Krotoski DM, Nosek MA, Turk MA (eds): Women with physical disabilities: Achieving and maintaining health and well-being. Baltimore, MD, Paul H. Brookes Publishing, 1996, pp 431–440

 Rosenthal BJ, Scheinberg LC: Exercise for multiple sclerosis patients. In Basmanjian JV (ed): Therapeutic Exercise, ed 5. Baltimore, MD, Williams and Wilkins, 1990, pp 243–244

 Schapiro R. Multiple Sclerosis: A Rehabilitation Approach to Management. New York, Demos Publications, 1994

- 22. Schwartz CE, Foley FW, Rao SM, et al: Stress and the course of disease in multiple sclerosis. Behav Med 25:110–116, 1999
- 23. Stuifbergen A: Meeting the demands of illness: Types and sources of support for individuals with MS and their spouses. Rehabilitation Nursing Research 1:14–23, 1992
- 24. Stuifbergen A: Health promoting behaviors and quality of life among individuals with multiple sclerosis. Schol Inq Nurs Prac 9:31–50, 1995
- 25. Stuifbergen A: Physical activity and perceived health status in persons with multiple sclerosis. J Neurosci Nurs 29:238–243, 1997
- 26. Stuifbergen A: Barriers and health behaviors of rural and urban persons with MS. Am J Health Behav 23:403–414, 1999
- 27. Stuifbergen AK, Roberts GJ: Health promotion practices of women with multiple sclerosis. Arch Phys Med Rehabil 78:S3–S9, 1997
- 28. Stuifbergen AK, Rogers S: Health promotion: An essential component of rehabilitation for persons with chronic disabling condition. Adv Nurs Sci 19:1–20, 1997
- 29. Swank RL: Multiple sclerosis: Fat-oil relationship. Nutrition 7:368-376, 1991
- 30. Thierry JM: Promoting the health and wellness of women with disabilities. J Women's Health 7:505–507, 1998
- 31. Thompson AJ, McDonald WI: Multiple sclerosis and its pathophysiology. *In Asbury AK, McKhann GM, McDonald WI (eds): Diseases of the Nervous System: Clinical Neurobiology, ed 2. Philadelphia, WB Saunders, 1992, pp 1209–1228*
- 32. Timmerman G, Stuifbergen AK: Eating patterns in women with multiple sclerosis. J Neurosci Nurs 31:152–158, 1999
- 33. US Department of Health and Human Services Public Health Services. Healthy People 2000 (DHHS Publication No. PHS 91-50212). Washington, DC, US Government Printing Office, 1990
- 34. US Department of Health and Human Services: Healthy People 2010 Initiative to Guide Prevention Agenda for Next 10 Years. Washington, DC, HHS News, January 24–28, 2000
- 35. Van Noort JM: Multiple sclerosis: An altered immune response or an altered stress response? J Mol Med 74:285–296, 1996
- 36. Vickery BG, Edmonds ZV, Shatin D, et al: General neurological and subspecialist care for multiple sclerosis: Patient's perceptions. Neurology 53:1190–1197, 1999
- 37. Walker S, Sechrist K, Pender N: Health promoting lifestyle profile II. The University of Nebraska Medical Center, Omaha, NE, 1995
- 38. Walker SN, Sechrist KR, Pender NJ: The health-promoting lifestyle profile: Development and psychometric characteristics. Nurs Res 36:76–81, 1987
- 39. Wineman NM: Adaptation to multiple sclerosis: The role of social support versus functional disability, and perceived uncertainty. Nurs Res 39:294–299, 1990
- 40. Wingerchuk DM, Noseworthy JH, Weishenker BG: Clinical outcome measures and rating scales in multiple sclerosis trials. Mayo Clin Proc 72:1070–1079, 1997

Address reprint requests to

Alexa K. Stuifbergen, PhD, RN The University of Texas at Austin School of Nursing 1700 Red River Austin, TX 78701

e-mail: astuifbergen@mail.utexas.edu

# QUALITY OF LIFE FOR WOMEN WITH PHYSICAL DISABILITIES

Denise G. Tate, PhD, Sunny Roller, MA, and Barth Riley, PhD

Nearly one quarter (21.3%) of women in the United States are disabled—28.6 million.<sup>27</sup> Although women with physical disabilities make up a large segment of our population, information is sparse about their characteristics, the barriers they face in their daily lives, their special health problems and health care needs, and the quality of their lives—as individuals and as a group.<sup>31</sup> In a culture traditionally dominated by nondisabled men, women with disabilities are devalued and forced to subsist invisibly along the perimeter of life. They have little opportunity to experience vigorous prosperity, flourishing health, and full social participation. Even though the 1990s opened new doors for visibility and introduced embryonic hope for change, forced social, political, and economic exclusion continues to rob and oppress women with disabilities. Their quality of life (QOL) is often ignored, halted, and degraded.

Quality of life is a multidimensional construct that includes economic, physical, psychological, and social aspects.<sup>52</sup> For the purposes of this article, these domains are subcategorized into three designated areas: (1) economics, (2) health (physical and psychological), and (3) social

This work was supported by Grant No. 5 RO1 HD035053 03S2 from the National Center for Medical Rehabilitation Research, National Institute for Child and Human Development, National Institutes of Health; and Grant No. H133N50012-99 for the University of Michigan Model Spinal Cord Injury System from the National Institute on Disability and Rehabilitation Research.

From the Department of Physical Medicine and Rehabilitation (DGT, SR); the Model Spinal Cord Injury Care System (DGT), University of Michigan, Ann Arbor, Michigan; and the Department of Disability and Human Development, University of Illinois, Chicago, Illinois (BR)

PHYSICAL MEDICINE AND REHABILITATION CLINICS OF NORTH AMERICA

participation. Issues in each of the three areas contribute significantly to the overall QOL levels experienced by women with disabilities and are addressed separately.

Economics is of critical importance in the shaping of QOL. It can be quite expensive to live well with a disability. Purchasing quality health care coverage is imperative. Vigilant attention to health care is a special responsibility that women with disabilities must assume because they are usually prone to extra health problems, including the onset of new enervating health conditions, as they age. Special equipment must often be purchased. Extra supports, such as remote car-starters, accessible vans, or speaker telephones that are seen as conveniences by nondisabled people are often necessities to those who must manage a disability on a daily basis.

Women with disabilities face "double jeopardy" in the work place because of their gender and their disability status. Carol Gill comments, "We live in a society that, in many ways, has little faith in us." Allison, a polio survivor with a complex disability, remarks, "It always seems to take me over a year to prove myself—to become fully accepted—at a new job. Even if the bosses have known my work to be excellent in the past, they don't quite believe it. This is true with everyone to an extent, but I believe, for women with disabilities, cynicism or suspicion about you is the first perception. I remember at one of my first job interviews . . . they told me I wasn't hired because I would be a systemwide insurance risk. It takes a lot of energy to cut through the double incompetence barrier and prove yourself over and over and over again. It is possible, but during the work-site inquisition, it can be frightening and lonely."

Statistics show that, as women, this group is less likely to participate in the work force, and they earn less than men. As people with disabilities, women contend with a lack of jobs, inaccessible work environments, and much lower wages than those with no disability.27 According to McNeil,35 approximately 68% of women with nonsevere disabilities were gainfully employed. Similarly, data from the US Census Bureau indicate that only 28.5% of women on work disability were employed, compared with 75.8% of women not on work disability. As might be expected from these findings, a substantial percentage of women on work disability earn incomes at or below poverty levels, whereas 40.5% of women with severe levels of work-related disability were earning incomes at or below the poverty level.39 For those who are working, anecdotal evidence shows that women with disabilities have more difficulty obtaining appropriate job accommodations than men with and without disabilities. "One woman was threatened with suspension because she asked her secretary to retrieve a notebook from her car because it was too heavy for her to carry. . . . Asking for time off for doctor and therapy appointments only seems to further the assumption that women are the weaker of the sexes, not that they are trying to cope with the problem or to maintain their health."33

Physical and psychological health is the second contributing factor

that builds QOL. Writing about the health service needs for women with disabilities, Gill et al<sup>31</sup> point out that women with disabilities are beginning to take control of their own health care. They also write, however, that women with disabilities have experienced repeated violations of their rights to self-determination and have been neglected in medical research, professional training, health policy, and the development of health service delivery. Although strides in medical care have enhanced tremendously the support and stabilization of life in emergency rooms and intensive care units, cracks in the health care system have become increasingly apparent in the chronic phase—with little or no response to women's needs.<sup>18</sup> Thierry<sup>56</sup> elaborates, "Women with disabilities face substantial barriers that limit their access to health care services. These include physical, attitudinal and policy barriers: lack of information about how disability affects health; limited finances; and insufficient personal assistance." In a recent study conducted by Nosek et al, a high percentage (31%) of study participants were refused care by physicians because of their disability. They also reported considerable difficulty locating physicians who were knowledgeable about their disability to help them manage their pregnancy.<sup>44</sup>

When seeking reproductive health care, women with disabilities are often treated as if they are asexual, yet their sexual desires and interests are no different from those of women in general.<sup>41</sup> In this vein, it has also been documented that women with severe disabilities are less likely to receive regular pelvic examination than are women without disabilities.<sup>42</sup> They are also at the same risk for violent physical and sexual abuse as able-bodied women, but experience it over longer periods of time. Often the abuse takes the form of withholding medication, orthopedic equipment, transportation, or personal assistance.<sup>44</sup>

As Thierry<sup>56</sup> reports, the broader issues of health and wellness for women with disabilities are frequently ignored. Level of physical fitness, exercise, and activity participation may have an effect on long-term function and QOL. For women with disabilities, maintaining a high QOL is directly related to maintaining physical functioning.<sup>55</sup> Of notable concern is the prevention of later life-debilitating physical or mental health conditions that occur more frequently among women having a primary disabling condition. These are referred to as *secondary conditions* and include pain, osteoporosis, chronic bladder infections, fatigue, depression, and trouble with weight management.<sup>55</sup>

Finally, of equal importance in creating QOL is social participation. Community and social ties play an important role in the maintenance of QOL and life satisfaction. The presence of a disabling condition can limit opportunities for social relationships as well as community integration. Double and sometimes triple (if also racial) discrimination and social stigma against women with disabilities further limit these opportunities and, equally importantly, can make the woman with a disability feel vulnerable to rejection and ostracism when attempting to form community and personal relationships. Crewe<sup>11</sup> reports that women with disabilities are subject to limited opportunities for social interaction and

support and reduced access to pleasurable experiences that can affect resilience. This social participation can include lack of opportunities for friendships, including dating/romantic relationships, marriage/sexual relationships, and childbearing, as well as networking and participating in a diverse community life. In Nosek's landmark study, she reports that "women with physical disabilities have as much sexual desire as women in general; however they do not have as much opportunity for sexual activity." In spite of these findings, a large majority (87%) of women in the national study had had at least one serious romantic relationship or marriage. Of those who were not married or in a relationship at the time of the study, 42% said it was because no one had asked them.

Nosek also comments on self-esteem issues. She says that "self-esteem in women with physical disabilities is more strongly influenced by social and environmental factors than by the fact of having a disability." Traditionally, women with disabilities have not been encouraged to bear children or take on the role of motherhood. The study sample report reveals that only 38% had borne children, compared with 51% of women without disabilities. Another issue women with disabilities face is having been left out of the American feminist movement. As Gill points out, "women with disabilities have added a new element to the conscience and consciousness of the women's movement. We have pointed out its absence." Once again left on the perimeter, women with disabilities have been excluded from meeting in inaccessible locations with no alternate formats for blind and deaf women. They have been painfully left off agendas supposedly covering women's concerns.

### QUALITY OF LIFE RESEARCH AND OUTCOMES AFFECTING WOMEN

The overwhelming number of issues that women with disabilities face are just beginning to be addressed. To understand more fully how to help improve this large group's QOL, it is important to examine the concept of QOL and its unique place in the context of the US disability paradigm. It is also helpful to know about recent studies, however limited, relative to the QOL of women who have disabilities. These will begin to inform health professionals, policy makers, and women with disabilities, themselves, on what is known about improving QOL. Early study findings can serve as an impetus to foster greater investigation and application of new knowledge in this neo-current and much-needed field of inquiry.

Although research on QOL is abundant, few studies have looked at these issues as they affect women with disabilities. In fact, very little rehabilitation research has been devoted to women with disabilities. Although the number of well-conceived and available studies is too small to draw major conclusions, the authors focus on the relationship of QOL to key outcomes, as discussed earlier, affecting women with disabilities.

### Objective and Subjective Outcomes of Quality of Life

Objective measures of QOL can relate to concrete and discrete outcomes such as diagnosis of impairment, disability, health status, employment, or economic status. Examples include number of diagnoses, functional impairment scores, number of jobs during the past year, or wages and benefits received. Subjective outcomes are often measured in terms of the individual's judgment of his or her well-being. Examples of subjective QOL outcomes include happiness, psychological well-being, morale, and life satisfaction.

MIT OF ELLE FOR WOMEN WITH PHISICAL DISABILITIES

Quality of life therefore means many things to many people. <sup>15</sup> Some emphasize material possessions, others focus on the integrity and functioning of the body, some refer to the quantity and quality of interpersonal relations, and others focus on life satisfaction or mental and spiritual well-being. Being a woman and having a disability can affect, directly or indirectly, aspects of life that have been declared by researchers to constitute QOL, or at least found to greatly influence people's judgments of QOL—health, personal safety, independence, the ability to earn an income, access to material comforts, the ability to have and raise children, the likelihood of developing a close relationship with a member of the opposite gender, or a close supportive network of friends. For women with disabilities, especially, body image, self-concept, and one's understanding of self may be significantly affected.

Consumer advocates point out that simply having a disability does not necessarily diminish one's QOL. Provided resources are available (especially access to adequate health care, assistance with coping and adjustment, and a supportive social network) and provided that the social climate, public policies, and environmental barriers do not prevent the woman with a disability from fulfilling desirable societal roles of marriage, work, leisure, civic duties, and other activities, the QOL of women with disabilities can be very similar to that of the average nondisabled woman.

Limited information is available regarding what are the determinants of QOL for women with disabilities in general. Even less is known about how subjective QOL changes over time after disability and how adjustment may assist the process of enabling positive changes. Most importantly, we do not know enough about how being both disabled and a woman can specifically affect these QOL outcomes.

Long-term adaptation to chronic illnesses and disability is one of the major areas of concern in the medical and psychological rehabilitation literature.<sup>13</sup> Although roughly 50% of the people with disabilities around the world are women, most of the theoretical and empirical studies were carried out on populations of males with disabilities.<sup>8, 12, 23, 38</sup> Since the early 1980s, because of a growing social and professional awareness of the importance of gender differences, there has been a slight increase on the number of studies dealing with women who have chronic physical disabilities.<sup>5, 14, 24, 32, 37, 45</sup> These studies, carried out in Canada, England, and the United States, not surprisingly, revealed that this group has the

o late et al

lowest socioeconomic condition (e.g., high unemployment, low income level, and lower marriage rates), receives fewer benefits from vocational rehabilitation services, and usually is more dependent on the welfare system. One could easily assume that these factors, in addition to the chronic functional limitation, may increase the difficulties experienced in their daily lives and, consequently, may lead to a poor level of adjustment and adaptation. Findings, however, have been mixed.

In one study about motherhood after spinal cord injury,<sup>36</sup> the authors found the families in the study to be well adjusted and having little need for external help. They reported a well-functioning social network and seemed socially integrated as individuals and as families. On the other hand, several studies found that women with moderate to severe functional limitation attributable to rheumatoid arthritis reported a broad range of limitations in fulfilling their daily familial tasks and roles.<sup>1, 21, 22, 48</sup>

In addition, Hafstrom and Schram,<sup>22</sup> in 1984, reported that women with functional disabilities are the least satisfied with their function as homemakers, mothers, and spouses when compared with a control group. Other studies found that women with various physical disabilities reported having higher levels of anxiety, depression, and psychological distress.<sup>17, 34, 58</sup>

## Interactions Between Objective and Subjective Outcomes of Quality of Life

Dangoor and Florian<sup>13</sup> provide some excellent insight into the role of subjective and objective indicators of QOL and their effect on long-term psychosocial adaptation for women with disabilities. Using Antonovsky's concept of sense of coherence (SOC), these authors examine the relationships among medical, socioeconomic, and internal resource variables on adaptation outcomes of women with physical disabilities. In his theoretical model, Antonovsky<sup>3</sup> emphasizes the importance of SOC as a crucial and relevant stress-resistance resource. According to this model, SOC is related to physical and emotional health and is the core concept locating the person on the health–disease continuum. Persons with high SOC scores use nonregressive constructive means of coping with life's hardships whereas those with low scores use maladaptive coping mechanisms such as engaging in pessimistic interpretation of events and becoming anxious and depressed.

Findings from Dangoor and Florian's study<sup>13</sup> clearly indicate that socioeconomic status (high rate of unemployment, low educational level, low familial income level) plays the most important role in explaining the variation of three outcomes: impact of disability on daily life, mental health, and familial adaptation. These findings corroborate data from previous studies that delineate that high rates of unemployment and poor economic status of the families increase the disparity between material necessities and available resources and therefore have a nega-

tive impact upon the personal and familial well-being of women with physical disabilities. 12, 14, 32, 38 Most interesting are the findings that all disability status variables, used frequently as gold standards in rehabilitation services such as determining medical diagnosis or severity of functional limitation, were found to be nonessential in explaining the various aspects of the women's long-term adaptation. It seems that socalled objective indicators of disability status do not reflect the subjective perception and meaning that these women have attributed to their chronic physical condition. It might be that components of hope, such as a sense of goal-directed determination and a sense of ability to find ways to solve problems and meet daily goals, for example, have an important effect on the woman's perception of her chronic condition and her overall QOL. It seems that when a woman is equipped with a high level of SOC, she can more effectively cope with the daily hardships and familial role difficulties, and use the limited financial and concrete resources that are available in her surroundings more efficiently.

A high level of SOC might contribute to an improved sense of mastery, which restrains emotional states such as anxiety and depression, and seems to be crucial in improving mental and familial well-being. The findings of this study emphasize the importance of subjective factors in the women's perception of their chronic stressed condition and their QOL, whereas most medical and vocational rehabilitation services base their policymaking and clinical interventions on objective QOL indicators such as disability and demographic characteristics.

## FACTORS AFFECTING THE QUALITY OF LIFE FOR WOMEN WITH DISABILITIES

In addition to psychological factors such as adaptation, other important factors affecting QOL for women with disabilities include their physical health, social support, and economics. These major factors are reviewed subsequently.

#### **Health Outcomes**

A very specific approach to defining QOL, including subjective or objective components, is that of health-related quality of life (HQOL). The term is increasingly used in the medical and allied health literature to refer to components of overall QOL that center on or are directly affected by health.<sup>54</sup> Health-related QOL components can include signs, symptoms, treatment side effects, and physical, cognitive, emotional, and social functioning. Health-related QOL components can interact with nonhealth-related QOL dimensions in a number of situations.<sup>40</sup>

An example of a nonhealth-related problem for women with disabilities that can be devastating to women's QOL is abuse. In its national study of women with physical disabilities, the Center for Research on

Women with Disabilities defined emotional abuse as being threatened, terrorized, corrupted, or severely rejected, ignored, or verbally attacked. Physical abuse was defined as any form of violence against her body, such as being kicked, hit, restrained, or deprived of food or water. Sexual abuse was defined as being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape. These nonhealth-related factors may affect a woman's ability to cope with disability and to respond to interventions. It therefore is important that rehabilitation professionals routinely assess for potential abuse or other major nonhealth factors affecting QOL.

There is a new emphasis on investigating health problems unique to women, as evidenced by the National Institutes of Health Office of Research on Women's Health and Women's Health Initiative. Perhaps the best known definition of health is stated in the preamble of the World Health Organization's charter: Health is a state of complete physical, mental, and social well-being and not merely the absence of disease. This inclusive concept of health emphasizes the importance of appropriate health care (i.e., orthopedic, neurologic, and gynecologic) and access to care for women with disabilities. Adequate insurance and benefits to cover these health needs become key to ensure health and well-being.

A study by Shackelford, Farley and Vines<sup>51</sup> on women with SCI reports that women are significantly involved in more automobile crashes than men, whereas men are involved in more falls. Women are more reliant on Medicaid, whereas men report more Medicare and worker's compensation coverage. Women also reported less use of medication any time during treatment.

As stated earlier, women who are aging with disabilities experience new aspects of health such as the occurrence of secondary conditions associated with the original disability and an increase in comorbidities. For practitioners, obtaining information regarding secondary conditions of women with disabilities can be a demanding task. In addition, women may find it frustrating when trying to locate information about themselves.

Prevention and wellness models have evolved as positive, health-oriented alternatives to the disease orientation to educate women about their health and potential secondary conditions. Any secondary condition has the potential to affect a person's QOL and independence, and perhaps may even become life-threatening if not treated. Wellness programs for women with disabilities are designed to positively impact their QOL. These programs encourage exercise, weight control strategies, stress management, good nutrition, and a spectrum of health-promoting tactics to minimize risk factors to poor health.

Within the past 5 years, several nationally funded studies have been conducted to investigate wellness programming for women with disabilities. Researchers at the University of Michigan, Temple University, State University of New York, the Texas Medical Center in Houston, the University of Kansas, and the University of Texas in Austin have focused on testing the effectiveness of wellness interventions that are customized for this group.

#### **Economics and Employment-Related Factors**

Poor health can also affect the ability to work and become a productive member of society. Persons with disabilities in general, and women in particular, often find themselves unemployed, out of work, or in low-paying jobs. Considering the general trends in society, it can probably be assumed that women with more severe disabilities have even lower incomes and, perhaps, even less access to adequate resources and benefits.<sup>59</sup>

Data obtained from a 1991 International Labor Office report on women and disability in the United States<sup>26</sup> show the strong contrast in employment between women and men with severe disabilities, and between women and men with less disability. The study shows that 91% of women with severe disabilities were unemployed or not in the labor force, compared with 79% of men with severe disabilities. Forty-six percent of women who are less severely disabled were unemployed or not in the labor force, compared with 12% of men with less severe disabilities.

Psychological factors associated with feelings of lack of freedom to choose her own career or destiny, lack of empowerment, low self-esteem, and physical and psychological dependency, may interfere with her ability to advocate for her needs and actively seek resources to obtain paid employment and benefits. In writing about women with disabilities' problems regarding employment, Campling<sup>10</sup> states: "As with education, in theory, women have equal opportunity with men in employment. In practice, women are often discriminated against in the labor market. This is even more so in the case of women with severe physical disabilities, where it may be assumed that they are content to stay home."

As Campling points out, it is regrettable that, in the search for work, women with disabilities are often more discriminated against than men with disabilities. Ironically, however, because of the nonmanual and traditional nature of what is regarded as women's sphere of activity, it is often easier for women to adapt than men.

The conditions of age, poverty, or illiteracy combine with gender and disability to provide triple discrimination in employment. As Safilies-Rothschild<sup>50</sup> states: "In many societies women live longer and, therefore, the older chronically disabled group becomes disproportionately composed of women. We know that there are masses of women around the world who are unskilled and uneducated. Many become beggars because of the limited possibilities."

It is clear from these testimonials on employment that women with disabilities have achieved some of the lowest levels of economic development and resulting QOL in the world. The effects of this phenomenon go well beyond the women themselves, to potentially affect the entire society at large. By creating so many barriers to women who age with disabilities (fewer material goods and resources, poor health and social economic status) society is, in turn, creating many obstacles to improving the QOL of the population in general.

#### The Role of Social Support in Quality of Life

Sociocultural factors—that is, social resources and support and the general attitude toward disability—exert perhaps a more powerful influence on the wellness and QOL of women with disabilities than on those of the population at large. It is a barrier, a stressor, and a force that can hone resilience or cause defeat.<sup>28</sup> Exposure to negative feedback alleging that women with disabilities are ugly, worthless, a burden to society, and unable to ever fulfill their proper role as women; the absence and, in some cases, withholding of information about one's body; and environmental barriers compounded by the lack of appropriate assistive technology are not factors most people have to deal with in their daily lives. On the other hand, sociocultural elements such as encouraging, supportive family and friends have an inestimable value in counteracting the negative forces. Their effect on the development of a positive

self-concept deserves serious investigation.

Social support is defined as the expression of positive effect of one person on another; the endorsement of another person's behaviors, perceptions, or expressed views; and the giving of symbolic or material aid to another. 46 The large and growing body of theoretical and empirical evidence in this area indicates that social support plays an important role in enhancing health and QOL. This is particularly true with respect to emotional support. Social support and coping affect the way individuals experience stress in four ways: (1) preventing the stressor from occurring, (2) making the stressor less demanding, (3) altering the meaning of the stressor to neutralize its psychological impact, and (4) managing the symptoms of stress.46 Whereas coping is acting on one's own behalf in an attempt to deal with stressors, social support is when others act on behalf of the individual. Social support may provide the necessary motivation to engage in and maintain health-promoting behaviors or to adhere to medical regimes in the face of illness. 4, 16, 61 Social support may help women with disabilities adjust to life stressors that limit their QOL as well as influence disease processes directly.<sup>53</sup> Several studies of persons not identified as having a disability suggest that social support is related to improved health and emotional well-being,9,60 reduced substance abuse,<sup>2</sup> lower mortality rate,<sup>7</sup> and an increase in health-promoting and wellness behaviors.25

Contrary to most research that views social support as a positive influence, some authors have pointed out that by buffering the individual from the negative effects of stress, social support can at times have a negative impact on health and well-being. <sup>57</sup> For instance, social support that is overprotective in nature could foster helplessness and dependent

dency, lead to poor motivation for behavioral change, and delay rehabilitation. Bailey and Kahn<sup>6</sup> observed that some individuals with diabetes were wary of spousal efforts of help, and reported deliberate noncompliance with their self-care routines to exert control over their situation.

#### Social Support and Women with Disabilities

Women with disabilities have historically experienced limited access to various resources and opportunities, including employment and adequate health care. Similarly, there is both direct and indirect evidence that women with disabilities experience lower levels of social support. According to the *Chartbook on Women and Disability in the United States*, women with severe mobility limitations (unable to walk) had a higher divorce rate than women with mild mobility limitations. Only 44% of women with severe mobility limitations were married, compared with 68% of women with no mobility limitation. Only a few studies have looked at the influence of marital status on QOL for persons with disabilities. Findings suggest that marriage plays an important role in providing social, emotional, and physical support, with those who are married reporting better QOL compared with those who are not married.

In a national study on women and aging, more than 90% of older women with a disability reported having at least one person with whom they could share feelings or rely on for assistance.<sup>29</sup> Forty-five percent of women with severe disabilities reported that they could use more emotional support, however, compared with 30% of women with less severe disabilities. The authors of the study concluded that support from family and friends and assistance with daily living activities are vitally important influences on the lives of older women with disabilities in areas

ranging from functional status to life satisfaction.

Despite evidence suggesting that women with disabilities have limited social support, there is relatively little research concerning the effect of social support deficits on the health, functioning, and QOL of women with disabilities. In a study of women with systemic lupus, satisfaction with social support was directly related to lower levels of psychological distress. Social support was not found to buffer the effects of physical stress, however. Similarly, in a study of older women with disabilities, social support was found to increase the likelihood of being emotionally vital. The relationship between social support and emotional vitality remained significant after controlling for level of disability.

Further empirical efforts are required to identify the various determinants and effects of social support among women with disabilities and to investigate interventions aimed at ameliorating social support deficits. In a health-promotion program outcomes study for persons with disabilities, for instance, anecdotal evidence from female participants indicates that participation in the program had markedly improved their feelings of social connectedness and support.<sup>49</sup> Moreover, several participants reported feeling disappointed when the program ended.

Although social support was not directly examined in this study, these findings suggest that health-promotion programs of this kind may serve a dual role in promoting physical health and emotional well-being through the provision of social supports.

#### RECOMMENDATIONS

This article provides the readers with a discussion of the many factors affecting the QOL of women with disabilities. To effectively assist women with disabilities in rehabilitation, consideration must be given to the interfaces existing among disability, gender, and race because these variables impact education, employment, and QOL. Each woman enters rehabilitation with her own beliefs, attitudes, values, and goals. As a result, there is no cookbook for assisting women in rehabilitation. There are, however, at least three major responsibilities for anyone who advocates for women with disabilities. First, optimal personal and intellectual growth must be promoted. Second, an environment conducive to growth and development must be established and maintained. Third, rehabilitation professionals must be committed to developing an astute awareness about women with disabilities. This includes building a deepened personal and social view of gender, culture, and disability differences.

In addition to the three responsibilities cited, rehabilitation professionals must consider carefully the following assumptions: (1) Discrimination based on disability, gender, and race is operative in our society. (2) Women are not treated with equal status compared with their male peers. (3) We are either part of the problem or part of the solution. Typical emotions aroused by these assumptions range from anger to fear to empathy and commitment (verbal and action). Nevertheless, as professionals, our role is to best serve the interests of this special group, and, if adequate services are to be provided, these assumptions must be discussed, clarified, and resolved.

The need to conduct quality research on the QOL of women with disabilities has been noted throughout this article. As pointed out by a professional woman with a disability, "Much of what we are seeking is the inclusion of good research. We want more information about our physiology and the effects of different treatments and preventive approaches. We want contraception research and pregnancy information, and we want to know how to care for ourselves as we age. We want new options developed that are healthier for us and amenable to our control. We also want to learn about the effects of stress in our lives and how to remain emotionally healthy. Furthermore, we need substantial research on health policy to document how such policies affect women with disabilities and to recommend needed changes. As women with disabilities think about our inclusion in research, we are thinking big. We are referring to inclusion on all levels. Our goal is to have a major

role in framing the questions, setting the funding priorities, participating as subjects, and disseminating the results."

#### **SUMMARY**

This article emphasizes the role of several factors on the QOL of women with disabilities. Future studies might examine ways to merge these factors to examine their long-term consequences in the lives of women with disabilities and, hence, society at large. Findings should provide a basis for policymaking and clinical rehabilitation interventions designed to promote greater QOL for women with disabilities—a QOL that offers vigorous prosperity, flourishing health, and full social participation.

#### References

- 1. Allaire SH: Employment and household work disability in women with rheumatoid arthritis. Journal of Applied Rehabilitation Counseling 23:44–51, 1992
- Aneshensel CS, Huba JG: Depression, alcohol use and smoking over 1 year: A fourwave longitudinal causal model. J Abnorm Psychol 92:134–150, 1983
- Antonovsky A: Unraveling the Mystery of Health: How People Manage Stress and Stay Well. San Francisco, Jossey-Bass, 1987
- Arpin K, Fitch M, Browne GB, et al: Prevalence and correlates of family dysfunction and poor adjustment to chronic illness in specialty clinics. J Clin Epidemiol 43:373– 383, 1990
- Asch A, Fine M: Introduction: Beyond pedestals. In Fine M, Asch A (eds): Women with Disabilities: Essays in Psychology, Culture and Politics. Philadelphia, Temple University Press, pp 1–37, 1983
- Bailey BJ, Kahn AM: Apportioning illness management authority: How diabetic individuals evaluate and respond to spousal help. Qualitative Health Research 3:55–73, 1993
- Berkman LF: Assessing the physical health effects of social networks. Annual Review of Public Health 5:4113–4132, 1984
- 8. Britt JH: Psychosocial aspects of being female and disabled. Journal of Applied Rehabilitation Counseling 19:19–23, 1988
- Brown MA: Social support, stress, and health: A comparison of expectant mothers and fathers. Nursing Res 35:72–76, 1986
- 10. Campling J: Better lives for disabled women: London, Virago Limited, 1989
- 11. Crewe N, Clark N: Stress and women with disabilities: *In* Kratoski DM, Nosek MA, Turk MA (eds): Women With Physical Disabilities: Achieving and Maintaining Health and Well-Being. Baltimore, MD, Brookes Publishing, 1996, pp 193–202
- 12. Danek MM: The status of women with disabilities revisited. Journal of Applied Rehabilitation Counseling 23:7–13, 1992
- 13. Dangoor N, Florian V: Women with chronic physical disabilities: Correlates of their long-term psychological adaptation. Int J Rehab Res 17:159–168, 1994
- 14. Deegan MJ: Multiple minority groups: A case study of physically disabled women. *In* Deegan MJ, Brooks NA (eds): Women and Disability: the Double Handicap. New Brunswick, NJ, Transition Books, 1985, pp 37–55
- 15. Dijkers M: Quality of life after spinal cord injury: A meta-analysis of the effects of disablement components. Spinal Cord 35:829–840, 1997
- 16. Frankel BG, Turner RJ: Psychological adjustment to chronic disability: The role of

- social support in the case of the hearing impaired. Canadian Journal of Sociology 8:273-291, 1983
- 17. Fuhrer MJ, Rintala DH, Hart KA, et al: Depressive symptomatology in persons with spinal cord injury who reside in the community. Arch Phys Med Rehab 74:255-260,
- 18. Gill C, et al: Health services for women with disabilities: Barriers and portals. In Reframing Women's Health. Thousand Oaks, NY, Sage Press, 1994, p 357
- 19. Gill CJ: Women with Disabilities. Web site: http://www.ncpad.org, March 2000
- 20. Gill C: Becoming visible: Personal health experiences of women with disabilities. In Kratoski DM, Nosek MA, Turk MA (eds): Women With Physical Disabilities: Achieving and Maintaining Health and Well-Being. Baltimore, MD, Brookes Publishing, 1996, p 6
- 21. Goodenow C, Reisine ST, Grady KE: Quality of social support and associated social and psychological functioning in women with rheumatoid arthritis. Health Psychol 9:266-284, 1990
- 22. Hafstrom JL, Schram VR: Chronic illness in couples: Selected characteristics, including wife's satisfaction with and perception of marital relationships. Family Relations 33:195-203, 1984
- 23. Hanna WJ, Rogovsky E: On the situation of the African American women with physical disabilities. J Appl Rehab Coun 23:39-45, 1992
- 24. Harrison DK, Wayne B: Female and male acceptance for rehabilitation. Journal of Rehabilitation 53:37-39, 1987
- 25. Hubbard P, Muhlenkamp AF, Brown N: The relationship between social support and self-care practices. Nursing Res 33:266–270, 1984
- 26. International Labor Organization: Work and family life: The role of the social infrastructure in Eastern European countries. Geneva, Switzerland, 1990
- 27. Jans L, Stoddard S: Chartbook on Women and Disability in the United States. An InfoUse Report. Washington, DC, US Department of Education, National Institute on Disability and Rehabilitation Research, 1999
- 28. Kahn BL: Aging and social support. In Riley MW (ed): Aging From Birth to Death: Interdisciplinary Perspectives. Boulder, CO, Westview Press, 1979
- 29. Kasper JD, Phillips CL, Simonsick EM, et al: n.d/2000). Instrumental and emotional support. In The Women's Health and Aging Study. http://www.nih.gov/nia/edb/whasbook/ chap7/chap7.htm
- 30. Keller SM: Social support and psychological distress in women with systemic lupus erythematosus. Dissertation Abstracts International A 60:1329, 1999
- 31. Kratoski DM, Nosek MA, Turk MA (eds): Women With Physical Disabilities: Achieving and Maintaining Health and Well-Being. Baltimore, MD, Brookes Publishing, 1996
- 32. Lonsdale S: Women with Disability: The Experience of Physical Disability among Women. London, Macmillan Education Ltd, 1990
- 33. Lortz MB, Karla M: Employment: About Journeys. Window on Wellness. Columbus, OH, Women with Disabilities Network, 1999, p 22
- 34. Manne SL, Zautra AJ: Spouse criticism and support: Their association with coping and psychological adjustment among women with rheumatoid arthritis. J Pers Soc Psychol 54:608–617, 1989
- 35. McNeil: Web site: http://www.census.gov/hhes/www/disable/sipp. Survey: SIPP, 1994-95,
- 36. Menz FE, Hansen G, Smith H, et al: Gender equity in access, services and benefits for vocational rehabilitation. Journal of Rehabilitation 15:31-40, 1989
- 37. Morris J: Able Lives: Women's Experience of Paralysis. London, The Women's Press,
- 38. Mudrick NR: Disabled women and public policies for income support. In Fine M, Asch A (eds): Women with Disabilities: Essays in Psychology, Culture and Politics. Philadelphia, Temple University Press, 1988, pp 245–268
- 39. National Institute on Disability and Rehabilitation Research: Chartbook on Women and Disability in the United States [Web document]. http://www.infouse.com/disabilitydata/womendisability 4 1.html, 1996
- 40. National Institutes of Health: Quality of Life Assessment: Practices, Problems and Promise: Proceedings of a Workshop. Bethesda, MD, 1990

- 41. Nosek MA: Sexuality and reproductive health. In Kratoski DM, Nosek MA, Turk MA (eds): Women With Physical Disabilities: Achieving and Maintaining Health and Well-Being. Baltimore, MD, Brookes Publishing, 1996, p 63
- 42. Nosek MA, Howland CA: Breast and Cervical Cancer Screening Among Women with Physical Disabilities. Arch Phys Med Rehabil 78:S39, 1997
- 43. Nosek MA, Howland CA, Young ME, et al: Wellness models and sexuality among women with physical disabilities. Unpublished paper, 1997
- 44. Nosek MA, Rintala DH, Young ME, et al: National Study of Women with Physical Disabilities: Special Summary. Houston, TX, Baylor College of Medicine, Center for Research on Women with Disabilities, 1997
- 45. Ontario March of Dimes: Women with Disabilities: Life in Northwestern Ontario. Thunder Bay, Ontario, March of Dimes, 1986
- 46. Pearlin LI, Anschensel CS: Coping and social support: Their functions and applications. In Aiken HA, Mechanic D (eds): Applications of Social Science to Clinical Medicine and Health Policy. New Brunswick, NJ, Rutgers University Press, 1986, pp 417-437
- 47. Penninx BW, Guralnik JM, Simonsick EM, et al: Emotional vitality among disabled older women: The Women's Health and Aging Study. J Am Geriatric Soc 46:807-815,
- 48. Reisine ST, Goodenow C, Grady KE: The impact of rheumatoid arthritis on the homemaker. Soc Sci Med 25:89-95, 1987
- 49. Rimmer JH, Silverman K, Braunschweig C, et al: Effects of a short-term health promotion intervention for a predominantly African-American group of stroke survivors. Am J Prev Med, in press
- 50. Safilies-Rothschild: Discrimination against disabled women. International Rehabilitation Review 4:37-45, 1977
- 51. Shackelford M, Farley T, Vines CL: A comparison of women and men with spinal cord injury. Spinal Cord 36:337–339, 1998
- 52. Shumaker S, Anderson RT, Czajkowski SM: Psychological tests and scales. In Spiker B (ed): Quality of Life Assessment in Clinical Trials. New York, Raven Press, 1990, pp 95-113
- 53. Siegrist J, Jonge A: Measuring the social dimensions of subjective health in chronic illness. Psychotherapy & Psychosomatics 54:90–98, 1990
- 54. Tate DG, Dijkers M, Johnson-Greene L: Outcome measures in quality of life. Stroke Rehabil 2:1-17, 1996
- 55. Tate DG, Riley BR, Perna R, et al: Quality of Life Issues Among Women With Physical Disabilities or Breast Cancer. Arch Phys Med Rehabil 78:S19-24, 1997
- 56. Thierry JM: Observations from the CDC: Promoting the health and wellness of women with disabilities. J Women's Health 7:506, 1998
- 57. Thompson SC, Sobolow-Shubin A, Graham MA, et al: Psychosocial adjustment following a stroke. Soc Sci Med 28:239-242, 47, 1989
- 58. Turner RS, Noh S: Physical disability and depression: A longitudinal analysis. J Health Soc Behav 29:23-37, 1988
- 59. Vash CL: Women and Employment. Sixth Mary E. Switzer Memorial Seminar. Conference Proceedings, Washington, DC, 1981
- 60. Ventura JN: Parent coping: A replication. Nursing Res 35:77-80, 1986
- 61. Wortman CB: Social support and the cancer patient: Conceptual and methodological issues. Cancer 53:2339-2360, 1984

Address reprint requests to Denise G. Tate, PhD Department of Physical Medicine and Rehabilitation University of Michigan

> 1500 East Medical Center Drive D4101 MPB Ann Arbor, MI 48109-0718