

**Self-Help, Mutual Aid, Adult Education, Empowerment
And Risk Factors for Stroke:**

A Review of the Literature 1995-2003

**Submitted by: Jennifer Poole, MSW, PhD (candidate)
To: The Self-Help Resource Centre
For: MOHLTC**

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Introduction/Defining the Terms

What follows is an annotated bibliography of *academic* literature published after 1995 on *self-help, mutual aid, empowerment, adult education and risk factors for stroke*. Literature includes peer reviewed academic journal articles both in print and on-line published in Canada, the US, Europe as well as other international sources. Literature was limited to those sources printed in English and available through the Universities of Toronto and Ryerson library systems. A full listing of all 61 entries can be found at the end of the review.

For the purposes of this review, **self-help/mutual aid** was defined as;

a process of learning with and from each other (similar to adult education). Participants provide each other with **mutual aid/support** in dealing with a problem, issue, condition or need. Participants learn to work together while acknowledging the diversity of their personal situation among the similarities of their shared issue. Together they investigate alternative solutions and are **empowered** by this process. (Rabbani 2002)

For the purposes of this review, **risk factors** follow the classification outlined by the American Stroke Council (Goldstein et al. 2001) and include:

- **nonmodifiable risk factors:** age, race/ethnicity, sex and family history
- **modifiable risk factors:** hypertension, smoking, diabetes, hyperinsulinemia¹, insulin resistance, asymptomatic carotid stenosis, atrial fibrillation, sickle cell disease, hyperlipidemia
- **potentially modifiable risk factors:** obesity, physical inactivity, poor diet/nutrition, drug and alcohol abuse, hypercoagulability, hormone replacement therapy, oral contraceptive Use (deemed potentially modifiable risk factors)

This review includes those studies that speak to both 1. self-help, mutual aid, support, adult education and empowerment and 2. one or more of the risk factors listed above.

¹ Please see the review of Goldstein et al. in this document for a explication of these and other risk factors.

The literature review has been divided up into sections. In each section, literature has been **organized by date of publication** with the most recent articles appearing first. The sections and their contents are explained as:

1. *Self-Help and Mutual Aid: Recent Developments*
 - a. general information and statistics on self-help participation since 1995
2. *Risk Factors for Stroke: General*
 - a. descriptions of what risk factors are for this condition and work on some of the current trends in the literature
3. *Risk Factors and Social Support*
 - a. findings on the relationship between social support and risk prevention/reduction/response
4. *Risk Factors and Self-help, Mutual aid, Empowerment and Adult Education*
 - a. studies on the use of self-help, mutual aid, empowerment and/or adult education models in response to/prevention of specific risk factors such as obesity, smoking, diabetes etc.
5. *Stroke Recovery and Secondary Prevention: Current Trends*
 - a. findings on factors vital to the recovery process and prevention of (another) stroke
6. *Stroke Recovery and Social Support*
 - a. research on the role of social support in the recovery/secondary prevention process
7. *Stroke Recovery and Self-Help, Mutual aid, Empowerment and Adult Ed.*
 - a. studies on the use of self-help, mutual aid, empowerment and/or adult education models in response to/secondary prevention of stroke
8. *Family/Caregivers and Social Support*
 - a. findings on the role of social support for caregivers of stroke survivors
9. *Family/Caregivers and Self-Help, Mutual aid, Empowerment and Adult Ed.*
 - a. findings on the role of self-help, mutual aid, empowerment and/or adult education models in caregiving for individuals post-stroke
10. *Policy Recommendations for Stroke Prevention and Care*
 - a. articles advocating for the use of self-help, mutual aid, empowerment principles in stroke prevention and care

Search Terms

In searching the literature, the following terms were used:

- Addiction
- Adult education
- Ageing
- Alcohol abuse
- Chronic illness
- Diabetes
- Diet
- Disability
- Drug abuse
- Empowerment
- Group
- Habits
- Health
- Heart
- Hypertension
- Lay help
- Lifestyle
- Mental health
- Mutual aid
- Mutual help
- Mutual support
- Nutrition
- Obesity
- On-line support
- Peer support
- Physical inactivity
- Risk
- Risk factors
- Self-care
- Self-help*
- Smoking
- Social determinants of health
- Social support
- Stroke
- Support Group
- Weight

**Note: In the health literature, the term self-help was frequently associated with information or manuals rather than the sharing of mutual support.*

Indexes

For this review, search indexes (or databases) used include:

- Ageline, CINAHL, Cochrane Collaboration, Embase, ERIC, Expanded Academic Index, HAPI, Healthstar, Medline, Psychinfo, Pubmed, Risk (abstracts), Sociofile, Sociological Abstracts, Social work Abstracts, Women's Studies International

Other limits

Literature was limited to that published in English between 1995-2003 in Canada, the US and other International sources.

General Findings/Highlights

- In the US, 8 to 11 million people participate in self-help groups each year, average member is 43, male and white (Fetto 2000)
- Individuals over 65 are twice as unlikely to attend self-help groups (Wistler 1995).
- Stroke risk factors, incidence and mortality are higher for non-whites, especially those who are African-American and Hispanic (Bradley et al. 2002, Claiborne Johnston et al. 2001, Din 2002)
- Those with lower SES are also likely to be more at risk for stroke and will also receive poorer rehabilitative care (Kapral et al. 2000, Kunst et al. 1998, Redfern et al 2000, Sayler et al. 2001).
- Risk reduction programs that incorporate culturally specific forms of social support and mutual aid (ie. native healing circles, African American lay preachers) are generally more successful with ethnic communities than those that do not (Bates 2000, Kieffer et al. 2002, Napoli 2002, Resnicow 2000, Voorhees et al 1996, Yanek 2001)
- Perceived levels of social support seem to moderate the effect of work day stress on hypertension and risk for stroke (Steptoe 2000)
- Low levels of social support increase risk of stroke (Agewall 1998, Rozanski 1999)
- Individuals with lower levels of family support are more likely to participate in self-help groups (Kessler et al. 1997)
- Not only are strong supportive social systems vital for the well-being of seniors who have had a stroke, but in Canada they may also operate

indirectly to reduce further strain on the healthcare system (Clarke et al. 2002)

- Patient education programs directed at reduction of feelings of helplessness and improved empowerment may result in considerably greater cost containment and better outcomes in stroke (Pincus et al 1998)
- The Trevoze self-help group in Pennsylvania is one of the most successful obesity programs in the US with most members able to keep 15% of weight off for upwards of five years (Latner et al. 2002)
- Empowerment may significantly assist individuals with mental health problems not only with their diagnoses but also their obesity (Ekpe 2001)
- Individuals treated in 12-step programs for alcohol abuse incur long-term health care costs up to 64% less than those treated in cognitive behavioural programs (Humphreys and Moos 2001)
- Self-help participation is highest for diseases viewed as stigmatizing (AIDS, alcoholism) and lowest for 'less embarrassing' issues (heart disease and stroke), individuals suffering from hypertension may attend groups such as Overeaters Anonymous (for obesity) rather than those that identify as stroke specific, they are also more likely to seek support after than before a stroke (Davison et al. 2000)
- Self-help/mutual aid/peer support is the core component of the national smoking cessation support service in the UK (Moore 2000)
- African Americans who have sickle-cell disease (a risk factor for stroke) and become highly involved in self-help groups report reduced emotional upset and decreased interference of the disease with their work and relationships (Nash & Kramer 1993 cited in Humphreys 1997).
- Because of their knowledge and personal experience, support groups should be viewed as important partners in community stroke education (Weltermann et al. 2000)
- Caregivers of stroke patients are willing and able to use on-line support (Pierce 2002)
- Adult education and self-help/mutual aid are valuable but neglected tools in stroke education, practitioners need to think more broadly in terms of tools and techniques (Hanger and Wilkinson 2001)
- Practitioners and policy makers need to recognize the importance of the public's growing use of self-help in stroke prevention and care as well as the cultural realities of patients' lives (Greenland 1996)

Self-Help/Mutual Aid-Recent Development

Fetto, J. (2000). Toplines: Lean on me. *American Demographics*, Dec.

The author notes that about 3 percent to 4 percent of the U.S. population, or between 8 million and 11 million people, participate in self-help groups each year. The average age of a self-help group member is 43 and is more likely to be male. 3.6 percent of men are attendees compared with 2.4 percent of women. White men and women are three times as likely to participate as African Americans.

Key words: self-help groups, recent statistics on participation in the US

Banks, Eric. (1997). The social capital of self-help mutual aid groups.

***Social Policy*, 28 (1): 30-39**

Citing recent research, the author proposes that, despite reports to the contrary, self-help/mutual aid is flourishing in the US. He links this argument to the rise of small, community capital-creating (n=5-10) groups as opposed to larger self-help organizations.

Key words: self-help/mutual aid, rise of, size of group, social capital

Wister, A. (1995). The relationship between self-help group participation and other health behaviors among older adults. *Canadian Journal of Community Mental Health* 14(2): 23-37

Using data from the Survey of Ageing and Independence (1991), Wister explores why older adults do (or do not) attend self-help groups. He argues that those over 65 appear twice as unlikely to attend a self-help group. Persons who are working are also less likely to attend. Higher education increases the likelihood of attending. For those 65 and over, participation in self-help groups is more likely if the individual also seeks professional help, relies on informal mutual aid and uses self and spiritual care.

Key words: older adults, participation in self-help groups, reasons for

Risk Factors for Stroke-General

Goldstein, L., Adams, R., Becker, K., Furberg, C., Gorelick, P., Hademenos, Hill, Howard, Jacobs, Levine, Sacco, Sherman, Wolf, and del Zoppo. (2001). Primary prevention of ischemic stroke: A statement for healthcare professionals from the Stroke Council of the American Heart Association. *Stroke*, 32:280-299

This article was included for its extensive review of all risk factors for stroke. A summary of these is listed below.

1. Nonmodifiable Risk Factors:

Age, Sex (stroke is more prevalent in men than in women, but mortality rates are higher in women than men), **Race/Ethnicity** (Blacks and some Hispanic Americans have high stroke incidence and mortality rates compared with whites due in part to higher prevalence of hypertension, obesity, and diabetes mellitus. Chinese and Japanese populations generally have high stroke incidence rates as well), **Family History**

2. Modifiable Risk Factors:

Hypertension (Incidence of stroke increases in proportion to both systolic and diastolic blood pressures. This relationship is "direct, continuous, and apparently independent."), **Smoking, Diabetes, Hyperinsulinemia, and Insulin Resistance** (Insulin-dependent diabetics have both an increased susceptibility to atherosclerosis and an increased prevalence of atherogenic risk factors, notably hypertension, obesity, and abnormal blood lipids) **Asymptomatic Carotid Stenosis, Atrial Fibrillation** (common arrhythmia), **Sickle Cell Disease, Hyperlipidemia** (Abnormalities of serum lipids such as triglycerides, cholesterol, low-density lipoprotein [LDL], and HDL)

3. Potentially Modifiable Risk Factors:

Obesity (Defined as a body mass index 30 and over predisposes to cardiovascular disease in general and to stroke in particular)
Physical Inactivity (Regular physical activity has well-established benefits for reducing the risk of premature death and cardiovascular disease. The beneficial effects of physical activity have also been documented for stroke)
Poor Diet/Nutrition (May be a protective relationship between stroke and consumption of fruits and vegetables especially green leafy vegetables and citrus fruit and juice)

Drug Abuse (Use of amphetamines, "crack" cocaine, and heroin is associated with increase in the risk of both ischemic and hemorrhagic stroke)

Alcohol Abuse (For hemorrhagic stroke, cohort studies have shown that alcohol consumption has a direct dose-dependent effect. For cerebral infarction, chronic heavy drinking and acute intoxication have been associated with an increased risk among young adults. In older adults, risk is increased among heavy-drinking men)

Hypercoagulability, Hormone Replacement Therapy (The Framingham Heart Study found a 2.60-fold increase in the relative risk of atherothrombotic stroke among women receiving hormone replacement therapy compared with nonusers),

Oral Contraceptive Use (based on early studies with high-dose preparations and women who are cigarette smokers)

Recent Trends in the Risk Literature for Stroke:

Diet and Ethnicity

Bradley S., Jacobs, Boden-Albala, I-Feng and Sacco. (2002). Stroke in the young in the Northern Manhattan Stroke Study. *Stroke*. 33:2789-2793.

The authors identified all cases of first stroke in Northern Manhattan from 1993 to 1997 and calculated stroke rates for those 20 to 44 years of age. 74 cases of first stroke in young patients were discovered (47% women, 12% black, 80% Hispanic, 8% white). Case fatality rates at 30 days were higher in blacks (38%) and Hispanics (16%) compared with whites (0%). The authors conclude that blacks and Hispanics have greater stroke incidences than young whites.

Key Words: incidence, mortality, racial differences, stroke, young adults

Din, Rebecca. (2002). Diet and cardiovascular disease. *American Journal of Public Health*, 92(7): 1050-1051

The author reviews and comments on the article by Resnicow et al (see this review) urging further programming and study on culturally-specific food education and support, specifically those that partner with Black churches.

Key words: diet, risk factor, ethnicity, black churches

Fang, X., Kronmal, R., Li, S., Longstreth, W., Cheng, X., Wang, Wu, Du, and Siscovick, D. (1999). Prevention of stroke in urban China: A community-based intervention trial. *Stroke*, 30:495-501.

Because stroke has been the second leading cause of death in large cities in China since the 1980s, in 1987, a community-based intervention trial was initiated in 7 Chinese cities to reduce multiple risk factors for stroke. For each city, 2 geographically separated communities with a population of about 10 000 each were selected as either intervention or control communities. The intervention included weekly visits to community clinics, traditional and western pharmacology, health information as well as assistance with exercise, weight and

alcohol control. Health education (leaflets and manuals distributed door to door) was also provided. After 3.5 years, 174 new stroke cases had occurred in the intervention cohort and 253 in the control cohort. The 3.5-year cumulative incidence of total stroke was significantly lower in the intervention cohort than the control cohort. The incidence rates of nonfatal and fatal stroke, as well as ischemic and hemorrhagic stroke, were significantly lower in the intervention cohort than the control cohort. **Key words: ethnicity, community prevention, multiple risk factors, population health interventions**

Non-Prescription Drug Use

Bak, S., Andersen, M., Tsiropoulos, I., García Rodríguez, A., Hallas, J., Christensen, K. and Gaist, D. (2003). Risk of stroke associated with nonsteroidal anti-inflammatory drugs: A nested case-control study. *Stroke*, 34:379-386

Nonsteroidal anti-inflammatory drugs (NSAIDs including ibuprofen but not aspirin) have been associated with bleeding complications and may affect the risk of hemorrhagic stroke. The authors performed a population-based case-control study to estimate the risk of the above in users of NSAIDs in Denmark. Identifying all patients with a first-ever stroke discharge diagnosis in the period of 1994 to 1999, 40 000 random individuals were selected. Results indicate that current exposure to NSAIDs is not a risk factor for hemorrhage, but offer no protection against first-ever ischemic stroke. **Key Words: anti-inflammatory agents, nonsteroidal , stroke, hemorrhagic**

Previous Incidence of Stroke (and socioeconomic status)

Redfern, J., McKeivitt, C., Dundas, R., Rudd and Wolfe, C. (2000). Behavioral risk factor prevalence and lifestyle change after stroke: A prospective study. *Stroke*, 31:1877-1881.

The authors endeavoured to find out whether stroke survivors in London, UK changed their behavioural risk factors in any significant way after having a stroke. Although survivors had a 15-fold increased risk of recurrent stroke, at 1 year after stroke, 22% of patients still smoked, 36% of patients were obese, and 4% drank excessively. Younger patients, whites, and men were more likely to smoke, and younger whites were more likely to drink excessively. Women and nonwhites were more likely to be obese. The authors argue that continued risk activity was associated with specific sociodemographic groups (SES, Race) indicating the need for targeted and community specific efforts to prevent stroke and its recurrence. **Key Words: lifestyle risk factors, ses, race, smoking, drinking, obesity, stroke prevention and recurrence**

For similar findings, see Salyer, J. et al. (2001). Lifestyle and health status in long-term cardiac transplant recipients. *Heart & Lung: The Journal of Acute & Critical Care*, 30(6): 445-457

Risk Factors and Social Support

Brown, S., Garcia, A., Kouzekanani, M., Kamiar, H. and Craig L. (2002). Culturally competent diabetes self-management education for Mexican Americans: The Starr County Border Health Initiative. *Diabetes Care*, 25(2): 259-268.

The authors report on a study of 256 randomly selected Mexican Americans between 35 and 70 years of age with type 2 diabetes. Over 3 months, participants received weekly education sessions on nutrition, blood glucose, exercise and 6 months of biweekly *support group* sessions to promote behavior changes. The approach was culturally competent in terms of language, diet, social emphasis, family participation, and incorporation of cultural health beliefs. Participants showed significantly lower levels blood glucose at 6 and 12 months and higher diabetes knowledge scores. **Key words: diabetes, culture, support group**

Kieffer, E. Willis, S., Arellano, N. and Guzman, R. (2002). Perspectives of Pregnant and Postpartum Latino Women on Diabetes, Physical Activity, and Health. *Health Education & Behavior*, Vol. 29 (5): 542-556

Obesity, impaired glucose tolerance (IGT), gestational diabetes mellitus (GDM), and Type 2 diabetes are prevalent among Latino women of childbearing age, particularly in low-income communities. This study brought together Latino women in three focus groups to find out 1. their knowledge of risk factors for diabetes and 2. their suggestions for a culturally-specific activity program. Few women identified activity as a risk factor, but most indicated a need for *social support*, as isolation, expressed as being *encerrado* (closed in the house) was perceived as a major barrier to physical activity. It was explained as the outcome of personal and family concerns about safety and 'appropriate' maternal behavior. **Key words: diabetes, pregnancy, Latino women, activity, social isolation and lack of social support as barriers to**

Koffman, D., Bazzarre, T., Mosca, L., Redberg, R., Schmid, T. and Wattigney, W. (2001). An evaluation of Choose to Move 1999: An American Heart Association physical activity program for women. *Archives of Internal Medicine*, 161(18): 2193-2199

The authors evaluated the effect of Choose to Move program designed by the American Heart Association for women across the United States. Participants received a welcome kit and manual with weekly information about how to manage cardiovascular disease risk factors and how to build a *support network* for lifestyle change. Ninety percent of the participants were white and 56% were aged between 35 and 54 years. Among the participants who completed the week 12 follow-up evaluation, the percentage who reported being active increased from 32% to 67% at the program's end . Those limiting excess calories or fat

increased from 72% to 91% at week 10 follow-up. **Key words: diet and nutrition, obesity, exercise, self-help materials, social support networks**

Steptoe, A. (2000). Stress, social support and cardiovascular activity over the working day. *International Journal of Psychophysiology*, 37:299-308

The study explored the effect of stress on blood pressure during the 'working day' and whether it was buffered at all by perceived levels of *social support*. 104 school teachers (37 men and 67 women) had their blood pressure and heart rate measured every 20 min. Participants rated the degree of stress they were experiencing at the time of each measurement. They also completed support questionnaires which placed them in high or low support categories. After controlling for body mass, high stress was associated with increased blood pressure and heart rate. However, the impact of stress was buffered by social support, with no significant increase in blood pressure or heart rate with stress in the high support group. **Key words: stress, blood pressure, effect of social support on**

Rozanski, A., Blumenthal, J. and Kaplan, J. (1999). Impact of psychological factors on the pathogenesis of cardiovascular disease and implications for therapy. *Circulation*, 99(16): 2192-2217.

The author reviews a plethora of recent studies with "clear and convincing evidence that psychosocial factors contribute significantly to coronary artery disease (CAD)". These factors include (1) depression, (2) anxiety, (3) personality factors and character traits, (4) social isolation, and (5) chronic life stress. The author also finds that they tend to cluster together. Citing Berkman et al who observed a nearly 3-fold increase in subsequent cardiac events for those reporting a low level of *emotional support*, he underscores the importance of programs targeted towards alleviating depression, anxiety and social isolation. **Key words: cardiovascular disease, link to mental health, social isolation and low levels of social support**

Stern, E. B., Berman, M. E., Thomas, J., and Klassen, A. (1999). Community Education for Stroke Awareness: An Efficacy Study. *Stroke*, 30: 720-723

This study compared the efficacy of a stroke prevention video with that of a video plus professionally-facilitated *support group* discussion for 657 older adults living in 'independent living settings'. Results indicated that facilitation did not increase knowledge any more than using the video alone.

Key Words: audiovisual aids, professionally-led support group, risk factors, stroke prevention, education

Agewall, S., Wikstrand, J. and Fagerberg, B. (1998). Stroke was predicted by dimensions of quality of life in treated hypertensive men: *Stroke*, 29: 2329-2333.

412 Swedish men at risk for stroke or heart attack due to high cholesterol, smoking or diabetes were also assessed on their satisfaction with quality of life (*level of social support*, control, social activities etc). Authors argue patients with poor quality of life and low levels of social support are more likely to suffer from stroke. **Key words: stroke, quality of life, risk factors, social support**

Petty, T. (1998). Strategies in preserving lung health and preventing COPD and associated diseases: The National Lung Health Education Program (NLHEP). *Chest*, 113(2) Supplement 2: 123S-163S

The author explains the parameters of the national health education program in the States, reviewing the importance of a number of different interventions in the prevention of heart and lung disease including, but not limited to, formal and *informal support groups*. **Key words: multiple risk factors, heart and lung health, intervention and prevention, role of social support and support groups**

Pincus, T., Esther, R., DeWalt, D. and Callahan, L. (1998). Social conditions and self-management are more powerful determinants of health than access to care. *Annals of Internal Medicine*, 129(5): 406-411.

The authors question current thinking that access to primary care improves health and argue instead for investment in education, self-care, empowerment and social support. They state;

"Among persons younger than 65 years of age, arthritis and hypertension occur in about 25% of persons with less than 8 years of education. Similar patterns are evidenced for back pain, heart attack, peptic ulcer, diabetes, chronic bronchitis, renal disease, epilepsy, stroke, and tuberculosis."

"social support and simple geographic differences may affect health more than recognized biomedical risk factors"

"Investment in education, improvement in social conditions, and research on self-management may improve health in persons of low socioeconomic status more than expanded access to medical care".

"Patient education programs directed at reduction of feelings of helplessness and improved self-efficacy may result in considerably greater cost containment and better outcomes in chronic diseases than do current efforts to restrict medications and visits to specialists".

Key words: risk factors, social determinants, importance of self-care, social support, empowerment and education in preventing disease

Risk factors and Self-Help, Mutual aid, Empowerment and Adult education

Latner, J.D., Wilson, G., Stunkard, A. and Jackson, M. (2002). Self-help and long-term behavior therapy for obesity. *Behaviour Research and Therapy* 40: 805-812

The authors explore the phenomenal success of the Trevoze Behaviour Modification Program, a *peer led self-help group for weight loss*. The program boasts one central group in Trevoze, Pennsylvania and 63 satellite groups with approximately 10-40 members each. Average weight loss is approximately 15-17% of initial body weight, and is often maintained after 3, 4 and 5 years. The authors suggest that the success rate is tied to the group's unique combination of rules, support, low cost, mandatory attendance and screening. Each prospective member must go through an unusual 5 week screening program during which they must keep and submit food records, attend all weekly meetings and lose 15% of their total assigned weight loss (unless this is over 80 pounds). If screened successfully, individuals may join as members, but this can only take place once and any violation of other rules results in 'termination'. **Key words: obesity, weight loss, physical activity, diet and nutrition, self-help group**

Napoli, Maria. (2002). Holistic health care for Native women: An integrated model. *American Journal of Public Health*, 92(10): 1573-1575
Due to the severity of illness-in particular, diabetes, alcoholism, and arthritis, providing health care services to Native women has become a challenge. The author describes a successful health-promoting community-specific 'circle' for native grandmothers involving activity (walks, yoga), storytelling, meal preparation, health education, field trips, bead work and mutual aid.

"The women in this group were all grandparents. They all had diabetes and Arthritis and were recovering from alcoholism. The purpose of the group was to offer these women an opportunity to deal with physical and emotional pain and to experience an intimate connection to each other. ...They shared stories about relatives, home remedies to relieve pain, and new ways to cook traditional foods."

Key words: diabetes, alcohol abuse, native women, elderly, mutual aid, activity

Ekpe, H. (2001). Empowerment for adults with chronic mental health problems and obesity. *Nursing Standard* 15(39): 37-42

Obesity is a common problem among people with mental health problems and a major risk factor for stroke. Noting the importance of self-care, self-efficacy and *group support*, the authors analyze how *empowerment* might alleviate obesity in this population. They argue that interventions based on lifestyle and behavioural

approaches that do not consider the wider psychosocial and environmental factors might not produce the desired change in individuals with health-risk behaviour. Conversely, an autonomous individual with raised self-esteem and efficacy acquired through membership of a group could become self-empowered, thus enabling individuals and groups to take control of factors affecting their health—such as obesity. The nurse's role in the empowerment process involves being an advocate, mediator, networker and partner in the development of patient-led supports. **Key words: empowerment, mental health, obesity, role of self-care and empowerment, patient-led support groups**

Humphreys, K. and Moos, R. (2001). Can encouraging substance abuse patients to participate in self-help groups reduce demand for health care? A quasi-experimental study. *Alcoholism: Clinical and Experimental Research*, 25 (5):

This study evaluated whether patients who are treated in 12-step programs (rather in cognitive behavioural programs) rely less on professionally provided services and more on *self-help groups* after discharge, thereby reducing long-term health care costs. Using a larger sample from an ongoing research project, 887 male substance-dependent patients were evaluated in terms of involvement in self-help groups (e.g., Alcoholics Anonymous), costs of mental health services and clinical outcomes. Patients treated in cognitive behavioural programs averaged almost twice as many outpatient visits after discharge (22.5 visits) as opposed to patients treated in 12-step treatment programs (13.1 visits), and also received significantly more days of inpatient care (17.0 days in CB versus 10.5 in 12-step), resulting in 64% higher annual costs in CB programs (\$4729/patient). Psychiatric and substance abuse outcomes were comparable across treatments, except that 12-step patients had higher rates of abstinence at follow-up (45.7% versus 36.2% for patients from CB programs). **Key Words: alcohol abuse, self-Help groups, health care costs-offsets**

Toljamo M. A. and Hentinen Entinen. M. A. (2000). Adherence to self-care and social support. *Journal of Clinical Nursing*, 10: 618-627

The authors studied adult patients (n=213) with insulin-treated diabetes from two outpatient clinics in Northern Finland. Using questionnaires, they developed measures for levels of self-care and social support (including emotional, informational, peer, and financial). The authors found that a fifth were neglecting their self-care due in part to poor metabolic control, smoking and living alone. However, with support from family and friends, living alone was not predictor of neglect of self-care. Those with poor metabolic control perceived themselves as getting *peer support* from other persons with diabetes (although this support did not lower their glucose levels). **Keywords: diabetes, self-care, social support, peer support**

Yanek et al (2001). Project Joy: Faith based cardiovascular health promotion for African American women. *Public Health Reports, Supplement 1, 116: 68-81*

The authors report on an extensive church based risk reduction program aimed at weight loss, improved nutrition and activity for African-American women aged 40 and over. Dividing participants into three groups, 1. activity 2. activity and spirituality 3. *secular self-help group*, they found those in the first and second groups saw the most change and expressed the highest levels of satisfaction. Those in the secular self-help group expressed the least satisfaction and had the least behavioural change. It is the opinion of the researchers that it is not possible to maintain non-spiritual health education program within the Black church system. **Key words: obesity, activity, diet and nutrition, race/ethnicity, Church-based support and education programs, self-help**

Bates, V., Bates, N., Bergeron, L., Danyluk, H., Iserhoff, R., Napash, L., Petawabano, B., Petawabano, L. and Torrie, J. (Special Working Group of the Cree Regional Child and Family Services Committee). (2000). Planning research for greater community involvement and long-term benefit. *Canadian Medical Association Journal, 163(10): 1273-1274.*

This is a thoughtful reflection on how a diabetes prevention initiative for pregnant Cree women in Northern Quebec could have been more successful. Reviewing the initiative, which involved individual counseling with pregnant women by a non-Cree nutritionist, the working group notes that physical activity and nutrition did not improve. They suggest future interventions need to include: Cree-led weekly mutual aid group sessions, Cree elders and midwives and culturally-specific education techniques. Although grateful for the 'help' with the prevalent diabetes issue in their community, the authors see no improvement without Cree leadership and the inclusion of experiential knowledge. **Key words: mutual aid, culturally specific groups for, Cree, diabetes**

Clark, N., Janz, N., Dodge, J., Schork, A., Fingerlin, T., Wheeler, J., Liang, J., Keteyian, S. and Santinga, J. T. (2000). Changes in functional health status of older women with heart disease: Evaluation of a program based on self-regulation. *Journal of Gerontology (Social Sciences) 55B:S117-S126.* 570 women over 60 were assigned to control or *mutual aid program* groups. The latter were composed of 6-8 people and were co-led by a health educator and a *peer*. Group activities included sharing information, talk and physical activity. At 12 months, participants demonstrated fewer symptoms (associated with heart disease), improved 'ambulation' and lost more body weight. **Key words: body mass index, age, sex, mutual aid, health education, brisk factors, heart disease, seniors**

Davison, K. , Pennebaker, J. and Dickerson, S. (2000). Who Talks? The social psychology of illness support groups. *American Psychologist*. 55 (2): 205-217

In perhaps one of the most comprehensive and thoughtful studies on *self-help groups* written in the last 20 years, the authors measured voluntary participation in self-help groups for 20 disease categories in 4 metropolitan areas (New York, Chicago, Los Angeles, and Dallas) and on 2 on-line forums. They find self-help participation (in person and on-line) highest for diseases viewed as stigmatizing (e.g., AIDS, alcoholism, breast and prostate cancer) and lowest for less embarrassing but equally devastating disorders, such as heart disease and stroke. In addition, the authors note that although stroke is highly related to hypertension, those with high blood pressure will seek support after a stroke much more readily than before it. Individuals suffering from hypertension may also attend other groups such as Overeaters Anonymous (for obesity), groups for diabetes and others that do not identify as stroke specific. **Key words: self-help groups, illness, age, obesity, hypertension, alcohol abuse, drug abuse, US, factors related to participation**

Healy, P. (2000). Let patients with diabetes make their own decisions. *Nursing Standard*, 14(27): 8

The author reports on a new British study by Walker et al. that questions the focus on compliance in diabetes care. According to the study, hospital-based specialist nurses believe that patient compliance is a key issue for them, but the study suggests nurses should instead be focusing on *empowering* patients to make informed choices. Compliance, the author writes, "is not a concept that is of any use in chronic illness management or care". **Key words: empowerment, diabetes, informed choice, problems with compliance**

Moore, L., Andrews, S. (2000). Establishing a smoking cessation support service. *Nursing Standard*, 15(7): 41-44

In the UK, establishing a smoking cessation support service has become a health priority. The authors report on the paramount role that *mutual aid* and peer support have played in these support services. In small groups (n=6), the effect of peer support is "encouraging and motivating, thus fostering a sense of belonging and camaraderie. Members of the smaller group were seen to share their experiences of attempting to quit and the difficulties associated with this. Sharing their feelings of guilt and pressure offered relief from the stress of cessation". **Key words: smoking, UK, mutual aid, peer support**

Resnicow, K., Yaroch, A., Davis, A., Wang, D., Carter, S., Coleman, D. and Baranowski, T. (2000). GO GIRLS!: Results from a nutrition and physical activity program for low-income, overweight African American adolescent females. *Health Education & Behavior*, 27 (5): 616-631

This article describes a mutual aid and education intervention designed for inner-city, overweight African American adolescent women. Fifty-seven participants were recruited from four public housing developments to participate in the program over two years. Each program session included an educational activity, 30 to 60 minutes of physical activity, preparation of low-fat meals and *mutual aid*. Pre and post test questionnaires demonstrated significant changes in nutrition knowledge, low-fat practices, perceived changes in low-fat practices, and levels of social support. The authors suggest that the inclusion of African American peer educators would improve the program. **Key words: mutual aid, education, activity, obesity, African American girls**

Schiff, M. and Bargal, D. (2000). Helping characteristics of self-help and support groups: Their contribution to participants' subjective well-being. *Small Group Research*, 31(3): 275-304

The authors explored *self-help groups for overeating and obesity* (Overeaters' Anonymous) and professionally-led support groups for mental illness, investigating relationships between the groups' helping characteristics (i.e., instilling hope, caring and concern) and two variables: participants' subjective well-being and general satisfaction with the group. The research sample consisted of 117 participants belonging to 11 groups meeting in Israel. Comparison of the groups revealed that 12-step group members were far more satisfied with the group and gave higher evaluations for most of the helping characteristics. **Key words: self-help groups, support groups, obesity, mental health, hope, well-being, satisfaction**

Anderson, D. and Wadden, T. (1999). Treating the obese patient: Suggestions for primary care practice. *Archives of Family Medicine* 8(2):156-167.

Reviewing recent research on obesity, the authors note new recommendations of more modest 5% to 15% reduction in initial weight for significant reduction in risk. Noting current options for weight loss including behavioral or pharmacological management, they also suggest *self-help approaches*, such as Overeaters Anonymous (OA) and Take Off Pounds Sensibly (TOPS), are another option, "providing valuable group support" necessary for the maintenance of weight loss. **Key words: obesity, risk factor, self-help, weight loss options, group support**

Glasgow, R., Fisher, E., Anderson, B., LaGreca, A., Marrero, D., Johnson, S., Rubin, R. and Cox, D. (1999). *Diabetes Care*, 22(5): 832-843.

The authors summarize research on self-management and patient *empowerment*, interventions with children and adolescents and depression. They highlight the considerable gap between this "encouraging research" and the infrequent incorporation of such contributions into practice, making suggestions for how it can be presented in a more convincing and accessible manner and integrated with

other promising genetic, medical, nutritional, technology, health care, and policy opportunities. **Key words: empowerment, diabetes, research on, presentation of**

Ruesch, A., Gilmore, G., (1999). Developing and implementing a healthy heart program for women in a parish setting. *Holistic Nursing Practice*, 13 (4): 9-18

The authors studied the development and efficacy of 'Hearts to God', a risk reduction program for middle-aged, white women members of a parish in the US. The program included regular small group *mutual aid* meetings, education and the development of a manual integrating spirituality, stewardship and cardiovascular health promotion. Positive feedback from participants is used to demonstrate how this program fills a health education void regarding heart health and stroke prevention for women and how spiritual communities are important but often overlooked collaborators in risk reduction. **Key word: age, sex, spirituality, education, self-care, mutual aid**

Walker, R. (1998). Diabetes: Reflecting on empowerment. *Nursing Standard*, 12(23): 49-56.

Although the author does not offer any new research in this article, she draws on a good deal of literature to provide readers with a powerful argument and opportunity for reflection on *empowerment* in nursing care of individuals with diabetes. She also outlines how nurses can include empowerment in their practice in addition to the standard pharmacological and behavioural approaches. **Key words: diabetes, empowerment, practice models of**

Kearney, M. (1997). Drug treatment for women: Traditional models and new directions. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 26(4): 459-468

The author reviews current models of drug treatment for women including 12 step programs that 'emphasize powerlessness'. Using a feminist analysis, she outlines what she sees as a more *empowering* and woman-centric model of care that includes: cultural compatibility, treating women in context of their life circumstance and community, spirituality and the relational model of empowerment. **Key words: empowerment, drug abuse, treatments for, 12 step groups, critique of**

Humphreys, K. (1997). Individual and social benefits of mutual aid self-help groups. *Social Policy*, 27 (3)

The author reviews research on *mutual aid/self-help groups (mash)* prior to 1995 with respect to various health issues. He cites a number of important studies that relate to risk factors for stroke.

1. **Obesity and weight loss**- One of the largest MASH studies ever conducted showed that a *peer-led self-help* organization in Norway produced significant weight loss among members. Average weight loss over 8 weeks in a sample of 10,000 participants was 15 pounds. Follow-up studies showed that most group participants maintained their weight loss a year later (Grimsmo, Helgesen & Borchgrevink, 1981).

2. **Alcohol abuse**-Using meta-analysis, Emrick and colleagues (1993) combined data from more than 50 studies of Alcoholics Anonymous (AA) and concluded that AA involvement is moderately associated with reduced alcohol problems and improved psychological adjustment.

3. **Sickle Cell Disease**-African Americans who have sickle-cell disease and become highly involved in MASH groups report reduced emotional upset and decreased interference of the disease with their work and relationships (Nash & Kramer, 1993).

4. **Diabetes**- A group of East Asians living in Coventry, U.K., have operated a successful MASH organization for diabetic immigrants for a number of years. The research team that helped start the group also evaluated its effects over a one-year period and found that individuals attending two or more times had a 22 percent increase in knowledge about diabetes (based on standardized interviews), and were 12 percent less likely to have high levels of glycated hemoglobin (Simmons, 1992). In contrast, individuals attending the group once or never showed little change on these important outcomes at 1-year follow-up. Another study supplemented traditional professionally-provided patient education with a professionally organized but patient-run MASH group. Male diabetic patients who had their diabetes education supplemented with MASH groups showed better knowledge of diabetes, higher quality of life, and lower depression than patients who received only the education component (Gilden et al., 1992).

Key words: self-help research on risk factors prior to 1997, alcohol abuse, obesity, weight loss, sick cell, diabetes

Kessler, R., Mickelson, K. and Zhao, S. (1997). Patterns and correlates of self-help group membership in the United States. *Social Policy* 27(3): 27-47

Results of this study indicated that more than 25 million Americans are estimated to have participated in a *self-help group*. More than one third of the participants are involved in groups for substance use problems. The second largest segment attend groups around food, obesity and weight issues. One distinctive finding is that those with lower levels of family support were more likely to participate in self-help groups than those with higher levels of support. **Key words: self-help group participation, substance abuse, obesity, food**

Voorhees, C., Stillman, F., Swank, M., Heagerty, P., Levine, D. and Becker, D. (1996). Heart, body, and soul: Impact of church-based smoking cessation interventions on readiness to quit. *Preventive Medicine*, 25: 277-285.

The authors compared the effectiveness of a culturally-specific Church-based quit program with the distribution of generic materials on smoking cessation. The Church-based program included one to four pastoral sermons on smoking, testimony during church services from individuals going through the quit process, training of volunteers as lay smoking-cessation counselors, access to individual or *group support* supplemented with spiritual audiotapes containing gospel music, a day-by-day scripturally guided stop-smoking booklet, and baseline and follow-up health fairs. Results showed participants in the culturally specific Church program were significantly more likely to make progress than those just receiving materials. In addition, Baptist participants in the intervention program were three times more likely to make progress than others. **Key words: smoking cessation, race/ethnicity, Church based self-help programs, success of**

Carleton, R., Lasater, T. Assaf, A., Feldman, H., McKinlay, S. (1995). The Pawtucket Heart Health Program: Community changes in cardiovascular risk factors and projected disease risk. *American Journal of Public Health* 85 (6): 777-785.

The authors report on a community-wide education program and whether it changed cardiovascular risk factors and disease risk in Pawtucket, RI. After all citizens aged 18-64 participated in multilevel education, screening, *mutual aid* and counseling programs for 7 years, projected cardiovascular disease rates were significantly (16%) less, as were increases in body mass index. However, other results were less encouraging. The authors note that although cardiovascular risk reduction at the community level is feasible, maintenance requires a sustained community effort with reinforcement from state, regional, and national policies and programs. **Key words: population health, community education, mutual aid, risk factors, policy recommendations**

Hildingh, C., Fridlund, B. and Segesten, K. (1995). Social support in self-help groups, as experienced by persons having coronary heart disease and their next of kin. *International Journal of Nursing Studies*, 32(3): 224-232.

In this qualitative study, the authors tried to understand how social support works in a number of Swedish *self-help groups* for older adults with CHD. Run by the members and supported by the Swedish National Association for Heart and Lung Patients, 'Heart ten' participants expressed "a feeling of solidarity and fellowship" which encouraged members to share their experiences. This sharing, argue the authors, 'enhanced their well-being and encouraged them to go ahead and sort of their situations' (227). The authors suggest that "the self-help group related to CHD may be a cornerstone in a network of support" (231).

Key words: self-help, coronary heart disease, social support, Sweden

Sobel, D. (1995). Rethinking medicine: Improving health outcomes with cost-effective psychosocial interventions. *Psychosomatic Medicine*, 57(3): 234-244

The author, an MD, makes an overwhelming case for the importance and effect of thought, emotion, self-efficacy, *empowerment* and confidence on health. Citing multiple studies (including those on *self-help and empowerment*), "what goes on in a person's head", he writes, "can have a dramatic effect on the onset of some diseases, the course of many, and the management of nearly all". Nearly one-third of patients who visit a doctor have bodily symptoms as an expression of psychological distress. Another third have medical conditions that result from behavioral choices such as smoking, alcohol and drug abuse, poor diets, and so forth (also linked to emotion). Among the remaining patients with medical diseases such as arthritis, heart failure, or pneumonia, the course of their illness can be strongly influenced by their mood, coping skills, and social support.

Key words: emotion, mental health, empowerment, self-efficacy, social support as factors in health

Stroke Recovery and Secondary Prevention: Current Trends in the Research

Ethnicity and Race

Claiborne Johnston, S., Fung, Gillum, Smith, Brass, Lichtman and Brown. (2001). Utilization of intravenous tissue-type plasminogen activator for ischemic stroke at academic medical centers: The influence of ethnicity. *Stroke*, 32:1061-1068.

The authors measured the overall rate of usage of tissue-type plasminogen activator (tPA) for ischemic stroke at academic medical centers to determine whether ethnicity was associated with usage. Between June and December 1999, 42 academic medical centers in the United States each identified 30 consecutive ischemic stroke cases. Medical records were reviewed and information on demographics, medical history, and treatment were abstracted. The authors found that African Americans were one fifth as likely to receive tPA as whites (1.1% African Americans versus 5.3%; $P=0.001$), and the difference persisted after adjustment (OR 0.21, 95% CI 0.06 to 0.68; $P=0.01$). Medical insurance type was independently associated with tPA treatment. After adjustment for ethnicity and other demographic characteristics, those with Medicaid or no insurance were one ninth as likely to receive tPA as those with private medical insurance (OR 0.11, 95% CI 0.02 to 0.17; $P=0.003$). **Key Words: race, African American, association with poor treatment of stroke**

Exercise

Duncan, P., Richards, L., Wallace, L., Stoker-Yates, J., Pohl, P., Luchies, C., Ogle, A., Studenski, S. (1998). A randomized, controlled pilot study of a home-based exercise program for individuals with mild and moderate stroke. *Stroke*, 29: 2055-2060.

30-90 days after stroke, twenty minimally and moderately impaired patients who had completed rehab were randomly placed in control and experimental groups. The experimental group received therapist-supervised, 3-times-per-week, home-based exercise program. The control group received usual care as prescribed by the patients' physicians. The experimental group tended to improve more than the control group with respect to measures of neurological impairments and lower extremity function. **Key words: group exercise, stroke rehabilitation**

Socioeconomic Status

Kapral, M., Hua Wang and Mamdani, Tu. (2000). Effect of socioeconomic status on treatment and mortality after stroke. *Stroke*, 33:268-275.

Reviewing information on all patients with acute stroke admitted to hospitals in **Ontario** between April 1994 and March 1997, socioeconomic status for each patient was inferred on the basis of median neighborhood income. Secondary analyses compared the use of medications, inpatient rehabilitation services, and carotid endarterectomy by socioeconomic status. Of 38 945 patients, each \$10 000 increase in median neighborhood income was associated with a 9% reduction in the hazard of death at 30 days and a 5% reduction in the hazard of death at 1 year. Patients in the lowest income quintile were less likely than those in the highest to receive in-hospital physiotherapy, occupational therapy and speech pathology. There were no differences in the use of medications or carotid endarterectomy based on socioeconomic status. Waiting times for carotid surgery, however, were significantly longer in the lowest income quintile than the highest (90 days versus 60 days). "Other potential explanations for the higher mortality observed with lower socioeconomic status include greater disease severity or an increased prevalence of cerebrovascular disease risk factors and other comorbid conditions. In addition, medication adherence, stress, social isolation, and other unmeasured factors may all be important income-related determinants of survival after acute stroke". **Key Words: ses, class, stroke outcome and treatment**

Kunst, AE, del Rios, Groenhof and Mackenbach (1998). Socioeconomic inequalities in stroke mortality among middle-aged men: An international overview. *Stroke* 29:2285-2291.

In all countries reviewed, manual classes had higher stroke mortality rates than nonmanual classes. This difference was relatively large in England and Wales, Ireland, and Finland and relatively small in Sweden, Norway, Denmark, Italy, and Spain. In most countries (including the US), inequalities were much larger for stroke mortality than for ischemic heart disease mortality. Socioeconomic differences in stroke mortality are a problem common to all countries studied. **Key Words: SES, class, risk, stroke mortality**

Stroke Recovery and Social Support

Clarke, P. ,Marshall, V., Black, S. and Colantonio, A. (2002). Well-being after stroke in Canadian seniors: Findings from the Canadian Study of Health and Aging. *Stroke*. 33: 1016-1021.

Using data from the Canadian Study of Health and Aging II, the authors looked at a national sample of 5395 community-dwelling Canadian seniors and compared health, social and demographic characteristics for 339 stroke survivors to community-dwelling seniors who had not experienced a stroke. Stroke survivors reported a lower sense of well-being and worse mental health. However, both were eased by the presence of strong *social supports*.

“Social supports have elsewhere been found to be associated with a higher quality of life in stroke survivors...and our results help to explicate the operative role that social support plays as a moderator of the effects of disability on well-being....Collectively, these findings highlight the salience of support systems for well-being after stroke and emphasize the ongoing importance of developing appropriate programs that enhance and reinforce the social supports and social networks of stroke survivors. Not only are strong supportive social systems vital for the well-being of seniors who have had a stroke, but they may also operate indirectly to reduce further strain on the healthcare system.” (1020)

Key Words: aging, disability, evaluation, quality of life, social support

Chang, A., Mackenzie, Yip and Dhillon (1999). The psychosocial impact of stroke. *Journal of Clinical Nursing*, 8: 477-481. Using various scales in their Hong Kong study of stroke survivors and ‘healthy people’, the authors find that self-esteem and levels of *social support* are important factors in rehabilitation, affecting who recovers and how. **Key words: social support, self-esteem, rehabilitation, stroke, Hong Kong**

Stroke Recovery and Self-help, Mutual aid, Empowerment or Adult education

Al-Shafi, Rustam. (2000). Stroke-Conference Reports. *Journal of the Royal College of Physicians of London*, 34(1):97-99.

The author reports on a medical conference around new issues with stroke, the third leading cause of death world-wide. He highlights a presentation made by the leader of Different Strokes in the UK. Promoting *self-help and fostering mutual support*, the group was set up by younger stroke survivors for younger stroke survivors. The author concludes that the challenge now is to “maintain this momentum with government support” and increase public awareness and support for stroke. **Key words: self-help, stroke survivors, medical acceptance of, proposed policy around**

Dowswell, G., Lawler, J. Dowswell, T., Young, J., Forster, A. and Hearn, J. (2000). Investigating recovery from stroke: A qualitative study. *Journal of Clinical Nursing*, 9: 507-515

To examine the qualitative experience of patients and caregivers during the year of recovery after a stroke, the authors used semi-structured interviews with a purposively selected sample of 30 patients and 15 caregivers. Patients had very individual yardsticks for measuring their recovery including the degree of congruence between their lives before and after stroke. Four of the 30 patients mentioned the importance of social support in recovery and especially the *mutual aid* available in certain rehabilitation programs and stroke clubs.

They sent a taxi to take me to the Social Service Day Centre. I just go on a Monday now. I've tried to kid them on to take me more, but it's nice you meet other people there and there's all different ones and you say, well, they're worse than me! You always see somebody worse. (509)

Key words: recovery, stroke, individual process of, social support, mutual aid

Shapero Sabari, J., Meisler, J. and Silver, E. (2000). Rehabilitation in practice: Reflections upon rehabilitation by members of a community based stroke club. *Disability and Rehabilitation*, 22 (7): 330- 336

The authors did an ethnographic study of a *co-led self-help group* for stroke patients and caregivers. 10 participants of this on-going group met bi-weekly at the home of a group member. Six of the participants were stroke survivors and the remaining four participants were wives of the male stroke survivors. Group members ranged in age from 45- 75 years and were all from middle and professional socioeconomic backgrounds. All resided, and had participated in rehabilitation programs in a major urban community. Length of time post-stroke ranged from eight months to five years. Ethnographic analysis identified a number of themes in group discussions including perceptions around 'being dumped by the system too soon', lack of individualized and personal care post stroke and lack of information about other supports in the community. The study suggests that members in such groups need more care post stroke. **Key words: self-help group, stroke patients, caregivers, discussions in, themes of, poor perception of formal stroke care**

Weltermann, B., Homann, Rogalewski, Voss, and Ringelstein, E., (2000). Stroke knowledge among stroke support group members. *Stroke*, 31: 1230-1233

The authors surveyed 11 German stroke *support/mutual aid groups* and found 80.3% had good symptom knowledge, 64.7% had good risk factor knowledge, and 79.7% had good action knowledge. Stroke knowledge was excellent in 44.0% of subjects. The authors suggest that because of their knowledge and personal experience, support groups should be viewed as important partners in community

stroke education. **Key words: self-help groups for stroke, knowledge of stroke in, potential role in community stroke education**

Family/Caregivers and Social Support

Lincoln, N., Francis, V., Lilley, S., Sharma, J. and Summerfield, M. (2003). Evaluation of a stroke family support organiser: A randomized controlled trial. *Stroke*, 34:116-121

Stroke patients admitted to hospital in the north of Britain and their informal caregivers were randomly allocated to receive the FSO service or standard care. Assessments were done at 4 and 9 months after recruitment. The study found no significant differences in patients' mood, independence or caregivers' mood, strain, or independence. However, both patients and caregivers in the intervention group were significantly more knowledgeable about whom to contact for stroke information, practical help, community services, and emotional support. **Key Words: caregivers, stroke management, stroke knowledge, social support**

Brereton, L. and Nolan, M. (2002). Seeking: A key activity for new family carers of stroke survivors. *Journal of Clinical Nursing*, 11: 22-31.

The authors report on a study of family caregivers in the UK and, following a series of lengthy interviews, identify various themes common to all. These include: uncertainty and confusion, a sense of isolation, relative lack of *support*, feelings that their own needs were overshadowed by those of the stroke survivor and that their *experiential knowledge* of their relative was often overlooked by professionals. The authors advocate for more collaboration between caregiver and professional and more attention to their support and information needs. **Key words: caregivers, lack of social support, experiential knowledge, neglect of by professionals**

Harding, J. and Lincoln, N. (2000). An observational study of the Stroke Association family support organizer service. *Clinical Rehabilitation*, 14: 315–323.

Family support organizers (FSOs) were observed on home and hospital visits to stroke patients and their caregivers in the North-West and Midland regions of Britain. The majority (71%) of visits took place in the patient's home, with both patients and carers (39%). The authors found that FSOs spend more time engaged in practical rather than emotionally supportive activities, raising questions about their role in stroke recovery and care. **Key words: recovery, social support, types needed by patients and caregivers following stroke**

Family/Caregivers and Self-help, Mutual aid, Empowerment or Adult education

Pierce, L., Steiner, V. and Govoni A. (2002). In-home online support for caregivers of survivors of stroke: A feasibility study. *Computers, Informatics, Nursing*, 20(4): 157-164.

This small study (n=5) aimed to determine if caregivers of survivors of stroke were willing and able to use in-home mediated *on-line mutual aid* and information. Investigators developed a site called The Caring Web to provide interaction with a nurse specialist, educational information about stroke, caring, and caregivers using linked Web sites and opportunities for on-line mutual aid and discussion between caregivers. Despite some preliminary technical issues, findings suggest caregivers were willing and able to use Caring Web and receptive to using the Internet for health information and social support. **Key words: on-line mutual aid, caregivers of stroke patients**

Policy Recommendations

Hanger, C. and Wilkinson, T. (2001). Stroke education: Can we rise to the challenge? *Age and Ageing*, 30: 113-114.

Noting that psychosocial and family issues have been neglected in stroke discourse, the authors point to the *adult education model* as well as *self-help/mutual aid* as valuable but neglected tools in stroke education. They argue that practitioners need to think more broadly in terms of tools and techniques. **Key words: stroke education, practice, adult education**

Hill, M. (1998). Behavior and biology: The Basic Sciences for AHA Action. Presented at the 70th Scientific Sessions of the American Heart Association. November 9, 1997. Orlando, Florida. *Stroke* 29:739-742

The author argues that "unhealthy habits account for about 54% of known contributions to heart disease". Behavioral and biological interventions can reduce morbidity, disability, and death due to heart disease and stroke. The author proposes a new paradigm for risk factor management that should:

- develop the health promotion skills of health professionals and the public
- encourage patients, providers, and the healthcare system to work together as partners
- help patients make decisions about treatment
- develop a comprehensive approach to risk factor management, "The Compliance Action Program," which will involve patients, providers, and the healthcare system.
- expand interdisciplinary health-focused models

- recognize the importance of the public's growing use of *self-help* as well as cultural and ethical issues in communities and patients' lives

Greenland, P. (1996). The future of cardiovascular medicine: An opportunity for prevention and rehabilitation. *Journal of Cardiopulmonary Rehabilitation*, 16 (4): 219-225

Reviewing the history of cardiovascular medicine in the US and recent changes and issues, the author makes a number of recommendations for good medicine in the future: "risk factor modification should remain an important need", system-wide approaches will be an increasing focus of prevention and rehabilitation in cardiology, home care or other nontraditional care forums (such as support groups) will be increasingly used, traditionally undeserved populations will need extra attention. **Key words: cardiovascular medicine, future recommendations for, importance of target groups and risk factors in prevention**

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