

Stress Management and Coping Skills for Women with Disability

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PSYCHOSOCIAL FACTORS IN MANAGING STRESS

Selye (1974) defined stress as " the nonspecific response of the body to any demands made upon it," and stressors can be physical, psychological and interpersonal. Due to the fact that women may have fewer caregiving resources and significantly fewer financial resources than men, women living with disabilities are at a greater risk of increased stress. Individuals with physical disabilities have been found to have a greater lifetime incidence of anxiety and depressive disorders (Aoki, Hishada and Ishida, 1995; Turner and McLean 1989). In a review of research regarding adjustment to disability, Livneh and Antonak (1994) concluded that most disabled individuals experience anxiety, denial, and depression before attaining acceptance and adjustment to disability.

There are very few studies looking at gender differences in coping with a disability or with regard to the impact of stress upon health. As is typical in most medical research, women frequently are not included in research studies, or are included in disproportionately small numbers in the samples. In July 1990, Congress passed legislation to help improve the inclusion of women in medical research under the Women's Health Equity Act. Since that legislation, the National Institutes of Health established an Office of Research on Women's Health and strengthened its policies regarding including women and people of color in clinical research (Hornyak and Green, 2000). In addition, there has been a history in medical care of a separation between psychological or psychosocial issues and what are considered to be purely medical factors. It is only recently that there has been more of an effort to look at health care from a perspective that integrates a biological, psychological, and social perspective.

As Gilchrist (1998) noted, "Gender specific barriers exist in both access to and quality of care for U.S. women." Although women use health services more frequently than men do, they are more likely than men to:

- encounter financial barriers to obtaining care;
- not receive preventative services;
- have their health concerns dismissed by a male physician as being "merely" emotional;
- have serious medical conditions be misdiagnosed and mistreated by physicians who have received no training in women's health;

- have serious health affecting conditions (e.g., eating disorders, chemical dependency, depression, and sexual dysfunction) be missed or ignored by their health care providers; and
- face an especially confusing service system, where it is unclear which type of provider (gynecologist, family/primary care physician, internist) they should turn to as their appropriate source of care (p. 288).

Gilchrist's writings refer to *all* women; the difficulties of obtaining quality health care is only increased for women with physical disabilities. Due to the many issues which are present in coping with a disability, it is essential that the psychosocial aspects of health care for disabled women be considered. Particularly important is the interrelationship between the physical limitations or restrictions a disabled woman may experience and the impact of these limitations/restrictions on her body image, self-esteem, sense of competence, sexual relationships, and family/partner relationships, as well as her ability to manage financial pressures, the higher risk for depression and anxiety, and possible ongoing pain. Approaching the care of women with physical disabilities from the framework of an integrated bio-psycho-social model -- rather than separating medical from psychological approaches -- is essential. Such a model is more comprehensive, and in the long run may lead to more clinically-effective, as well as cost-effective, treatments. In addition, many resources are already available that could assist women with coping with their disabilities and with the potential stress or pain, but often women are not provided with education or resources to assist them with developing coping skills.

IDENTIFYING STRESSORS

Crewe and Clarke (1996) outline frequent stressors for women with disabilities including difficulties with transportation (which may include needing extra time, planning, and additional cost) and barriers such as unshoveled sidewalks, lack of curb cuts, and inaccessible bathrooms. Even the effects of people staring may take a psychological toll. For those who need help with personal care, a major stressor is finding reliable personal care assistance. As women with disabilities are the lowest paid of any group of workers, the difficulties related to obtaining good personal care may be exacerbated by an inability to afford consistent attendants. Other stressors can be caused by a woman's experience of abuse by a caregiver or partner. Under most state laws, caregiver abuse is not considered domestic violence, and a disabled woman who is experiencing abuse by a personal assistant may find that she is not eligible for services in a shelter. A disabled woman who is experiencing abuse by a partner may not be able to find accessible facilities in a battered women's shelter, and thus may be limited in her ability to find a safe haven or access support services (Platt, 1999).

In terms of relationships, it has been shown that women with early onset disabilities usually date later and have their first sexual experiences later than women without disabilities (Rouso, 1996). Women with disabilities are less likely to be married than disabled men, and are more likely to become divorced. Disabled women with children are often single mothers (Fine and Asch, 1985). It is frequently difficult for women who have been "conditioned" to be the caregiver to accept having to be cared for, and they may feel ongoing shame or psychological conflict over their need to receive care. All of this contributes to lower income, fewer resources and a lack of social support.

In a research study exploring perception of stress in individuals with spinal cord injury, Rintala, Hart and Furher (1996) reported that women with spinal cord injuries had more perceived stress than men with similar injuries. Spinal cord-injured women reported more depressive symptomatology than the men in the sample, and were more likely to be living with a child. Spinal cord-injured men had higher incomes, more education and greater mobility than women with comparable injury. Fine and Asch (1985) also found that disabled women were less likely to be employed and have lower incomes than disabled men, or to live at or below the poverty level.

Special stressors exist for disabled women in certain subpopulations that are subject to particular difficulties. The "double jeopardy" was coined to refer to the dual discrimination that African-American women face. Glenn (2001) describes African-American women with disabilities as facing further disadvantage or "triple jeopardy", because they represent three distinct minority groups in American society based upon their gender, race/ethnicity, and disability. A woman who is disabled and who is also a woman of color and/or a lesbian may have to deal with multiple levels of jeopardy and, often, marginalization that can cut her off from her expected communities of support, and cause additional life stress.

Disabled lesbians face not only the same stressors as nondisabled women, such as lower income and barriers to employment, but additional stressors, such as fears of being discovered and/or losing a job because of sexual orientation, ostracism by family members, hidden domestic violence, or problems resulting from homophobia. Researchers have found that as many as 72% of lesbians surveyed described having received negative responses from health care providers due to their sexual orientation, including not receiving appropriate treatment, being refused care, or being sexually harassed (Warren, 1993, O'toole, 1996).

In a recently published anthology of writings by disabled lesbians -- one of the very few resources for lesbians with disabilities -- co-editor Victoria A. Brownworth refers to the additional isolation faced by disabled lesbians, who frequently do not have access or inclusion within the feminist or lesbian community due to their physical disability (Brownworth and Raffo, 1999). In addition, many of the resources of the gay community have targeted services to people with HIV/AIDS, and few resources are left for meeting the needs of disabled lesbians. Moreover, the stressors of disability or injury are considerably increased if a lesbian's partner lacks legal access or acknowledgment by the medical establishment or the biological family when she requires medical treatment or hospitalization. The biological family can assume legal decision-making over the lesbian partner; in a famous legal battle, Sharon Kowalski's birth family was able to deny any role to her partner, Karen Thompson, when Sharon was hit by a drunk driver and was permanently and severely disabled (O'Toole, 1996).

MEDICAL FACTORS ASSOCIATED WITH STRESS

Cannon (1932) was the first to describe the body's physiological changes in reaction to stress. He coined the phrase "fight or flight response" to describe physical preparation for dealing with a threat to survival, by either direct confrontation or escape. Seyle (1974) discovered the cerebral cortex sends an alarm signal to the hypothalamus when a threat is perceived. The hypothalamus then stimulates the sympathetic nervous system, and the release of the hormones epinephrine and norepinephrine from the adrenals, to prepare the body for fight or flight. Respiration, muscle tension, heart rate, blood

pressure, and perspiration increase, senses sharpen, and pupils dilate. Blood is directed away from the extremities and digestion to the larger muscles to help prepare the body to fight or run away (Davis et al., 1988; Benson, 2000). These fight or flight responses were intended to be short-term.

In chronic stress situations, overactivity in bodily systems such as the musculo-skeletal, cardiovascular, or gastrointestinal system can result. This may cause stress hypertension, which can damage coronary arteries over time. Chronic digestive difficulties such as colitis or diverticulitis can also result. Stress responses can inhibit sexual functions and can cause amenorrhea. Asthma, bronchitis and other respiratory conditions can arise. Continued loss of insulin during chronic stress responses may contribute to do the onset of diabetes. In addition, stress is related to headaches, fatigue and possibly arthritis (Davis, *et al.*, 1988). Komaroff (2001) notes that "Because chronic stress can inhibit the deposition of calcium in bone, it is linked to osteoporosis and skeletal atrophy. Under truly extreme conditions chronic stress can stop children from growing." It appears that in chronic stress situations, it is partly the glucocorticoid secretions from the adrenals which have an effect upon the immune system. They can affect the production of white blood cells, which are critical to the destruction of invading bacteria and viruses. Over time, this can create vulnerability to infection or disease. The continued depletion of norepinephrine during chronic stress may also contribute to major depression.

Recent research by Taylor et al. begins to address a huge gap in the stress response literature, i.e., almost all studies have been conducted with men only and have always held that "fight or flight" is the main response to stress (Taylor, et al., 2000; Azar, 2000). Females may respond to stressful situations differently than males, by protecting themselves and their young through nurturing behaviors and the formation of alliances with a larger social group, particularly other women, referred to as the "tend and befriend" model. After looking at neuroendocrine responses in research, they found that women do show the same immediate hormonal and sympathetic nervous system responses to acute stress. However, in rat behavior studies there is some evidence to show that there may be a physiological response to stress that inhibits the flight reaction via the release of the hormone oxytocin. Some studies have even found that mothers tend to be more nurturing and caring when they are most stressed. In both animal and human studies there is evidence to suggest that females prefer being in social groups especially with other females, while males do not, during times of stress. In humans, women are much more likely than men to seek out and use social support in all types of stressful situations, including health-related concerns. "It is one of the most robust gender differences in adult human behavior," writes Taylor. This research may open a new line of inquiry regarding affiliation needs, and suggests the value of support groups for women who are coping with acute and chronic stressors.

TREATMENT APPROACHES/ COPING SKILLS

Medical researchers and psychoimmunologists have been studying the effectiveness of various techniques to reduce, reverse or mediate some of the detrimental consequences of chronic stress, with most studies focusing upon cancer. Innovative new programs have begun to address stress management along with medical management, in order to help compliment treatment and promote healing and recovery. As a pioneer in stress management techniques, Dr. Herbert Benson developed a program through Harvard Medical School in 1975 which used components from meditation practice for cardiac

recovery and other medical conditions. His book, *The Relaxation Response*, was revised and republished in 2000. His technique promoted self-healing and appeared to help not just hypertension, but headaches, cardiac rhythm irregularities, pre-menstrual syndrome, anxiety, and mild to moderate depression. The “relaxation response” can decrease the over activity in the central nervous system, leading to reduction in blood pressure, slowing of heart rate, slowing of breathing rate, as well as decreased blood lactate, and return of balanced function to the gastro-intestinal system- all of which can be experimentally measured in the body. Similar findings have now been found in the use of progressive relaxation techniques and clinical hypnosis.

Based at the University of Massachusetts' Medical Center, Dr. Jon Kabat-Zinn's stress management program, based on mindfulness meditation and yoga techniques, has been taught nationally and now is part of stress management programs at hospitals and clinics across the country. Meditation can increase a disabled woman's confidence in her ability to handle physical and emotional pain as well as to manage the other areas of her life and feel less out of control (Kabat-Zinn, 1990).

Practices such as meditation, relaxation, hypnosis, and biofeedback may have a direct physiological impact upon the body, but even when that does not occur, people's perception of pain and their ability to cope with it can be altered. Participatory self-help techniques can provide a woman with a disability with an increased sense of direct control and can also promote healing in a way that complements medical interventions. We suggest that providers ask questions (about social support, attendant coverage, etc.) to assess stress, and make referrals to services such as:

Support Groups

Spiegel's groundbreaking study in 1989 showed an increase in mean survival time for women with metastatic breast cancer, when they participated in a support group. The groups were led by a therapist for 90 minutes, once weekly for one year. Participants expressed feelings about their disease and its impact upon their lives. The group was an attempt to combat social isolation and to provide support and coping skills. A self-hypnosis strategy was included for pain control. The dramatically beneficial results perhaps are consistent with the hypothesis of Taylor, *et al.* (2000) regarding the powerful role of affiliation in mediating the negative physiological impact of stress in women. Many national and regional chapters provide local support groups and educational services, such as the MS Society, National Cerebral Palsy Foundation, American Diabetes Association, etc.

Meditation Classes

Local meditation classes are readily available through religious groups, adult education programs or community centers. Many forms of meditation utilize diaphragmatic breathing techniques, which promotes physiological relaxation. Meditation often focuses upon acknowledgement of suffering and painful emotions, which may be helpful for ongoing adjustment. Mindfulness methods in the model of Kabat-Zinn are taught at many hospitals and clinics across the country.

Exercise

Aerobic exercise can be of great value in stress reduction as well as overall health. Some recreation programs designed specifically for people with disabilities offer weight

training with a volunteer assistant to help one-on-one with set-up and spotting. Swimming can be an excellent non-weightbearing aerobic exercise. Many local YWCA/YMCA's and Easter Seals Societies have pools that are accessible and that may have lifts to assist in entry and exit from the water. Changing facilities vary, so women may need to call ahead to ensure shower and changing areas are adequate, especially if a mat table is needed.

Local classes in Yoga, Tai Chi or other martial arts are frequently helpful in stress management and relaxation. However a preliminary call to inquire about accessibility and adaptation of the class to accommodate disabilities is essential. Many groups report that people with physical disabilities are welcome, however individuals still have the experience of arriving for class and finding that there is no way the exercise can be adapted to accommodate them, or the building is not accessible to them.

Psychotherapy

Falvo (1991) outlines how disability can pose multiple threats to one's sense of self and identity, physical well-being and sense of body integrity, sense of independence, privacy, ability to fulfill customary roles, pursue life goals and future plans, and one's ability to sustain relationships. In chronic disability or illness, anxiety can arise from the threat of these losses. When support groups do not offer enough help, especially in cases of clinical depression, suicide risk or anxiety attacks, referral to a psychologist, psychiatrist or licensed clinical social worker is recommended.

Hypnosis

Clinical hypnosis has been found to help enhance patients sense of self-control, and through self-hypnosis an individual can continue to work on symptom reduction in the areas of pain or stress in the absence of the therapist (Kaye and Schindler, 1990). Hypnotic interventions can be helpful in reducing anticipatory anxiety. For pain management (with a limited number of highly hypnotizable people), techniques may incorporate the use of hypnotically induced analgesia.

Body image is frequently an area of increased concern for women with a disability. Hornyak (2000) has designed a treatment model for utilizing hypnosis and body image for women with physical illnesses. Treatment goals are formulated around seven dimensions:

- restoring comfort;
- restoring a sense of competence;
- accepting appearance;
- coping with unpredictability;
- addressing body integrity;
- enhancing aliveness; and
- evolving identity.

Generally, hypnosis is established through an induction procedure that includes suggestions for becoming relaxed and promoting a sense of well-being. Hypnosis is used to address a wide range of women's health concerns, including chronic pelvic pain,

breast and gynecological cancers, cardiac disorders in women, childbirth and infertility, menopause, eating disorders and physical illness (Hornyak and Green, 2000).

Progressive Relaxation

Deep muscle relaxation techniques are described as having the ability to reduce physiological tension, which is incompatible with anxiety (Davis, et al., 2000). Excellent results have been found when this is applied in the treatment of tension, anxiety, insomnia, depression, fatigue, irritable bowel, neck and back pain, and high blood pressure. This technique involves moving through the body and focusing upon particular muscle groups and learning to distinguish between sensations of tension versus deep relaxation. Generally, all muscle groups are included but it is easy to adapt this procedure to just move through the muscle groups for which an individual is able to have sensations.

Biofeedback

Often biofeedback is combined with other stress reduction exercises including deep breathing techniques or visualization. Biofeedback machines provide immediate information about physiological states, including muscle tension, skin surface temperature, brainwave activity, skin conductivity, blood pressure and heart rate (Davis, et al., 2000). Initially the instrumentation can help an individual develop the ability to read tension in various bodily systems and how to lower muscle tension or blood pressure or increase temperature in order to counteract stress or pain. The individual is taught how to detect the early signs of hyperarousal and to utilize other techniques to help correct this. Over time, one is trained to do this without the use of the instrument. There are several types of biofeedback training:

Electromyogram (EMG) training, the most frequently used, which involves monitoring of skeletal muscle tension to treat muscular tension, insomnia, anxiety, psychosomatic disorders, colitis, menstrual distress and tension headaches.

Thermograph or temperature training, which monitors fluctuations in body temperature. Generally, skin temperature lowers due to peripheral vasoconstriction, which occurs during anxiety or stress experiences. This technique is based on the premise that voluntarily raising skin temperature will produce an antistress effect. Temperature training has been successful with migraine headaches and vascular problems often associated with cold hands and feet (Davis, et al., 2000.).

Galvanic skin response (GSR) training, which measures the electrical potential in skin by monitoring tiny changes in the concentration of salt and water in sweat gland ducts, thus monitoring the sympathetic branch of the autonomic nervous system. GSR training is often used in the treatment of excessive sweating, phobias and anxiety states, usually in conjunction with EMG and temperature training.

EEG training, which is a method of monitoring brain waves, which is frequently used in the treatment of insomnia and to promote relaxation.

Political Action/Social Change

Involvement in local political work or community organizations to create wider accessibility, education about needs of disabled women, funding for enhanced vocational rehabilitation and to promote full inclusion are proactive ways to channel

anger or frustration into productive societal change. The ability to take action and channel stress into positive activities can be an effective way to reduce the debilitating effects of stress.

RESOURCES

Organizations:

American Psychological Association

750 First Street, NE
Washington, D.C. 20002-4242
(800) 374-2721 TTD/TTY: (202) 336-6123
www.apa.org

Provides information about training and licensure of psychologists, treatment, and publications on hypnosis, stress and pain management, cognitive-behavioral therapies, etc. In addition, most counties have local affiliate chapters listed in the Yellow Pages, and each state has an association, which can provide referrals to local psychologists with cognitive-behavioral, stress or pain management, hypnosis or biofeedback specialties.

American Society of Clinical Hypnosis

130 East Elm Court, Suite 201
Roselle, IL. 60172-2000
(630) 980-4740 www.asch.net

Provides information about clinical hypnosis, certification of practitioners, and referrals to providers.

Association for Applied Psychophysiology and Biofeedback

10200 W. 44th Ave., Suite 304
Wheat Ridge, CO 80033-2840
(800) 477-8892 www.aapb.org

Provides information about the field, and referrals to biofeedback practitioners.

Center for Cognitive Therapy

5435 College Ave.
Oakland, CA.
(510) 652-4455

Provides group and individual treatment for depression, anxiety, phobias, social skills training, etc.

Center for Mindfulness in Medicine, Health Care, and Society

University of Massachusetts Medical School
55 Lake Ave., North
Worcester, MA 01655
(508) 856-2656

Founded by Dr. Jon Kabat-Zinn in 1975. The Center provides information on stress-reduction programs and runs a clinic for treatment. Mindfulness meditation practice tapes which accompany his book *Full Catastrophe Living* can be ordered from www.mindfulnessstapes.com. There are many practitioners who offer classes in this method through other stress management programs nationwide.

Mind/Body Medical Institute

110 Francis St.

Boston, MA 02115

(617) 632-9543 www.mbmi.org

Founded by Dr. Herbert Benson who started the Relaxation Response method. There are affiliate locations in several states across the country.

Spirit Rock Meditation Center

P.O. Box 169

Woodacre, CA 94973

(415) 488-0164 www.spiritrock.org

Provides classes, day long and residential retreats in insight meditation, with occasional special programs for women, gays & lesbians and people of color.

The Stens Corporation

6451 Oakwood Drive

Oakland, CA. 94611

(800) 25-STENS

Sells biofeedback equipment and trains professionals.

Self-Help Books:

A Woman's Guide to Coping With Disability (3rd ed.)

(2000). Resources for Rehabilitation

Provides resources about federal laws, housing, driving, travel, medical care including pregnancy and childbirth, sexuality, assistive devices, books, and referrals to organizations.

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness;

by Jon Kabat-Zinn, Ph.D. (1990) New York: Delta.

An introduction to mindfulness meditation and yoga, with tapes which can be purchased for independent relaxation practice. The walking meditation and yoga sections are not adapted for physical disabilities or wheelchair dependence however.

Managing Pain Before It Manages You,

by Caudill, M. M.D., Ph.D. (1995). New York: Guilford Press.

A popular self-help workbook for managing chronic pain.

the Relaxation Response

by Herbert Benson, M.D. (2000) New York: Avon

Provides information about meditation for relaxation and stress reduction. Dr. Benson's work has focused on medical conditions including high blood pressure and heart disease, chronic pain and the harmful effects of stress.

The Relaxation and Stress Reduction Workbook,

by Davis, M., Eshelman, E.R., and McKay, M., 5th Edition (2000). Oakland, CA: New Harbinger

One of the best available self-help workbooks for stress management, with chapters on breathing techniques, visualization, meditation, time management, work stress, etc.

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