recommendations

1. Clinical Care
   - Self-management and behavioural interventions need to be integrated into routine clinical care for those women who need or want them.

2. Health Care Professional Education
   - Education about the importance of headaches as a women’s health problem and the range of behavioural interventions that may be of value needs to be communicated to both primary care practitioners and health care providers in specialty settings.

3. Public Education
   - Educational and self-management materials need to be developed that address basic aspects of headache management and provide information about rebound headaches associated with analgesic use. These materials must also be presented in a linguistically and culturally appropriate manner for Francophone, immigrant, and Aboriginal women.

4. Research
   - Research the most cost-effective self-management behavioural interventions and how they might be manualized for delivery in primary care and community settings.
The body's acquired immune response is responsible for protection from pathogenesis, such as viral, bacterial, or fungal infection. At its elemental level, the acquired immune system components are B cells, T cells, phagocytes, and complement proteins. Ill health results in an individual when there is disorganization in the development or differentiation of these cells, synthesis of their products, or regulation of their processes (Benjamini et al., 1996).

Immunodeficiency disorders define immune system conditions characterized by a deficiency or malfunction of one or more of its key elements (Benjamini et al., 1996). Acquired Immunodeficiency Disorder (AIDS) is a disease resulting from exposure to the Human Immunodeficiency Virus (HIV) that causes a systemic suppression of the immune system response, specifically targeting T-cell production. HIV infection and subsequent immune system suppression causes increased susceptibility to opportunistic infections and malignancies in host individuals (Miller & Eoyang, 1992). AIDS patients face a chronic and deteriorating disease progression as their body attempts to protect itself from pathogenic invaders.

**Epidemiology**

It is currently estimated that 30.6 million persons worldwide are living with HIV/AIDS (Eller, 1999). Health Canada (2000a) reports that 45,000 to 53,000 Canadians were living with HIV infection by the end of 1999 and, during the same time period, AIDS cases in adult women increased from 11.9% in 1996 to 16.5%. Of 16,913 reported AIDS cases in Canada, by the end of 1999, 8% were among both female women and children (Health Canada, 2000a). These statistics represent the alarming increase in the incidence of women with AIDS. By the year 2000, women were expected to account for more than half of the new HIV infections worldwide (UNAIDS, 1998). This statistic presents particular concern to young women, ages 15 - 30, since research shows that this population is at high risk for HIV infection. By December 31, 1999, 45,534 positive HIV tests had been reported in Canada, 1.5% among youths aged 15 - 19 and 28% among women aged 20 - 29 (Health Canada, 2000b). Epidemiological studies also show that women of some ethnic origins are at higher risk for HIV/AIDS infection. Canadian statistics show that a greater percentage of Aboriginal women are HIV-infected, in comparison to non-Aboriginal women (Health Canada, 2000c). US statistics from 1996 identified AIDS as the leading cause of death among African-American women aged 25 - 44 (Simoni & Ng, 2000). Furthermore, Rothenberg et al. (1987) reported on the cumulative probability of survival in individuals with AIDS in New York City. Within the researchers' cohort of 5833 subjects, they found that women, particularly those of Black or Hispanic ethnicity, have one of the poorest survival rates during the first year of illness (Rothenberg et al., 1987). Health Canada (2000a) reports that age-specific death rates for women with AIDS aged 25 - 44 are approaching mortality rates for other leading causes of death in this age group, such as heart disease and lung cancer.

**Impairment in Quality of Life & Psychosocial Morbidity**

Psychosocial morbidity in HIV/AIDS has been correlated with disease stage and progression. A recent review established that psychological distress or depression in individuals with HIV is related to disease progression over five years (Chesney & Folkman, 1994). Due to the progressive debilitating nature of this chronic illness, it is not surprising that deteriorating health would correlate with a downward spiral of psychological well-being and life quality (Chesney & Folkman, 1994). HIV has been shown to negatively affect many dimensions defining quality of life including physical, emotional, and social functioning, and problems with fatigue, pain, social stigma, and sexual dysfunction. In comparison to men, women have decreased scores on role and social functioning (Chesney & Folkman, 1994). The authors suggest that this may be attributed to the lack of support systems available to women with HIV relative to their male counterparts.
Sex & Gender Specific Issues
Despite the growing prevalence of HIV/AIDS and its severity in women, research examining disease course and treatment intervention has focused on men, specifically bisexual and homosexual populations. Past epidemiological trends have guided research in this direction; however, current research shows that heterosexual activity is becoming a predominant HIV risk factor and is the primary HIV risk factor in young women (Miller et al., 2000). While research is striving to address these more current trends, there remains a significant lack of literature that discusses HIV/AIDS from a female perspective. In a report written by Health Canada (2001) on Canada’s Response to Women and HIV/AIDS, it was stated that the inequality between the sexes negatively affects the impact of HIV/AIDS on women through decreased access to care and services and increased discrimination. The report also addresses key areas of concern and identifies particular needs of women coping with HIV/AIDS.

The psychological experience of living with HIV/AIDS appears to vary directly by gender. In a recent review, Mellers et al. (1994) found numerous studies that reported a higher incidence of psychopathology or psychiatric morbidity in HIV-infected women than in infected men. Bungener et al. (2000) reported that HIV-infected women frequently present with depression, anxiety, and increased distress. The use of avoidant coping strategies has been correlated with increased levels of distress in both men and women (Siegel et al., 1997); however, the investigators state that further study is needed to assess gender differences in relation to efficacy of coping strategies. Specific attention must be paid to the unique psychosocial experience of women with HIV/AIDS. Castaneda (2000) places emphasis on the need for interventions to acknowledge women’s social role as an “interdependent nexus of relationships, responsibilities, and obligations to others”. For example, women’s role as the primary caregiver for children must be addressed in the context of interventions in order to ensure their success.

Current literature suggests that HIV-infected minority women may experience even greater levels of psychological distress than HIV-infected Caucasian women (Simoni & Ng, 2000). Research also shows that culture plays a defining role in women’s psychosocial experience of HIV/AIDS. Bungener et al. (2000) reported that significant differences were found in a comparison of psychological and psychosocial factors between HIV-positive African and European women. The key findings highlighted showed that more European women disclosed their HIV-positive status to family and friends and that HIV-positive African women had a greater desire to have children. Collectively, the implication of these findings on clinical intervention emphasizes the importance of cultural awareness in developing treatment programs for AIDS patients.

In addition to present disease conditions, research suggests that psychological profiles of HIV-positive women may be affected by past traumatic experiences. A study conducted by Simoni and Ng (2000) utilized retrospective self-reports to examine trauma, coping, and depression in African-American and Latino women with AIDS in New York City. The researchers reported a prevalence of early trauma, particularly child abuse, in HIV-positive women and suggested that such trauma heightened one’s risk for revictimization and was correlated with the use of ineffectual avoidant coping strategies and greater depressions levels. Simoni and Ng (2000) suggested that future research should identify factors that enable women to cope successfully with early trauma and their HIV status. Simoni and Cooperman (2000) proceeded in this field of research and conducted interviews with women living with HIV/AIDS in New York City to identify stressors and strengths. A majority of participants were abuse survivors and reported high levels of spirituality, mastery, and HIV-related social support as sources of strength. These resources were positively correlated with decreased depressive symptomatology (Simoni & Cooperman, 2000). Several limitations reduce the strength of the results reported by both Simoni and Ng (2000) and Simoni and Cooperman (2000), including no HIV-negative control group for comparative data analysis and the use of self-report.
However, this research raises important issues to be further addressed, including: the incorporation of self-esteem and empowerment training in psychological interventions for women with HIV/AIDS; the role of spirituality and religious activity for AIDS sufferers; the use of thorough psychosocial evaluations to facilitate appropriate psychological interventions; and the importance of cultural awareness in research initiatives targeting women with HIV/AIDS.

**Interventions Fostering Adaptation to Illness**

The development of pharmacological advances such as protease inhibitors and the initiation of combination drug therapies has extended the life expectancy of individuals living with HIV (Eller, 1999). In this regard, HIV has become characterized as a chronic illness with an increase in incidence and severity of physical and psychological symptoms (Eller, 1999). Side effects of combination drug therapy also contribute to the development of symptoms and lowered quality of life (QoL) (Eller, 1999). Unfortunately, currently individuals diagnosed with HIV/AIDS face a reality of irreversible, deteriorating health over time. Considering this dismal projection, several behavioural interventions have been studied in HIV-infected individuals for their positive effect on psychological well-being, including improvements to QoL, coping skills, symptom experience, and psychological distress.

**Education**

**Level of Evidence - IV**

There is surprisingly little literature on the role of education in adaptation to HIV/AIDS. Most of the educational literature is directed towards primary prevention.

**Multimodal/Integrative Programs**

**Level of Evidence - II-1**

While multimodal and integrative programs are common in clinical practice, they have been less well studied. A computer-based support and education system for people living with HIV/AIDS was studied using a randomized controlled design (Gustafson et al., 1994). Compared with the control group, the computer health enhancement support group reported higher QoL in several dimensions and reductions in health care costs. The intervention was acceptable to all segments of the HIV/AIDS population including women, minorities and those with lower levels of education. A six month randomized trial of a combined education and support program for HIV-infected individuals resulted in a decrease in unsafe sexual behaviours (Cleary et al., 1995).

**Stress Management**

**Level of Evidence - II-1**

The Center for AIDS Prevention Studies at the University of California has initiated a group-based intervention, Coping Effectiveness Training (CET), founded on the cognitive theory of stress and coping (Chesney & Folkman, 1994). CET is considered unique in that it teaches a meta-strategy approach for choosing effective strategies to maximize the reduction of psychological distress. The curriculum also includes training in the appraisal of stressful situations and the assessment of appraisal-coping fit. Preliminary studies show that CET intervention may improve coping, depression, and positive morale in HIV-positive and HIV-negative males (Chesney & Folkman, 1994). Future studies will need to include female subjects to enhance the generalizability of these findings; however, the potential use of a multi-faceted psychological intervention may be successful at helping people with HIV/AIDS cope with the stressful realities of their daily lives.

**Cognitive-Behavioural Approaches**

**Level of Evidence - I**

Numerous studies have examined the role of cognitive behavioural therapy (CBT) in reducing the psychological distress experienced by HIV-infected individuals. Empirical research generally shows that CBT can alleviate depressive symptomatology in HIV-infected males (Church, 1998); however, the non-inclusion of women in similar studies diminishes the opportunity for cross-comparison. Furthermore, in consideration of the different psychosocial and socioeconomic issues women face in comparison to men, the efficacy of CBT found in recent studies cannot be generalized to the female population.
One study that examined the outcome of cognitive behavioural and support group brief therapy for depressed HIV-infected people attempted to recruit female participants. However, the few women who entered the study preferred to participate in female-only groups, and consequently, the sample was too small to be included in the published research analysis (Kelly et al., 1993).

Despite supportive findings, many questions remain regarding the use of CBT to reduce psychological distress in HIV-infected males. Specifically, evidence is inconclusive regarding the superiority of CBT in comparison to other treatments during the acute treatment phase of HIV/AIDS (Church, 1998). Markowitz et al. (1998) conducted a randomized, clinical trial comparison study of various behavioural interventions on a subject cohort (15% women). The investigators found that interpersonal psychotherapy and supportive psychotherapy with imipramine were significantly more efficacious than CBT or support therapy alone in reducing depressive symptoms in HIV-infected individuals (Markowitz et al., 1998). Another study examining the use of cognitive behavioural interventions on QoL in persons with HIV found differential effects for guided imagery and progressive muscle relaxation in relation to disease stage progression (Eller, 1999). These results suggest that further research is needed to substantiate recommendations for the use of psychological treatment interventions for HIV/AIDS associated depression.

One explanation for the varied results observed in using CBT is its appropriateness in a clinical population whose internal reality may accurately depict the objective reality of their stressful life situation (Church, 1998).

**Behavioural Approaches**

**Level of Evidence - III**

There has not been systematic attention to behavioural approaches in adaptation to HIV/AIDS, although relaxation and behavioural approaches to pain management are commonly used in clinical practice. A recent study showed mood improvement during relaxation training among HIV-seropositive men (Cruess et al., 2000).

**Other Psychotherapies**

**Level of Evidence - I**

Interpersonal psychotherapy (IPT) has been studied in HIV/AIDS with positive benefits for depressed individuals (Markowitz et al., 1992; Markowitz et al., 1995; Markowitz et al., 1998). Women treated with IPT were described in the 1998 study and in a single case report by Swartz et al. (1997).

**Social Support**

**Level of Evidence - III**

Social support has been an integral part of much of the work on behavioural adaptation to HIV/AIDS. There has been little systematic study of social support. In a study comparing interpersonal therapy with supportive therapy, the former was found to be more effective in relieving symptoms of depression (Markowitz et al., 1995), although this is not surprising. Social support can be offered through various means, as is demonstrated by Siegel et al. (1999) in their study on the impact of pet ownership on AIDS-associated depression. The results of the study showed that males with AIDS who owned pets reported less depression than those who did not own pets. Furthermore, in an interview study of gay men with AIDS, pets were reported to reduce feelings of isolation and alienation, provide affection and nurturing, reduce stress, allow owners to feel valued and needed, and are a constant presence emotionally and physically (Carmack, 1991). Although these findings need to be replicated with women subjects, enhancing social support through pet ownership may be therapeutic for HIV-infected women.
Exercise
Level of Evidence - III
Exercise has received limited study. There is new interest in its potential to treat the loss of skeletal muscle mass that is a common feature of HIV infection. Resistance training may attenuate or arrest this loss (Evans et al., 1998). It may also be helpful in lowering the hypertriglyceridemia associated with antiviral therapy (Yarasheski et al., 2001). Individual exercise prescriptions are important (O’Dell et al., 1996). There is some evidence that intense exercise may be contraindicated in individuals with full-blown AIDS (Shephard, 1998). There has been a call for large scale, randomized, controlled trials of exercise in HIV to assess its impact not only on cardiopulmonary fitness but broader aspects of QoL (Shephard, 1998).

Nutrition
Level of Evidence - III
Anorexia is a common problem in HIV infection and occurs via several mechanisms (e.g., local pathology in the oral cavity or esophagus; central nervous system disease affecting perception of hunger and eating mechanics; and non-medical factors such as psychosocial problems, poverty, and isolation) (Kotler, 1998). The lipodystrophy wasting syndrome associated with anti-retroviral therapy has further spurred interest in nutritional interventions to optimize QoL.

Mind-Body Approaches
Level of Evidence - IV
A wide variety of mind-body interventions are used by HIV patients (Ozsoy & Ernst, 1999; Sparber et al., 2000) but they have not been systematically studied (Ozsoy & Ernst, 1999). There has been little attention to sex and gender differences in mind-body interventions. Biggar et al. (1999) examined the role of religious activity in psychosocial adjustment in inner-city African American women. Half of the participants were HIV-infected and reported praying more but perceived prayer to be less effective in coping with chronic illness than their non-HIV infected counterparts. Results also indicated that the frequency of prayer predicted optimism about the future; however, religious activity was not related to current depressive symptoms. Although a direct correlation was not found between prayer and present psychological functioning, prayer was viewed as important to the HIV-infected women in this study. Furthermore, its role in psychosocial adjustment may be attributed to its ability to strengthen optimistic feelings about the future (Biggar et al., 1999). While several methodological limitations are noted by the primary investigators, this research provides a base for further study on the role of religion as a coping response for women with HIV/AIDS.

Interventions in Special Populations
Young Women
The increasing percentage of HIV/AIDS in young women was stated earlier in this report. The implication of this trend is magnified by the concern of pregnancy in HIV-infected women of childbearing age. Health Canada (2000d) reports a national prevalence rate of 3–4 pregnant women per 10,000 HIV-infected women and statistics further suggest that the risk of mother-to-child transmission is substantial. For example, by the end of 1999, 196 pediatric AIDS cases were reported and 78% were a result of perinatal transmission (Health Canada, 2000d). Comparative studies show that the prevalence of HIV/AIDS in women of childbearing age is less in Europe and North America than in developing countries (Ryder et al., 1999). However, although perinatal transmission may account for only a small proportion of the new cases of HIV infection in Western countries, the prognosis for these infants is terminal. Researchers recently conducted a prospective study examining 51 obstetrical and pediatric centers in the regions surrounding Paris, France. It was concluded that approximately one-third of the infants born to seropositive mothers will show markers of HIV-1 infection or of AIDS by 18 months of age, and that about one-fifth of this group will have died within the same time period (Blanche et al., 1989). Trends regarding the increased transmission of HIV from heterosexual activity in women are evident in both European and Western
countries, leading the investigators to further suggest that their results may be representative of women in Western countries (Blanche et al., 1989).

**Pregnant Women**

Recommendations from the European Collaborative Study (1992) assessing risk factors for mother-to-child transmission of HIV-1 suggested that HIV seropositive women considering pregnancy should be counseled on the basis of both laboratory and clinical findings. Certain immunological findings, such as a low T-cell count and the presence of p24-antigenaemia have shown to increase the risk of mother-to-child viral transmission of HIV (European Collaborative Study, 1992). In addition, preliminary findings suggest that HIV infection may be transmittable through breastmilk and that Caesarian deliveries may offer protection from mother-to-child transmission (European Collaborative Study, 1992). Further study is certainly warranted to determine the risks and protective interventions associated with childbirth and HIV-infected women.

Semba et al. (1994) have recommended nutritional intervention as a practical, inexpensive, and widely applicable measure to reduce rates of mother-to-child transmission of HIV-1. Recent research initiatives have examined the role of maternal Vitamin A deficiency in mother-to-child transmission of HIV-1. Pregnancy and HIV-infection are both risk factors for Vitamin A deficiency and one research team has found that Vitamin A deficiency increases the risk of mother-to-child transmission by a factor of three or four (Semba et al., 1994). Vitamin A is an essential nutrient that assists in maintaining the integrity of the immune system and mucosal linings. Its critical role in these physiological processes may help to explain the association between deficiency and increased mother-to-child transmission rates of HIV-1 (Semba et al., 1994.). Women at greatest risk for Vitamin A deficiency have diets of inadequate nutritional intake. For example, women in developing countries have a greater prevalence of Vitamin A deficiency than women in North America and Europe (Semba et al., 1994). Preventative research in western countries should assess Vitamin A levels in women who may be at risk for nutritional deficiencies such as women of low socioeconomic status, female athletes, and females with disordered eating patterns. Current studies have not addressed this potential area of research; however, it will be critical that such nutritional intervention studies consider other nutritional abnormalities that have been observed during HIV-infection, including vitamins A, E, B6, and B12, as well as riboflavin, copper, and zinc (Semba et al., 1994).

**Rural Women**

In a study examining HIV/AIDS related services for women in a rural community context, Castaneda (2000) discusses how contextual characteristics of rural communities affect the development of HIV/AIDS-related care and prevention services for women. Castaneda (2000) utilizes a social ecological perspective to highlight the importance of focusing on social environments to facilitate efficacious treatment interventions for women with HIV/AIDS in rural communities. Such research exemplifies the importance of targeting various subpopulations of women in order to clarify their unique experience of HIV/AIDS.

**Aboriginal Women**

Despite the greater risk of HIV/AIDS among Aboriginal women, little has been done in developing culturally sensitive interventions.

**Immigrant Women**

Despite the greater risk of HIV/AIDS among immigrant women, little has been done in developing culturally sensitive interventions.
Recommendations

1. Clinical Care
   • Behavioural interventions need to be integrated into routine clinical care for those women with HIV and AIDS who need or want them.

2. Health Care Professional Education
   • Health care professionals need to learn about the value of cognitive-behavioural approaches in the management of the pain, fatigue, and medication side-effects associated with HIV and AIDS.

3. Public Education
   • Educational materials need to be developed which address behavioural interventions that may facilitate adaptation to HIV and AIDS. These materials need to be produced in culturally and linguistically appropriate formats for Francophone, Aboriginal, and immigrant women. They should include cognitive-behavioural strategies to manage pain and fatigue, the role of exercise and nutrition, and strategies to deal with distressing thoughts related to the diagnosis.

4. Research
   • Develop appropriate and effective interventions for special populations including Francophone, Aboriginal, and immigrant women.
   • Research the value of mind-body approaches in terms of improvements in quality of life and psychological and psychosocial functioning. These interventions are increasingly being incorporated into programs but there is little evidence as to which of them may be most clinically effective and most cost-effective.
CHAPTER 9 MENTAL HEALTH

This chapter reviews the data on behavioural interventions in three psychiatric disorders—major depression, anxiety, and eating disorders. Recent guidelines have been published on major depression (Canadian Psychiatric Association & the Canadian Network for Mood and Anxiety Treatments, 2001) and anxiety disorders (Anxiety Review Panel of the Ontario Program for Optimal Therapeutics, 2000).

Major Depression

Major depression is characterized by a minimum of two weeks of either depressed mood or loss of interest or pleasure in usual activities and four of the following symptoms: significant weight loss when not dieting or weight gain; decrease or increase in appetite; insomnia or hypersomnia; psychomotor agitation or retardation; fatigue or loss of energy; feelings of worthlessness or excessive or inappropriate guilt; diminished ability to think, concentrate, or make decisions; recurrent thoughts of death, recurrent suicidal ideation, suicide attempt, or a specific plan for committing suicide (American Psychiatric Association, 2000). The symptoms usually cause significant distress or impairment in social, occupational, or other important areas of functioning. Major depression is one of the major mood disorders—the others are dysthymic disorder (chronic depression), depression not otherwise specified (including premenstrual dysphoric disorder, minor depressive disorder, recurrent brief depressive disorder) and depressive episodes in the context of a bipolar disorder.

Epidemiology

The lifetime prevalence of major depression in three Canadian studies varies from 8 – 8.5% with women experiencing rates approximately double that of men (see review in Parikh et al., 2001). The average age of onset ranges from the early 20s to the early 30s. It is increasingly recognized that major depression is most commonly a chronic/recurrent disease with relapses and recurrences across the life cycle (Parikh et al., 2001).

Impairment in Quality of Life & Psychosocial Morbidity

Major depression is associated with a marked impairment in quality of life (QoL). The World Health Organization has predicted that by 2020, major depression will be second only to ischemic heart disease as the leading cause of disability (Murray & Lopez, 1997). While mental health professionals have recognized the severe impact of major depression, the landmark Medical Outcomes Study brought the severity of depression to the attention of the wider health care community (Wells et al., 1989). Analysis of data from 11,242 outpatients documented that not only did individuals with major depression have worse physical, social, and role functioning; poorer perceived current health; and greater bodily pain than did patients with no chronic conditions, but the negative functioning associated with depressive symptoms was comparable with or worse than that associated with eight major medical conditions. These results have been replicated in other samples (Bonicatto et al., 2001; Wells & Sherbourne, 1999).

Sex & Gender Specific Issues

There has been an interest in understanding the basis for women’s greater risk for major depression and the ways in which depression in women and men differs in terms of presentation, diagnosis, and treatment (Endicott, 1998; Piccinelli & Wilkinson, 2000). Women appear to experience more chronicity with their depressions that may be related to differences in employment status, education, and marital status (Bracke, 2000). In a study of late-life depression, symptom patterns were similar in men and women (Sonnenberg et al., 2000). Constructs such as self-silencing have been proposed to account for women’s greater vulnerability to depression, but empirical work suggests that self-silencing is as likely to occur in men as in women (Duarte & Thompson, 1999). Preliminary evidence suggests that psychiatrists may be less likely to explore treatment preferences and sexual function and medication-related sexual side effects with women (Olfson et al., 2001).
Interventions Fostering Adaptation to Illness

Behavioural interventions are used not to foster adaptation to illness but rather to treat illness and lessen the likelihood of recurrence. The mainstay of the treatment of depression in the past twenty years has been medications but there is increasing interest in the role of the empirically validated psychotherapies - cognitive-behaviour therapy (CBT), interpersonal psychotherapy (IPT) and problem-solving therapy - and in the role of exercise. The recent clinical guidelines for the treatment of depressive disorders of the Canadian Psychiatric Association and the Canadian Network for Mood and Anxiety Treatments (2001) have reviewed both pharmacological and non-pharmacological treatments.

Education
Level of Evidence - II-1

There is increasing interest in the use of patient education and self-help learning materials in depression. A meta-analysis of six studies, some classified as educational and others as self-administered CBT, assessed the use of self-help books based in CBT and found positive benefits in mild-to-moderate depression (Cuijpers, 1997). Bibliotherapy has been recommended as a second-line treatment to be used as adjunct to first line treatments (Segal et al., 2001a). A self-administered educational and psychotherapy program showed benefit (Osgood-Hynes et al., 1998).

Multimodal/Integrative Programs
Level of Evidence - IV

No formalized multimodal/integrative programs have been described.

Stress Management
Level of Evidence - IV

Stress management has not been systematically studied as a single therapy in the management of major depression.

Cognitive–Behavioural Therapy
Level of Evidence - I

Research concerning the efficacy of CBT for major depression is quite extensive, and CBT is recommended as a first-line treatment for major depression in the mild-to-moderate range (Segal et al., 2001a). Questions remain as to how effective it is in more severe depression. There is stronger evidence for the use of these modalities in individual than group formats (Segal et al., 2001a).

There is also evidence for the value of self-help CBT, as noted earlier. Cuijpers (1997) conducted a meta-analysis to examine the efficacy of CBT self-help/bibliotherapy approaches and found that self-help CBT was associated with a significant improvement in comparison to waitlist control groups. There were no differences between the efficacy of self-help/bibliotherapy and individual or group therapy. Furthermore, the drop-out rates were comparable in all three treatment groups. However, this meta-analysis was based on only six studies. In an open trial, a self-administered psychotherapy for depression was delivered using a telephone-accessed computer system plus booklets in a sample involving patients from the U.S. and the U.K. and was found to be helpful for patients with mild-to-moderate depression (Osgood-Hynes et al., 1998). Two important issues in fostering optimal QoL in individuals with depressive disorders are the treatment of residual symptoms and relapse prevention. This is still a fairly new area of research. There is some evidence that adding CBT for patients with residual depressive symptoms after acute treatment with pharmacotherapy improves remission rates and reduces relapse/recurrence rates (Segal et al., 2001b). Relapse prevention may be improved through the use of CBT or modifications of CBT in individuals not receiving maintenance pharmacotherapy (Segal et al., 2001b). One example of an innovative modification of CBT has been the addition of mindfulness-based meditation in mindfulness-based cognitive therapy (MBCT) (Teasdale et al., 2000). This manual-based group intervention was designed to train recovered.
patients with recurrent depression to disengage from dysphoria-activated depressogenic thinking that may mediate relapse/recurrence. Meditation training facilitated treating thoughts and feelings as passing mind events instead of accurate perceptions of reality. A sample of patients (76% women) was randomized to regular treatment or regular treatment plus MBCT. The results showed that for patients with at least 3 previous depressive episodes (77% of sample) the addition of MBCT approximately halved the rates of relapse in the 60 week follow-up period. No such effect was noted for patients with two or less episodes. The authors strongly cautioned that MBCT is suitable only for recovered patients as preventive therapy and not for treatment of acute depression.

**Behavioural Approaches**  
**Level of Evidence - I**

Behaviour therapy for depression is based on observations that depressed patients have fewer positive reinforcers in their environment and thus therapy encourages them to increase activity levels and engage in behaviours that will increase pleasure and give them positive reinforcement and a sense of mastery (Segal et al., 2001a). Typically behavioural therapies are now incorporated into cognitive therapy and delivered as CBT. Segal et al. (2001a) reviewed the controlled studies on behaviour therapy that demonstrate its effectiveness in the short-term and are largely positive over six month follow-up.

**Other Psychotherapies**  
**Level of Evidence - I**

IPT for depression has been recommended as a first-line treatment in the Canadian guidelines for mild-to-moderate depression with a question as to whether it is as effective in severe depression (Segal et al., 2001a). There is some evidence from the National Institutes of Medical Health collaborative study that IPT may be superior to CBT in patients with more severe illness (Elkin et al., 1989). Marital therapy has been shown to be helpful in women with depression (Level of Evidence II-1). Segal et al. (2001a) reviewed the first of three comparative studies that showed that marital therapy was helpful when there was marital distress and concluded that it was a second line treatment.

**Social Support**  
**Level of Evidence - IV**

While both CBT and IPT encourage the use of social support, there have been few studies assessing social support as a single modality of therapy. A study of group CBT and mutual support group therapy for depression as conducted by professional and paraprofessional therapists (Bright et al., 1999) enrolled participants (71% women) (Bright et al., 1999). The CBT was based on the Feeling Good Seminar Series (Burns, 1999), whereas the mutual support group therapy included informal exchanges of information between individuals suffering from depression. Clinically significant improvement in symptoms was demonstrated for both approaches but at post-treatment, more patients in the professionally led CBT groups were classified as non-depressed or improved than in the nonprofessional groups.

**Exercise**  
**Level of Evidence - II-1**

There has been significant interest in the effect of exercise training on major depression with a recent review and meta-regression analysis (Lawlor & Hopker, 2001) as well as empirical studies (Babyak et al., 2000; Blumenthal et al., 1999; Dimeo et al., 2001). The work by Blumenthal’s group (Blumenthal et al., 1999; Babyak et al., 2000) showed that exercise training was a viable alternative to antidepressants in a sample of men and women over age 50 who were diagnosed with major depression. Although the antidepressants facilitated a more rapid initial clinical response than exercise, at 16 weeks exercise was as effective as antidepressants and improvement was maintained at 10 month follow-up. However, this was a group of volunteers willing to take part in an exercise study and, as Lawlor and Hopker (2001) have noted, there is a need for further good quality research in clinical populations.
Nutrition
Level of Evidence - IV
There have been few systematic studies on the role of nutrition.

Mind-Body Medicine
Level of Evidence - IV
There have been few systematic studies on the role of mind-body medicine.

Interventions in Special Populations

Children & Adolescents
The prevalence of depression in preadolescent children is 0.4 - 2.5% with an equal sex distribution. In adolescence, the prevalence increases to 5 - 10% and twice as many girls are affected as boys (Thorpe et al., 2001). A systematic review of CBT randomized controlled trials in 8 - 19 year olds supports its use in moderate depression (Harrington et al., 1998). Mufson et al. (1999) describe the evidence for IPT for depression in a controlled, clinical trial with adolescents. The recent Canadian clinical guidelines recommend CBT and IPT as first-line treatments for mild-to-moderate depression (Thorpe et al., 2001).

Pregnancy & Postpartum
There has been limited study of psychotherapy in pregnancy and the postpartum period. Depression occurs in approximately 10% of women during pregnancy and in 10 - 15% of postpartum women (Thorpe et al., 2001). There are studies suggesting the value of IPT in pregnancy and postpartum (O'Hara et al., 2000) and of CBT in the postpartum period (Appleby et al., 1989). A four session IPT based group intervention in pregnant women receiving public assistance who had at least one risk factor for postpartum depression prevented the occurrence of major depression in the first three months postpartum (Zlotnick et al., 2001). In contrast, educational intervention was ineffective (Hayes et al., 2001).

Menopause
This is a controversial and inadequately studied area (Thorpe et al., 2001).

The Elderly
It is estimated that one-sixth of individuals aged 65 and older suffer from clinically significant depressive symptoms and yet, despite efficacious treatment, only 12 - 25% of them receive treatment (Harman & Reynolds, 2000). There is a higher rate of relapse in this age group. There is less data on psychotherapeutic treatments as first-line treatments in the elderly compared to younger adults and inadequate evidence for IPT and CBT as second line treatments (Thorpe et al., 2001).

Aboriginal Women
Despite high prevalence rates (Abbey et al., 1993), there has been no systematic attention to non-pharmacological interventions.

Ethnoracial & Economic Adversity
Despite high prevalence rates, there has been no systematic attention to adapting non-pharmacological interventions to these special populations.

Anxiety Disorders
Anxiety may be a transient symptom or severe enough to constitute a disorder. The American Psychiatric Association DSM-IV-TR (2000) lists the following anxiety disorders: panic disorder, agoraphobia, specific phobia, social phobia, obsessive-compulsive disorder, post-traumatic stress disorder, acute stress disorder, generalized anxiety disorder, anxiety disorder due to a general medical condition, substance-induced anxiety disorder, and anxiety disorder not otherwise specified.

Epidemiology
Lifetime prevalence rates for each of the disorders have been reported as follows: panic disorder 1 - 3.5%; specific phobia 7 - 11%; social phobia 3 - 13%; obsessive-compulsive disorder 2.5%; post-traumatic stress disorder 8%; acute stress disorder 14 - 33% of those exposed to severe trauma; generalized anxiety disorder 5% (American Psychiatric Association, 2000).

Impairment in Quality of Life & Psychosocial Morbidity
QoL indices have only recently been used in anxiety disorders. Two recent reviews (Mendelowicz & Stein, 2000; Mogotsi et al., 2000) document that anxiety...
disorders markedly compromise QoL and psychosocial functioning in multiple domains. For example, in panic disorder, scores were significantly below population norms on all SF-36 subscales and scores on mental health and role-functioning were significantly worse than those in patients with a medical disorder and comparable to those in depression (Mogotsi et al., 2000). Panic disorder and post-traumatic stress disorder appear to be the most disruptive to QoL (Mendlowicz & Stein, 2000).

Sex & Gender Differences

There is some variation in the number of women versus men with the disorders. Disorders diagnosed more frequently in women include panic disorder (2–3:1), specific phobia (2:1), and generalized anxiety disorder (1.5:1). Equal numbers of men and women are seen with obsessive compulsive disorder (although in the childhood-onset variety boys predominate). In social phobia, more women are identified in community samples but equal numbers of men and women seek treatment. Information on post-traumatic stress disorder and acute stress disorder is less available and confounded by potential ascertainment biases. There has been little attention to the issue of sex and gender differences.

Interventions Fostering Adaptation to Illness

Behavioural interventions to foster adaptation to anxiety disorders in primary care have recently been reviewed by the Anxiety Review Panel of the Ontario Program for Optimal Therapeutics (2000) and recommendations have been made about including behavioural interventions in the standard care of individuals with anxiety seeking treatment in primary care. The guidelines consider the general treatment of anxiety as well as the specific diagnoses.

Education: The guidelines describe patient education as the first step. They detail the information individuals should receive including general information about anxiety and approaches to its management, lifestyle advice (e.g., decreasing caffeine use, regular aerobic exercise), and non-drug strategies including relaxation and breathing retraining exercises (e.g., slowing breath, diaphragmatic breathing). They also recommend referral where appropriate to community resources and supportive counseling which they describe as particularly helpful for chronic stress and particular life situations.

Self-Management: Self-management involves the use of books, manuals, and websites which provide the individual with an approach to managing their anxiety. The guidelines provide an extensive list of such resources including a consumer and self-help reading list, video resources, and internet resources.

Therapist Assisted Cognitive-Behaviour Therapy: The guidelines provide an overview of CBT and its use in the management of anxiety disorders. They outline patient factors that may favour CBT over pharmacotherapy and describe indications for referral. The guidelines include a glossary of CBT terminology and a list of practical treatment manuals for clinicians.

Interventions in Special Populations

There has been little systematic attention to non-pharmacological interventions in special populations.

Eating Disorders

Anorexia nervosa (AN) and bulimia nervosa (BN) are typically chronic disorders that are associated with significant impairment in quality of life.

Anorexia Nervosa

AN is defined in DSM-IV as a disorder characterized by the refusal to maintain body weight at or above a minimally normal weight for age and height and an intense fear of gaining weight or becoming fat, despite being underweight. Individuals with AN have a disturbance in the way in which their body weight or shape is experienced, experience an undue influence of their body weight on self-evaluation, or deny the seriousness of their body weight. AN is associated with amenorrhea, the absence of at least three consecutive menstrual cycles (American Psychiatric Association, 2000). AN is further subdivided into a restricting type and a binge-eating/purging type in which the person has regularly engaged in binge-eating purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
Epidemiology
The incidence of AN has increased in the past thirty years from approximately 3/100,000 to 17/100,000 with a current prevalence of 115/100,000 (Halmi, 1999). Males account for 4 – 6% of the anorexic population.

Impairment in Quality of Life & Psychosocial Morbidity
The course of anorexia varies from a single episode which ends in weight stabilization and psychological recovery to a relapsing course and at the most extreme end to death (Halmi, 1999). AN is associated with marked impairments in QoL although the use of formal assessments of QoL in this population are just beginning. Medical complications are common, secondary to the starvation state or purging behaviour in those with the purging subtype. Weakness, lethargy, and easy fatigability are common. Thoughts are dominated by fears of gaining weight and irrational worry about fatness. Most anorexics experience difficulties in physical functioning, meeting physical roles, and some experience pain related to secondary bone disease and emaciation. Social roles are disrupted and relationships are impaired.

Sex & Gender Specific Issues
AN occurs much more commonly in women, with men representing less than 10% of eating disorder cases (Andersen & Holman, 1997). Males reach a significantly higher BMI than women before they begin dieting. Interventions for males require attention to their past and future sexual role and preparation for return to male social roles. There has been less study of the effectiveness of antidepressants in men with eating disorders. Outcome with intensive treatment appears to be comparable with outcome in women.

Interventions Fostering Adaptation to Illness
Interventions may be directed to treating active symptomatology, maintaining gains made during such treatment, and preventing relapse. The literature on behavioural interventions remains small, and the results of many existing studies are limited by small sample sizes and, in many cases, high attrition rates.

Education
Level of Evidence - III
Education is often coupled with self-help in the eating disorder literature. It has been described as the first step in a “stepped care” approach. In AN, it is only suitable as a single intervention for mild cases. Individuals with moderate or severe symptomatology require individualized treatment and hospitalization in the case of emaciation, physical complications, suicide risk, or unresponsiveness to psychological treatment (Garner & Needleman, 1997). Education includes an introduction to the multiple causes of eating disorders; the cultural context of eating disorders; set-point theory and the physiological regulation of body weight; the effects of starvation on the brain and behaviour; the importance of restoring regular eating patterns; the determination of a healthy body weight; and the impact of vomiting, laxatives, and diuretics (Garner, 1997). Rock and Currna-Celentano (1996) argued that all treatment programs need to address the nutritionally depleted state of clients as semistarvation impairs cognitive functioning as well as the ability to focus on psychological, familial, and other issues. Refeeding protocols for individuals with AN have the goal of a slow but steady increase in weight. Individuals with AN are taught to develop specific meal plans to promote normalization of food intake. A new approach to food choices based on nutrient contributions, not energy intake (i.e., calorie count), is taught while formerly forbidden foods are introduced with reassurance. A diet with adequate dietary calcium and a low dose of multiple vitamins is emphasized, while strategies to reduce energy intake and manage hunger (e.g., overuse of caffeine drinks, chewing gum) are discouraged.

Multimodal/Integrative
Level of Evidence - II-1
Multimodal interventions are common for AN. They bring together medical management (weight restoration, rehydration, and stabilization of electrolytes), nutrition counseling, behaviour therapy (positive reinforcement for weight gain and response prevention for binge eating and purging), cognitive therapy, family therapy, pharmacotherapy in some cases, and self-monitoring. Self-monitoring includes
the use of a daily food record that provides a visual representation of dieting strategies (skipping meals, avoiding forbidden foods, and excessive restrictions on overall amount of food consumed). However, it is not a perfect technique. Wilson and Vitousek (1999) have noted that AN patients are prone to inflating reported serving sizes or caloric intake. Their aims may include convincing the therapist of their compliance with the meal plan or proving that they are given much more food that they can possibly consume. Self-monitoring may be expanded to include other symptomatology such as excessive body checking and excessive exercising. Strategies for promoting compliance include establishing a strong therapeutic alliance, allowing patients to play an active role in treatment, regular assessment and reinforcement of progress in homework assignments, and reassurance in case of setbacks (Wilson & Vitousek, 1999).

Depending upon the individual’s clinical status, these interventions may be delivered in an inpatient or outpatient setting. Severe emaciation, physical complications, suicidality, and failure in outpatient settings all mandate inpatient interventions.

**Stress Management**

**Level of Evidence - IV**

There are no studies of stress management as a unimodal intervention in AN.

**Cognitive-Behavioural Approaches**

**Level of Evidence - IV**

A cognitive-behavioural model for the treatment of AN rests on two core assumptions (Kleifield et al., 1996). First, anorexia is assumed to develop as a coping strategy for distressing life events. The preoccupation with food allows the individual to ignore whatever fear, anxiety, or depression was triggered by the distressing life events, while successful dietary restraint prompts feelings of confidence and control. Second, food restriction and avoidance become habitual patterns and are maintained independent of events that provoked them. According to Fairburn et al. (1999), in Western societies, the tendency to judge self-worth in terms of shape and weight is also present in AN. However, despite this theoretical framework, research into CBT for anorexia is scarce. Unlike interventions for BN and binge eating disorder, there is no agreed upon treatment manual for AN. Existing research into the efficacy of CBT for AN has mostly concentrated on comparing it with other therapies or describing case reports or case series. A study by Ball (1998, as cited in Wilson, 1999) compared individual outpatient CBT with behavioural family therapy and found no difference in outcome at six-month follow-up.

**Behavioural Approaches**

**Level of Evidence - III**

Behavioural treatment to promote weight gain in AN is well accepted and forms an integral part on inpatient treatment (Touyz & Beumont, 1997). It is targeted towards weight gain because it is only with treatment of the starvation effects that the individual can begin to think clearly enough to benefit from other therapies. Operant conditioning principles are used in the form of rewards for achieving desired behavioural or weight gain goals or negative consequences such as bed rest or the removal of other privileges when goals are not achieved. Response prevention for binge eating and purging may also be used. Touzy and Beumont (1997) emphasize the value of “lenient” and flexible rather than harsh approaches. The target behaviours may include weight goals, exercise restriction goals, weight maintenance, and excessive communication regarding food. Rewards and punishments are individualized so that they are salient to the individual.

**Other Psychotherapies**

**Level of Evidence - IV**

Unlike cognitive-behavioural approaches that focus primarily on individual symptoms of AN, interpersonal therapy focuses on social functioning in one of four problem areas (interpersonal disputes, role transitions, abnormal grief, or interpersonal deficits). McIntosh et al. (2000) discussed research findings that suggest families of individuals with AN exhibit
problematic communication patterns. However, it is not clear whether high family distress is a cause or consequence of AN. Also, studies suggest that the detrimental effects of AN on interpersonal functioning extend outside the family. Both sexual interest and activity have been demonstrated to decline with weight loss. Unfortunately, the efficacy and effectiveness of IPT as treatment for AN is unknown as few clinical trials have been conducted.

An alternative approach to psychotherapy for eating disorders was proposed by de Groot and Rodin (1998). Based on psychodynamic interpretation, the authors proposed that relative unresponsiveness to a child’s subjective experience and to child-initiated cues contribute to development of eating disorders in adult women. Overt eating disorder symptoms such as binge eating, purging, and starvation act as psychic organizers for these patients. Dynamic therapy first concentrates on patients’ bodily concerns and moves on to an emphasis on emotional states. The therapy emphasizes attending to subjective experience in a relational context and enhancing emotional awareness. To facilitate this, the therapist maintains a sustained curious or empathic inquiry. However, the authors note that only a subset of women with eating disorders may respond to this treatment, such as those who possess psychological mindedness, a capacity for impulse control, and motivation for insight. This approach has not been systematically evaluated.

**Exercise**

**Level of Evidence - IV**

Exercise, and in particular excessive exercise, was seen as a secondary symptom in anorexia until Davis et al. (1994) showed that for over 60% of anorexic women, sport and exercise was an integral part of the pathogenesis and progression of their illness. An interesting pilot study has looked at the use of graded exercise in improving QoL outcomes over three months (Thien et al., 2000). The exercise did improve QoL, although not to a statistically significant degree, and it did not produce a change in BMI or percent body fat.

**Nutrition**

**Level of Evidence - III**

An understanding of adequate nutrition, normalization of eating behaviour, and addressing fears around particular foods is key to successful outcomes (Beumont et al., 1997). Nutritional counseling may be helpful in improving nutritional status, assisting individuals to establish normal eating behaviours, promoting a “normal” attitude to food, and helping to develop appropriate responses to hunger and satiety cues. There are few studies of how to best operationalize these themes.

**Mind-Body Approaches**

**Level of Evidence - IV**

While some patients and families turn to mind-body interventions, there are no systematic evaluations of their use in AN.

**Bulimia Nervosa**

The DSM-IV-TR defines BN as recurrent episodes of binge eating (American Psychiatric Association, 2000). An episode of binge eating is characterized by both eating in a discrete period of time an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances, and a sense of lack of control over eating during the episode. In BN there are recurrent, inappropriate compensatory behaviours in order to prevent weight gain such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting; and/or excessive exercise. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for three months. Self-evaluation is unduly influenced by body shape and weight. BN does not occur only during episodes of AN. BN can be subtyped into purging type (e.g., self-induced vomiting, misuse of laxatives, diuretics, or enemas) or non-purging type (e.g., other compensatory behaviours such as excessive exercise or fasting).
Epidemiology
Prevalence rates of BN have been estimated to be 0.17 – 4% (Halmi, 1999). Males constitute 10 – 15% of the BN population.

Impairment in Quality of Life & Psychosocial Morbidity
Formal assessment of QoL is just beginning in BN. Clinical experience documents significant impairments. Medical complications because of electrolyte and metabolic abnormalities include weakness, lethargy, and parotid gland enlargement, as well as complications secondary to binge eating and recurrent vomiting, including acute dilatation of the stomach and esophageal tears. Depressive symptoms are common. Interpersonal relationships are often troubled and there are problems with self-concept, self-esteem, and impulsive behaviours. Rates of alcohol abuse are elevated.

Sex & Gender Specific Issues
Sex and gender differences have received relatively little attention. BN is primarily a women’s health problem.

Interventions Fostering Adaptation to Illness
Interventions may be directed to treating active symptomatology, maintaining gains made during such treatment and in preventing relapse. The use of a “stepped care” or sequenced approach to interventions has received considerable attention (Garner & Needleman, 1997) as many individuals respond to less intensive and less costly treatments. BN can usually be treated on an outpatient basis. Interventions for the self-management of BN are particularly important given that less than 10% of sufferers receive treatment (Hay & Bacaltchuk, 2001).

Education
Level of Evidence – II-1
As described in the AN section, education is often coupled with self-help in the eating disorder literature. It has been described as the first step in a “stepped care” approach. Education and self-help is more commonly used in BN than in AN. As in the use of education in AN, education in BN includes an introduction to the multiple causes of eating disorders; the cultural context of eating disorders; set-point theory and the physiological regulation of body weight; the effects of starvation on the brain and behaviour; the importance of restoring regular eating patterns; the determination of a healthy body weight; and the impact of vomiting, laxatives and diuretics (Garner, 1997). Self-help appears to be sufficient for some individuals with BN (Fairburn & Carter, 1997) while others benefit from guided self-help with a non-specialist primary care practitioner (Waller et al., 1996). Fairburn and Carter (1997) describe guided self-help as an alternative to brief CBT.

Multimodal/Integrative
Level of Evidence – II-1
Multimodal interventions are used in severe BN or moderate BN that has not responded to treatment (Garner & Needleman, 1997). Interventions may be offered in ambulatory or inpatient settings and include nutritional counseling, cognitive therapy, education, and at times pharmacotherapy (Halmi, 1999).

Stress Management
Level of Evidence – IV
There are no studies of stress management as a unimodal intervention in BN.

Cognitive-Behavioural Approaches
Level of Evidence – I
The use of cognitive therapy in BN was evaluated in a Cochrane Systematic Review by Hay and Bacaltchuk (2001) and its efficacy was supported in both reducing bulimic symptom severity and depressive symptom severity. They note, “While there is good evidence from controlled studies that cognitive-behavioural therapy (CBT), as described by Fairburn and Cooper, is an effective approach in bulimia nervosa, it has been recognised that for some patients it is unnecessarily intensive, and for others it is not sufficient”. CBT of eating disorders was first
manualized by Fairburn in 1981. A plethora of studies have followed (see Wilson et al., 1997 and Hay & Bacaltchuk, 2001 for reviews). CBT has three stages. The first stage involves focusing on behaviour change through establishing a sound therapeutic relationship, educating the individual about the cognitive approach to BN, establishing regular weighing, increasing knowledge about BN, and reducing the frequency of overeating by introducing a pattern of regular eating and alternative behaviours in response to the impulse to overeat. The second stage focuses on reducing dietary restraint and developing cognitive and behavioral coping skills to resist binge eating. The third stage focuses on relapse prevention strategies (Wilson et al., 1997).

**Behavioural Approaches**

**Level of Evidence - III**

Behavioural approaches, such as exposure and response prevention, do not appear to enhance the efficacy of CBT. Response prevention is used in inpatient settings.

**Other Psychotherapies**

**Level of Evidence - II-I**

Other psychotherapies are also efficacious in BN (Hay & Bacaltchuk, 2001). The question of whether CBT is superior to the other psychotherapies is unanswered. Hay and Bacaltchuk (2001) note that the other therapies are as efficacious as CBT compared to the waiting list control group for end of treatment scores on bulimic symptom severity and abstinence rates. In a trial comparing CBT, IPT, and a control group, CBT was superior at the end of treatment. However, its advantage did not hold at one-year follow-up, by which time IPT subjects had improved to the level of those in CBT (Agras et al., 2000). Agras et al. (2000) have argued that CBT should be considered first because it more rapidly engenders improvement. Self-help and guided self-help as described in the education section have also been considered as “other psychotherapies” and recommended (Hay & Bacaltchuk, 2001).

**Exercise**

**Level of Evidence - III**

There has been no research in this area but expert opinion is to encourage moderate activity as part of a healthy lifestyle (Beaumont et al., 1997).

**Nutrition**

**Level of Evidence - III**

There are many similarities with nutritional approaches to AN. The target of intervention in BN is the chaotic eating. Education focuses on understanding that the episodic gorging is largely a response to restricted eating. As with AN, there is a need for an understanding of adequate nutrition, normalization of eating behaviour and addressing fears around particular foods (Beaumont et al., 1997). Nutritional counseling may be helpful in improving nutritional status, assisting individuals to establish normal eating behaviours, promoting a “normal” attitude to food, and helping to develop appropriate responses to hunger and satiety cues. There are few studies as to how to best operationalize these themes.

**Mind-Body Approaches**

**Level of Evidence - IV**

While some patients and families turn to mind-body approaches, there are no systematic evaluations of their use in bulimia nervosa.

**Interventions in Special Populations**

**Children**

Eating disorders in prepubertal girls are particularly problematic and are associated with a “more complex pathogenesis” and a more severe course (Lask & Bryant-Waugh, 1997). Management is similar to that in adolescents and adults.
Children & Adolescents with Diabetes Mellitus
Young women with diabetes may be at increased risk of developing eating disorders (Rodin & Daneman, 1992) and may experience greater complications secondary to their diabetes because of their disordered eating (Rydall et al., 1997). There is a need for further research and for the development of interventions targeted to their special needs.

Pregnancy
The literature on interventions in pregnant women with eating disorders is limited and common sense recommendations include involving a high risk obstetrician, encouraging an emotional attachment with the fetus in order to promote optimal nutrition, and increasing support (Powers, 1997).

Recommendations

1. Clinical Care
   - There needs to be greater availability of cognitive-behavioural and self-management therapies for a wide range of mental health problems.
   - There needs to be greater availability of interpersonal psychotherapy for depression and bulimia nervosa.

2. Health Care Professional Education
   - Knowledge translation is essential. Education about cognitive-behavioural therapies needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula. There needs to be a focus on both brief and more complex interventions. Education about interpersonal psychotherapy needs to be included in all three curricula.
   - Education about eating disorders needs to be directed to primary health care providers.
   - Education about self-help strategies and available resources needs to be included in continuing professional development events for primary care and mental health practitioners.

3. Public Education
   - The public needs to be informed about non-pharmacological interventions for mental health problems as well as the advantages and disadvantages of pharmacologic therapy for women.
   - Information about self-help strategies needs to be more widely disseminated.
   - Educational materials need to be developed and modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
   - There needs to be greater research in “stepped care” approaches to depression and anxiety
   - Mindfulness-meditation coupled with cognitive-behavioural therapy appears to be a fruitful area for further research.
   - Innovative cost-effective strategies to prevent or decrease the burden of postpartum depression need to be evaluated.
**Chapter 10 Pelvic Pain**

Chronic pelvic pain (CPP) is a common condition among women. Kames et al. (1990) note that there has been little recognition of the need for, or appropriateness of, pain management treatment of CPP, despite the fact that it is one of the most common presenting complaints in general gynecological practice.

Despite its relatively high prevalence, CPP is poorly understood. The pain of CPP may be intermittent or continuous and is often unrelated to underlying gynecological pathology (Kames et al., 1990). In at least two thirds of women with CPP, there is no identifiable pathology (Fry et al., 1997). There is little relationship between pain severity and the degree of identifiable pathology.

Savidge and Slade (1997) have written: “Whereas in other areas of chronic pain research, broader based, multidimensional views of pain have been adopted, biomedical perspectives have dominated thinking and research within this area, producing findings which are limited in scope. The narrow research focus in the area of CPP has left a multitude of unanswered questions and it remains a challenge to researchers to begin to understand the psychological factors and models involved in CPP.”

**Epidemiology**

CPP represents 2% to 10% of outpatient gynecological referrals. Stones et al. (2000) report that approximately 15% of women aged 18 to 50 years are affected by CPP.

Cross-sectional studies have revealed that 30% to 60% of women experience dysmenorrhea, and 7% to 15% experience severe pain. The prevalence of dysmenorrhea among young women aged 17 to 24 years has been reported to be somewhat higher than older women, at 67% to 72% (Harlow & Park, 1996).

Dyspareunia is genital pain experienced just before, during, or after sexual intercourse. It is a chronic problem that may last many years or a lifetime. Although it is present in both sexes, it is far more prevalent among women. Mena et al. (1999) report that it occurs in approximately 10% to 15% of women in the general population. Conditions that may cause dyspareunia include vulvodynia, vulvar vestibulitis (a subset of vulvodynia), vaginismus, atrophic tissue or impaired lubrication, endometriosis and pelvic adhesions, adnexal pathology, retroverted uterus, pelvic relaxation, uterine fibroids, chronic cervicitis, pelvic congestion, urethral disorders, cystitis, and interstitial cystitis (Heilm, 2001).

The treatment of CPP is controversial and surgical and medical interventions often have a low success rate (Kames et al., 1990). Orthodox medical treatment includes hormonal manipulations and non-steroidal anti-inflammatory (NSAIDs). Surgical treatment may include the removal of endometrial implants, presacral neurectomy, lysis of adhesions, and hysterectomy (Kames et al., 1990).

Some research has shown a higher incidence of previous sexual abuse among women with CPP compared to women who experience either no pain or chronic non-pelvic pain (Collett et al., 1998).

**Impairment in Quality of Life & Psychosocial Morbidity**

Stones et al. (2000) report on a study that looking at the high degree of psychosocial morbidity associated with CPP. Using the British version of the SF-36 Health Survey Questionnaire, women were assessed on emotional, social, pain, energy, and psychological subscales in order to compare CPP patients with patients who had other illnesses. Compared to women with non-insulin dependent diabetes, hypertension, congestive heart failure, and clinical depression, only patients with clinical depression scored lower than CPP patients on all subscales except bodily pain.

Rannestad et al. (2000) conducted a study in which quality of life (QoL), pain, and psychological well-being were evaluated in women with benign gynecological disorders undergoing hysterectomy. Compared to controls, women with benign gynecological disorders scored significantly lower in the health/functioning subscale of the QoL Index. Included in this subscale are the following items: own health, healthcare, pain, energy, physical
independence, sense of control over one's own life, wish for a long life, sex life, responsibilities, usefulness to others, stress, leisure activities, travel, and retirement. Analysis of the data revealed that as pain increased, QoL decreased correspondingly.

Meana et al. (1999) report that women with dyspareunia who attribute their pain to psychosocial factors report higher levels of pain and psychological distress, lower levels of marital adjustment, and more problems with sexual function.

**Sex & Gender Specific Issues**

Chronic pelvic pain is also an issue in men with chronic prostatodynia, chronic orchialgia, and interstitial cystitis but there has been even less attention paid to these disorders than to CPP in women.

**Interventions Fostering Adaptation to Illness**

Behavioural interventions have received little study in CPP until recently. The focus has been on a biomedical and surgical perspective despite the lack of success of these approaches in CPP.

**Education**

**Level of Evidence - IV**

There is no discussion in the literature of educational interventions for CPP.

**Multimodal/Integrative Programs**

**Level of Evidence - III-I**

Kames et al. (1990) describe the effectiveness of an interdisciplinary pain management program for the treatment of CPP. The program was based on a model that views pain as a complex and multifaceted problem that requires both somatic and psychological interventions. The program comprised an initial evaluation, followed by treatment and six-month follow-up. Evaluation of subjects entailed the administration of questionnaires to assess psychological and pain parameters, an interview with and without the subject's significant others, a physical examination, and a differential epidural block to determine which neural elements were involved in each subject's pain experience. The six-to-eight-week treatment was structured but not uniform for each subject. All subjects received acupuncture twice per week and psychological therapy once a week. The psychological therapy included stress management, relaxation, hypnosis, anxiety and depression control, activity management, sex education, and cognitive therapy. Approximately half of the subjects received tricyclic antidepressants, approximately one third received NSAIDs, and narcotics for all subjects were decreased until they were eliminated. There were significant differences between subjects in the treatment and control groups. For the subjects who completed the treatment program, pain improvement was reported by 67% at post-treatment and by 65% at six-month follow-up. The percentage of unemployed subjects decreased from 45% at pre-treatment to 38% at post-treatment and 29% at six-month follow-up. An improved social life was reported by 44% of treated subjects at post-treatment and 65% at six-month follow-up. An improved sex life was noted by 27% of the treated subjects at post-treatment and 79% at six-month follow-up. Limitations of the study included a small sample size, the nature of the control group, and the non-random allocation to treatment. The control group comprised eight individuals, six of whom were also later patients in the treatment group. Women in the control group, were assessed after a two-month waiting list period, prior to the initiation of any treatment.

**Stress Management**

**Level of Evidence - IV**

There has been no systematic study of stress management in adaptation to CPP.

**Cognitive-Behavioural Approaches**

**Level of Evidence - IV**

Albert (1999) reports on a study in which group treatment for women suffering from CPP was evaluated over a period of ten weeks. The treatment was based on “psychosomatic psychotherapeutic principles” and “cognitive and operant behavioural therapy”. Each group participated in a 2.5 hour session. The first hour of each session included physical activities such as strength and conditioning training exercises for the pelvis, pelvic floor exercises, self relaxation, visualization, exercises to vent
aggression, exercises to build confidence, and body massage. The remaining 1.5 hours was devoted to group conversation. The participants also completed questionnaires and pain drawings four times over the course of the treatment. Participants experienced a significant decrease in average level of pain and intake of analgesics. Self-reported benefits included enhanced self-knowledge, self-responsibility, self-activeness, and self-control. One year following the end of treatment, 39% of the women were pain-free.

**Behavioural Approaches**

**Level of Evidence - III-I**

Bergeron et al. (2001) conducted a study in which women with dyspareunia caused by vulvar vestibulitis were randomly assigned to receive either 12 weeks of group CBT, 12 weeks of surface electromyographic (sEMG) biofeedback, or vestibulectomy. This was the first randomized trial to evaluate treatment for vulvar vestibulitis (Bergeron et al., 2001). The CBT employed in the study was delivered in a group setting over a two-hour period with seven to eight women per group. It included education about vulvar vestibulitis, the effects of dyspareunia on sexual desire, sexual anatomy, and a multifactorial view of pain; progressive muscle relaxation; abdominal breathing; Kegel exercises; vaginal dilatation; distraction techniques that focused on sexual imagery; rehearsal of coping self-statements; communication skills training; and cognitive restructuring. The sEMG biofeedback training was administered in eight 45-minute sessions over the 12 weeks. As well, subjects were provided with portable equipment for daily home practice. The goal of sEMG biofeedback was to decrease the instability and hypertonicity of the pelvic floor muscles. Subjects in all treatment groups experienced significant decreases in pain at post-treatment and at six-month follow-up, although the decrease was significantly greater among subjects in the vestibulectomy group. The researchers note that the results indicating the superiority of vestibulectomy must be interpreted with caution because seven subjects assigned to this intervention did not have the surgery.

Biofeedback can be used to strengthen the pelvic floor, facilitate relaxation and decrease resting tone of the pelvic floor, and enhance coordination of the pelvic muscles.

**Other Psychotherapies**

**Level of Evidence - IV**

There has been no systematic study of other psychotherapies in facilitating adaptation to pelvic pain.

**Social Support**

**Level of Evidence - IV**

There has been no systematic study of social support in facilitating adaptation to pelvic pain.

**Exercise**

**Level of Evidence - IV**

Locke and Warren (1999) reviewed that the evidence regarding the effect of exercise on dysmenorrhea and found it to be mixed.

**Nutrition**

**Level of Evidence - IV**

The only nutrition intervention reported in the literature is for a vegetarian diet which increases the serum concentration of sex-hormone binding globulin, which in turn binds with and inactivates estrogens. Barnard et al. (2000) carried out a crossover design study in which women ate a low-fat vegetarian diet for two menstrual cycles. For two additional menstrual cycles, they ate their usual diet and took a supplement placebo pill. Results revealed that the vegetarian diet was associated with a 19% increase in serum sex-hormone binding globulin concentration. Mean duration of dysmenorrhea decreased significantly from baseline to the vegetarian diet phase (from 3.9 ± 1.7 days to 2.7 ± 1.9 days) compared with the changed from baseline to the supplement phase (3.6 ± 1.7 days). Pain intensity also decreased significantly from baseline to the vegetarian diet phase. As well, mean body weight was lower during the vegetarian diet phase, 66.1 ± 11.3 kg versus 67.9 ± 12.1 kg.
Mind-Body Approaches
Level of Evidence - IV

There have been no systematic studies of pelvic pain.

Interventions in Special Populations
There has been no attention to issues of age, ethnicity, or sexual orientation in the intervention literature.

Recommendations

1. Clinical Care
   - Chronic Pelvic Pain (CPP) requires a comprehensive assessment including access to mental health care professionals.
   - Behavioural interventions need to be integrated into routine clinical care for those women who need or want them.

2. Health Care Professional Education
   - Education about CPP and the potential value of behavioural interventions needs to be communicated to both primary care practitioners and those health care providers in specialty settings.

3. Public Education
   - Education materials need to be developed that address basic aspects of CPP and these need to be modified to be linguistically and culturally appropriate for Francophone, immigrant, and Aboriginal women.

4. Research
   - Further research needs to be undertaken on CPP and the range of behavioural interventions that may be helpful in coping with the symptoms.
   - Research needs to be done into the value of a “stepped care” approach with CPP and the most cost-effective way of assisting individuals coping with it.
Respiratory disorders are associated with alterations in lung function which lead to impairments in multiple aspects of quality of life (QoL). This chapter will review what is known about behavioural interventions to improve adjustment to asthma and chronic obstructive pulmonary disease (COPD).

Asthma
Asthma is characterized by narrowing of the airways in response to a variety of stimuli coupled with varying degrees of airway inflammation. The airway obstruction associated with asthma varies widely over time and can change within a period of minutes.

Epidemiology
The prevalence of asthma is approximately 5%, which is a 75% increase from 1982 (Staton & Ingram, 2000). The incidence of asthma is highest in children under the age of five. In people over the age of 40 who first present with asthma, approximately 50% are cigarette smokers. While complete remission of asthma may occur in up to 25% of adolescents, it is much less common among adults. Severe asthma attacks can end in death and in the US the annual mortality rate is 0.5/100,000 (Staton & Ingram, 2000).

Impairment in Quality of Life & Psychosocial Morbidity
Gender and psychosocial morbidity secondary to asthma has received little attention. Women with asthma have been reported to have lower QoL as measured by the Medical Outcome Study (MOS) SF-36 questionnaire (Bousquet et al., 1994). In a study of individuals with asthma in a large health maintenance organization, women were found to report more daytime and nocturnal symptoms than men and worse QoL as assessed by the MOS SF-36 on physical functioning, social functioning, and bodily pain (Osborne et al., 1998). These differences in QoL were found in both younger (age 15 – 34) and older (age 35-55) age groups. Women in this sample were more likely to use health care services and medications. One study found lower rates of psychological distress but increased rates of health care utilization in women with asthma compared to men and that the perception of health status in asthmatic women was negatively influenced by their partners’ psychological distress, whereas such a relationship did not hold for male asthmatics (Afari & Schmaling, 2000).

Sex & Gender Specific Issues
In contrast to cardiovascular disease where there has been increasing attention to the role of sex and gender differences in disease presentation and management, there is only a preliminary literature examining sex and gender differences in asthma. This literature suggests that there are gender differences in asthma. Sex differences in airway behaviour over the life span have been recently reviewed by Becklake and Kauffmann (1999), who have brought together a diverse literature demonstrating that there are sex differences in airway behaviour which are determinants of the clinical presentations of airway disease. Early developmental issues, coupled with later hormonal differences as well as immunological determinants of airway behaviour, all contribute to sex differences in lung growth and physiology. A literature suggests that there are gender differences in the perception of breathlessness which results from the interplay of biological, environmental, and sociocultural factors such that women are more sensitive to changes in airway function (Becklake & Kauffman, 1999). Hospitalization rates have been reported to be higher in prepubertal boys than girls and higher in adult women compared to men (Skobeloff et al., 1992). There is some evidence that women are more likely to use improper technique with the use of metered dose inhalers which are integral to asthma treatment (Redline & Gold, 1994), although there is contradictory evidence (Osborne et al., 1998). There is some evidence that women with asthma are more than twice as likely to be active smokers as men (Osborne et al., 1998). Women were more likely than men to report symptoms of asthma despite similar pulmonary function as measured by prebronchodilator FEV1 % predicted and bronchodilator response (Osborne et al., 1998).
Interventions Fostering Adaptation to Illness

Asthma management includes relief of the acute respiratory symptoms associated with an asthma attack as well as prevention of exacerbations and chronic symptoms. Behavioural interventions have focused on the prevention of recurrent exacerbations (Devine, 1996).

Studies of behavioural interventions have been limited by small sample sizes and a lack of attention to issues of sex and gender and race and ethnicity. For example, in a meta-analysis of psychoeducational interventions, it was noted that 13% of studies did not report data on sex and 74% did not report data on race and/or ethnicity (Devine, 1996).

A variety of behavioural interventions have been recommended to enhance the management of asthma in adults. National and international guidelines developed over the past ten years all address the importance of asthma education and self-management strategies, but there is little agreement as to what specifically constitutes optimal education and self-management (Boulet et al., 1999; British Thoracic Society, 1990; Global Initiative for Asthma, 1996; Thoracic Society of Australia and New Zealand, 1989). The relative importance attached to various behavioural strategies has varied over the years as understanding of the pathophysiology of asthma has advanced. Asthma is characterized by inflammation and airway smooth muscle contraction. Earlier behavioural strategies focused on the smooth muscle contraction but it is now recognized as secondary in importance to the inflammation (Kotses, 1999). Current behavioural approaches seek to control inflammation indirectly through avoidance of triggers as well as optimization of medical management when inflammation occurs.

Education

Level of Evidence - II-I

While the literature has numerous methodological limitations and there has been scant attention to gender differences, a meta-analyses of psychoeducational studies reveals a moderate effect size (Devine, 1996). Recommendations about education are included in consensus guidelines from all of the major groups as noted above. Interestingly new data from a randomized controlled trial with pediatric asthma found that educational interventions increased knowledge but that actual changes in asthma severity only occurred with education provided in an interactive individual face-to-face individual intervention rather than with group education or home-based video education (Liu & Beekley, 2001). A comparison of education versus education plus self-management in a randomized controlled trial showed the best patient outcomes and QoL in the latter group (Cote et al., 2001).

Multimodal/Integrative Programs

Level of Evidence - I

“Self-management of asthma” is a generic phrase used for multi-modal programs. While education is an important component of self-management of asthma, self-management is broader and is defined as “the process whereby individual asthmatic patients make changes to their treatment in response to the recognition of changes in the severity of their asthma in accordance with predetermined guidelines” (Fishwick et al., 1997). This definition includes self-assessment as well as self-management skills in the context of agreed upon guidelines for treatment. Problems in self-assessment contribute to asthma mortality (Fishwick et al., 1997). Most self-management programs incorporate the use of peak flow measurements in addition to subjective symptomatology to delineate stages of asthma severity. Each stage of asthma severity has associated medical guidelines that specify medications to be taken or referral for emergency medical care. Guidelines should be tailored for the individual patient, and different models exist for operationalization of these guidelines (Fishwick et al., 1997). Clark and Notheur (1997) reviewed 18 adult self-management education programs consisting of clinical trials. While results varied across trials because of differences in the parameters measured, overall studies showed improvements in asthma knowledge, psychological status, decreased health care use, control of symptoms, control of environmental triggers, and optimal use of medications. Remarkably little attention has been paid to gender issues. Yoon et al. (1993) noted in their Australian sample that women were more likely...
to participate in an education program. Qualitative data from focus groups with individuals with asthma described the importance of acquiring information; self-regulating behaviours; relationships with clinicians; relationships with family, friends, and coworkers; and concerns related to intra and interpersonal aspects of asthma, but did not report any information about sex differences in these areas.

**Stress Management**  
*Level of Evidence - IV*

Stress management strategies have not been adequately evaluated in asthma. They may be incorporated into multi-modal interventions. They likely have the most benefit for those individuals whose asthma attacks are precipitated by emotional stressors.

**Cognitive-Behavioural Approaches**  
*Level of Evidence - IV*

Cognitive-behavioural therapies have received little attention in the asthma literature. There has been the suggestion that they may be helpful in coping with panic which occurs in conjunction with dyspnea in asthma (Smoller & Otto, 1998).

Writing about stressful experiences led to symptom reduction in a cohort of patients with asthma (Smyth et al., 1999).

**Behavioural Approaches**  
*Level of Evidence - IV*

Autogenic training and functional relaxation coupled with group therapy improved outcome in a small cohort of German adult asthma patients compared to that of controls (Deter & Allert, 1983).

Interest in relaxation in asthma has waned with the increasing recognition of the role of inflammation in the pathophysiology of the disease. Studies in the 1970s and early 1980s showed some positive results, but the studies were methodologically flawed.

**Other Psychotherapies**  
*Level of Evidence - IV*

There is no empirical data on the role of other psychotherapies in adaptation to asthma.

**Social Support**  
*Level of Evidence - IV*

There is no empirical data on the role of social support in adaptation to asthma.

**Exercise**  
*Level of Evidence - I*

There is recognition that individuals with asthma are less fit and this seems to relate to inactivity and sedentary lifestyle. Two recent reviews have supported the use of exercise in improving cardiopulmonary fitness, although there is insufficient data about whether such improvements translate into improved QoL. A systematic review of eight randomized controlled trials showed improvements in cardiopulmonary fitness, but there was no data on QoL (Ram et al., 2000). A review of the literature on exercise training in asthma coupled with expert opinion has resulted in recommendations for individual exercise prescriptions (Satta, 2000). Depending upon an individual’s clinical status, they may require little supervision through to participation in highly structured and monitored exercise rehabilitation programs similar to those for COPD.

**Nutrition**  
*Level of Evidence - IV*

Nutritional issues in asthma are poorly understood (Fogarty & Britton, 2000; Ziment, 2000) and research in this area is in its infancy. There is some epidemiological evidence that suggests that antioxidants, magnesium, and fat consumption may have etiologic significance and preliminary studies suggest that antioxidants may have a positive impact on the disease. There has been no attention to potential sex and gender differences in these studies.
Mind-Body Approaches
Level of Evidence - IV

A variety of mind-body approaches have been used, although there is a paucity of large randomized, controlled trials in this area (Lewith & Watkins, 1996). Recent Cochrane reviews have been unable to derive reliable conclusions about breathing exercises (Holloway & Ram, 2000) or the Alexander technique (Dennis, 2000) for asthma. Yoga was reported to be beneficial to young New Delhi Southeast Asian asthmatics (39% female) ranging in age from 11 – 18 years, although there was no control group, incomplete details were provided about potential gender differences in response to treatment, and the treatment was intensive including a 40 day hospitalization (Jain et al., 1991).

Interventions in Special Populations

There has been little systematic work on asthma education programs in special populations apart from children.

Children

The literature in children is limited and has not systematically examined potentially important variables such as gender, ethnicity, income, and rural versus urban location. An experimental intervention with a representative sample of Dutch childhood asthmatics over the age of 8 (39% female) revealed a positive impact for a program consisting of ten weekly one hour sessions including behavioural techniques, self-management training, and group therapy both at the end of the treatment and at six and twelve months follow-up. The treatment group was compared to two control groups and showed improved ability to manage their asthma; lower anxiety, health care utilization, and school absenteeism; and a heightened sense of self-efficacy and self-confidence in managing their symptoms. In younger children, parents are the focus of intervention. A Dutch asthma self-management protocol directed at parents of children aged 0 – 4 demonstrated improved outcome in terms of greater knowledge and sense of self-efficacy as well as the more frequent use of self-management and self-care behaviours (Mesters et al., 1994).

As with adults, negative outcomes are associated with barriers such as poverty, language, and culturally-based beliefs about illness (National Institutes of Health, 1995) and yet these issues have received little systematic study. A study of rural low income children in New Mexico demonstrated that in this sample of predominantly Hispanic or multiracial children, a self-management intervention delivered one-on-one led to improvements in parental self-efficacy, particularly related to the treatment of episodes rather than their prevention. Interestingly, there were no differences between high (clinic RN plus home visitor) and low intensity (clinic RN) interventions. A multi-media computer intervention, “Watch, Discover, Think and Act” designed to be a part of regular clinic visits, was developed for inner-city Afro-American and Hispanic children with asthma (Bartholomew et al., 2000a). The intervention focused on teaching two types of behaviour: asthma specific behaviours and self-regulatory processes. The report did not examine gender difference but noted that in the sample as a whole, there were improvements in symptom reports, functional status, knowledge, and self-management activities (Bartholomew et al., 2000b). A New Zealand study in a multiracial working class neighbourhood found improvements in knowledge and self-management plans with a lesser impact on asthma morbidity (Garrett et al., 1996). A comprehensive inner-city asthma program was demonstrated to reduce hospital and emergency room utilization in a prospective randomized trial with children aged 2 to 17 (Harish et al., 2001). More recently, positive results in terms of improved QoL were obtained in a cluster randomised controlled trial of a peer led program for adolescents (Shah et al., 2001).

Economically Disadvantaged and Marginalized Women

Failure to attend self-management programs was associated with low socioeconomic groups, minority ethnic groups, and illiteracy in one sample (Fitzgerald, 1994). While there have been interventions in these circumstances for children with asthma, as discussed above, we were unable to locate programs for adults.
Chronic Obstructive Pulmonary Disease

COPD has been defined as airflow obstruction accompanied by airway hyperactivity, potentially partly reversible, in the presence of chronic bronchitis or emphysema.

Epidemiology

COPD is one of the leading causes of morbidity and mortality in industrialized and developing countries; it is the number four cause of death in the U.S., and by 2020 will be the third leading cause of death worldwide (Viegi et al., 2001). COPD is strongly related to cigarette smoking, which accounts for 80–90% of cases (Staton & Ingram, 2000). Other risk factors include air pollution, some occupational exposures, and low socioeconomic status (Viegi et al., 2000).

Impairment in Quality of Life & Psychosocial Morbidity

COPD is characterized by a prolonged illness course with gradually decreasing respiratory function, increasing shortness of breath, and requirements for biomedical intervention, including medications and eventually home oxygen. As a result of the increasing shortness of breath, functional status is compromised and it becomes increasingly difficult to perform activities of daily living. Individuals with COPD typically report increasing losses in social functioning and many develop depression and anxiety. Anxiety has been described as “one of the most important factors determining quality of life in COPD” (Eiser et al., 1997). Ongoing hypoxia may lead to cognitive compromise (Abbey et al., 1996). COPD is often unpredictable and variable and can quickly decompensate. This leads many individuals with COPD into a hopeless/helpless stance. Sleep problems are common. Air travel is often curtailed. Oxygen supplementation may be helpful, but requires the individual to transport oxygen tanks and nasal prongs that many find a disturbing visible sign of their illness.

Sex & Gender Specific Issues

Women have 20–60% lower mortality rates from COPD than men and are less likely to die during hospital admissions, although they are more likely to die if they require mechanical ventilation (Becklake & Kauffman, 1999). There are rising rates of COPD in women which have been attributed to increasing levels of smoking.

Interventions Fostering Adaptation to Illness

The 1990s witnessed an explosion of interest in rehabilitation of COPD patients with the realization that rehabilitation could bring about a significant improvement in QoL and functional status. There has been remarkably little attention to sex and gender differences in behavioral interventions. There is some evidence that women are less likely to be involved in pulmonary rehabilitation programs, more likely to enroll in them for a shorter period of time, and are less active in pulmonary rehabilitation programs (Frey, 2000).

Education

Level of Evidence - II-I

Education has become an integral part of the management of COPD following recognition that it appears to contribute to improved QoL, although it does not appear to be sufficient on its own to improve QoL (Emery et al., 1998; Make, 1994). Emery et al. (1998) found increased psychosocial distress and lowered QoL in participants who received education and stress management without participating in an exercise program. A key component of education programs is the inclusion of specific information about walking exercise, relaxation and breathing retraining, and techniques to enhance compliance with prescribed exercise regimens (Make, 1994). More work needs to be done to understand the best approaches to education for COPD patients.
Multimodal/Integrative Programs
Level of Evidence - I
Multidisciplinary pulmonary rehabilitation programs are the most effective intervention in COPD for those patients not well controlled with medication. Interest in the area has grown over the past two decades and there are now a number of studies showing a positive impact for pulmonary rehabilitation on respiratory functioning and QoL including mental health. The cornerstone of the programs is exercise, but there are also educational interventions and at times behavioural or cognitive-behavioural components. With increasing skill in the delivery of pulmonary rehabilitation, these programs have moved from being inpatient to outpatient based. Recent randomized, controlled trials have shown benefits that persist up to 24 weeks (Finnerty et al., 2001), 18 months (Troosters et al., 2000), and 24 months follow-up (Guell et al., 2000). A recent randomized controlled trial showed that seven weeks of pulmonary rehabilitation provided greater benefits than a four-week program (Green et al., 2001).

Stress Management
Level of Evidence - IV
Stress programs are an integral component of many pulmonary rehabilitation programs but have received less systematic study as a unimodal therapy. Initial studies demonstrated improvements in appropriate medication use (Make, 1994).

Cognitive-Behavioural Approaches
Level of Evidence - II-1
Learning to assess thinking and replace unhelpful cognitions with more helpful ones has been incorporated into a number of programs with success (Make, 1994). Cognitive therapy is often directed towards the catastrophic thoughts that accompany shortness of breath (e.g., “I am going to die”) which in turn lead to heightened anxiety and increased physical symptoms of anxiety such as increased heart rate and respiratory rate. These increased physical symptoms of anxiety are then interpreted as further evidence of impending doom and the cycle escalates (Abbey, et al., 1996). Six 90-minute sessions of cognitive-behaviour therapy (CBT) produced a sustained improvement in exercise tolerance in a group of ten anxious patients (Eiser et al., 1997), although it did not impact on anxiety (this is expectable as it was probably too brief a course of therapy to alter anxiety symptoms). Decreased psychosocial distress was reported in a pilot study of five women and three men (Lisansky & Clough, 1996). A single two-hour session of group CBT with weekly phone calls to follow up for six weeks resulted in improvements in anxiety and depression compared to an attention matched educational intervention (Kunik et al., 2001).

Behavioural Approaches
Level of Evidence - IV
Many pulmonary rehabilitation programs incorporate relaxation training or self-hypnosis but have not systematically evaluated their role. There is some interest in the effect of breathing pattern training on ventilatory function, but the one study done to date did not obtain measures of impact on QoL (Esteve et al., 1996).

Other Psychotherapies
Level of Evidence - IV
There is no data on the use of other psychotherapies in COPD.

Social Support
Level of Evidence - III
A study by Frey (2000) of men and women who were affiliated with a lung disease group was limited by a low response rate (14%). Results showed that the minority of COPD participants affiliated with a lung disease support group were actively engaged in pulmonary rehabilitation and that men were more often taking part in such programs than women (35% of men, 25% of women). Despite affiliation with the support group only 23% of men and 20% of women currently attended meetings. There was no evaluation of why people chose to participate or not participate.
Exercise
Level of Evidence - I
Exercise is the hallmark of effective pulmonary rehabilitation. In addition to improving cardiopulmonary endurance, it appears to enhance psychological wellbeing through a variety of mechanisms including enhanced self-efficacy, social support inherent in the exercise setting, and release of endogenous opiates (Emery et al., 1998). Exercise training in COPD leads to gains in aerobic capacity, peripheral muscle strength, improved respiratory muscle function, increased exercise tolerance, and reductions in anxiety and fear (Bourjeily & Rochester, 2000). Exercise is a central part of pulmonary rehabilitation programs described above.

Nutrition
Level of Evidence - IV
COPD is associated with weight loss and nutritional deficits (Mackay, 1996a; Sridhar, 1999). The mechanisms underlying the weight loss remain poorly understood and are likely to be multifactorial and related to decreased dietary intake, increased energy required by respiratory changes, medications, and increased risk of infections and hypoxia. A preliminary small-scale study demonstrated that nutritional status can be improved with nutrition education integrated into a COPD rehabilitation program (Mackay, 1996b). While there have been only a few studies, it does not seem that simple supplementary feeding is helpful (Sridhar, 1999), although the literature continues to develop (Schols, 2000).

Mind-Body Approaches
Level of Evidence - IV
While a number of mind-body interventions are tried by individuals, there has been no systematic review of their use in COPD.

Interventions in Special Populations
There has been remarkably little attention to issues of ethnoracial diversity.

Recommendations

1. Clinical Care
   - Asthma self-management programs should be available on at least a regional basis.
   - Pulmonary rehabilitation programs should be available on at least a regional basis.
   - Smoking cessation programs tailored to the specific needs of women should be available on at least a regional basis.

2. Health Care Professional Education
   - Knowledge translation is essential. Education about self-management of asthma needs to be included in undergraduate, postgraduate, and continuing professional development educational curricula.
   - Education about self-help strategies and available resources needs to be included in continuing professional development events for primary care and specialists.
   - Education about smoking cessation strategies and motivational interviewing to promote smoking cessation need to be emphasized with both primary care practitioners and specialists.

3. Public Education
   - The public needs to be informed about self-management strategies for asthma and Chronic Obstructive Pulmonary Disease (COPD).
   - Educational materials need to be developed and modified so that they are linguistically and culturally appropriate for Francophone, Aboriginal, and immigrant women.

4. Research
   - Research needs to address the question of how best to deliver education about asthma.
   - The unique needs of women with respect to pulmonary rehabilitation programs needs to be better understood.
   - Nutritional approaches to COPD need to be better understood.
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