Perceived Health and Self-Efficacy Among Adults with Cerebral Palsy

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Perceptions of self-efficacy and health attitudes among people with cerebral palsy who are living in the community were explored. Their self-efficacy ratings were related to amount of mechanical and personal assistance needed and perceived financial resources. When compared with two other groups, people attending a health fair and people from a statewide disability advocacy group, participants with cerebral palsy scored lower on The Self-Rated Abilities for Health Practices Scale, particularly in the areas of exercise and nutrition. Participants also provided information about what prevents them from promoting their health. Suggestions for rehabilitation counseling practice are included.

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Historically, institutional settings constituted the framework in which an individual with a disability's health care needs were addressed (Batavia & Dejong, 1990). As more people with disabilities successfully move from institutional settings to the community, health maintenance and promotion are especially important.

Health promotion is defined as "activities directed toward increasing the level of well-being and actualizing the health potential of individuals, families, communities, and societies" (Pender, 1987, p.4). Pender distinguishes health promotion from disease prevention, which emphasizes behaviors aimed at avoiding specific diseases or health problems. Health promoting behaviors may be ongoing activities that become an integral part of one's life and include physical exercise, nutritional eating, social support, and stress management.

Pender's 1984 model of health promotion is particularly relevant for people with disabilities as it defines health and illness as qualitatively different constructs. Health is seen as an individual actualizing information and skills through goal directed behavior, competent self-care, and satisfying relationships with others. Individuals make adjustments in their lives to maintain their well-being with their surroundings. Absence of illness or disability is not a prerequisite for health; therefore, individuals diagnosed with a chronic illness or living with a disability may be healthy. The concept of health promotion also emphasizes self-care rather than expert-care, and promotes an active, independent attitude toward health care.

The construct of self-efficacy is also relevant for promoting health behaviors. How much effort an individual expends and how long they persist in the face of obstacles is determined by their beliefs about the consequences of their behavior and their beliefs about their ability to perform specific behaviors in certain situations (Bandura, 1982). Bandura argued that perceived self-efficacy for a given situation or behavior emerges from an individual integrating all of the information they have about the situation. Self-efficacy has emerged as a predictor of various health behaviors such as quitting smoking, weight loss, and continued exercise (Strecher, DeVellis, Becker, & Rosenstock, 1986).

Unfortunately, people with disabilities living in the community also experience many barriers to the maintenance and

improvement of their health, including discrimination from health care insurers, misperceptions by health care providers, and institutional bias in Medicaid policy (Dawidczyk, Arisco, & Anderson, 1992; Griss, 1991; Nosek, 1984). There are additional considerations as well. For example, exercising regularly may mean developing new skills, acquiring adaptive equipment, and becoming a part of a support network that facilitates participation. These barriers and considerations may influence a person's health care attitudes and behaviors, and interventions that enhance their health promotion.

People with disabilities have identified barriers to the use of health care services. Nosek (1984) noted that health care professionals may harbor misconceptions about the health of people with disabilities and that these misperceptions may lead to inappropriate treatment methods that may create barriers to the maintenance of good health status by people with disabilities. She indicates that health care professionals may focus so heavily on disability itself that they overlook other factors that may impact on health in their diagnosis or treatment strategies. In addition, Nosek has noted that health care providers may hold attitudes that people with disabilities are sick, which may contribute to people with disabilities as thinking of themselves as passive participants in their own health care, rather than as individuals responsible for, and contributing to, their well-being.

Other barriers have been identified that may impact on an individual's perceptions of health and well-being (Dawidczyk et al., 1992; Dawidczyk & Anderson, 1992). Provision of personal assistance services can be one of the biggest factors for people who have significant support needs to live in the community. Yet, people with disabilities may have few options for attendant care coverage and lack access to back-up or emergency services.

Health promotion for people with disabilities is critical, yet a recent national conference on primary care and disability concluded that health promotion issues have been largely ignored by the health care community (National Invitation Conference on Primary Care and Disability, 1989). Exercise, for example, contributes to both physiological and psychological health, inclusion into society, prevention of secondary disabilities, and level of independence (Katz, Adler, Mazzarella, & Luce, 1985; Marge, 1988; Moon & Renzaglia, 1982; Nosek, 1984). Fitness and exercise may be an important prevention for delaying complaints in the areas of endurance and musculoskeletal pain, complaints that may often be voiced by people with cerebral palsy at a younger age than the general population (Turk, 1993). Turk also notes that issues of flexibility and endurance should be addressed throughout adulthood to assist in maintaining a level of activity.

Marge (1988) has noted that the most neglected part of the typical rehabilitation program is health promotion. *Incorporating health promotion in rehabilitation planning may contribute to preventing secondary disabilities, preserving functional capacity, and reducing treatment costs (Wong and Neulicht, 1994).* Despite the recognized importance, we have little knowledge of the extent of health promotion among people with disabilities, particularly people with severe physical limitations. The purpose of this study, therefore, was to explore perceptions of self-efficacy and health attitudes among people with cerebral palsy who are living in the community.

Also of interest was how people with cerebral palsy's perceptions compared with the perceptions of two other groups, a group of people largely without disabilities that attended a health fair and another group of people originally contacted through a statewide disability advocacy group. The research questions were:

1. "How do people with cerebral palsy perceive their general, specific health promotion self-efficacy, and their health status?

2. What are the relationships between perceived general self-efficacy, specific health promotion self-efficacy, health status, and selected background and functional characteristics among adults with cerebral palsy?

3. Is there a positive relationship between perceived general self-efficacy, perceived specific health promotion self-efficacy, perceived health status and length of time living in the community among adults with cerebral palsy?

4. How do perceived general self-efficacy, perceived specific health promotion self-efficacy, and perceived health status compare across three groups: participants with cerebral palsy, people largely without disabilities attending a health fair, and members of a statewide disability advocacy group?

Method

Data collection for this exploratory *expost-facto* study consisted of the following. After approval from the Departmental Review Committee, a mailing list of approximately 120 names was acquired from the local chapter of the United Cerebral Palsy Association. All individuals were sent the Self-Rated Abilities Scale, the General Self-Efficacy Scale, the Perceived Health Status Scale, a background information form, and an introductory letter describing their rights as research participants. They were asked to return the completed questionnaires in a stamped, self-addressed envelope. Those contacted were also told that they could request assistance in completing the questionnaires from project staff. Only two individuals requested such assistance. *To include in this sample individuals with varying years of experience living in the community, adults who were recently deinstitutionalized and participating in a separate study were also asked to complete questionnaires by interview.*

A follow-up reminder was sent approximately two weeks later to encourage additional respondents to return the survey. Three questionnaires were eliminated because major sections of the survey were not completed, while another four surveys were eliminated because the respondent was under the age of 18. Because the mailing list included parents of children with cerebral palsy, and may have included a few advocates without disabilities as well, it is impossible to compute an exact return rate. Some questionnaires were also completed by family members or personal attendants with the person with cerebral palsy.

Participants

The sample consisted of 28 adults with cerebral palsy from whom completed questionnaires were received. The average age of the 28 adults was 34 years (range 18-49), and 82% were male (23 men, 5 women). They had lived an average of 14 years in the community. Of the participants, two-thirds reported living less than half their lives in the community, while only four had never

been institutionalized. Eighteen of the participants (64%) were white, six were Hispanic (21%), and two were African-American (7%). Twenty-five were married (89%).

Level of education for the participants varied with 15 having less than a high school education (54%) and seven people having completed high school (25%). Three people had some college (10%), two people had graduated from college (7%), and one individual had a graduate degree (3%). Four people worked full-time, 15 people worked part-time, and nine people did not work.

	Health Fair Sample (n=188)		Coalition (n=117)		Cerebral Palsy (n=28)	
Abilities Scale	Mean	S.D.	Mean	S.D.	Mean	S.D.
Exercise	19.88	6.38	16.68	7.62	12.36	7.71
Nutrition	22.15	4.53	20.59	5.02	16.14	7.23
Health Practices	22.55	4.63	22.80	4.16	18.64	7.31
Psychological Well Being	20.10	5.33	19.79	4.99	17.25	6.04
Health Rating	not	available	8.39	2.15	7.44	2.21
General Self-Efficacy	65.86	9.93	65.41	11.08	62.00	13.42

Table 1

Comparison of Mean Self-Rated Abilities for Health Practices Scale Scores for Persons with Disabilities and Health Fair Samples

Assistance was categorized into mechanical and personal. Mechanical assistance could include use of a wheelchair, amigo, walker, or other adaptive equipment. Sixteen people (57%) indicated that they needed mechanical assistance all of the time, with six people (21%) reporting that they needed no assistance. The remaining participants were evenly divided between needing assistance most of the time and some of the time (three individuals each). In general, participants needed less personal assistance with six people indicating that they needed assistance all of the time (21%), three people needing assistance most of the time (10%), seventeen people reported needing assistance some of the time (60%), and two individuals needing no personal assistance (7%). When participants were asked to indicate who usually helps them when they need assistance the three most commonly used sources were parents, friends, and paid attendants from an agency.

Description of Comparison Groups

Data from this group were compared with two other groups. The first comparison group were people who had attended a health fair held in a local public auditorium. *This group was recruited from those individuals who visited a health promotion display provided by a local school of nursing.* The sample was largely without disability as 80% identified themselves as not having a disability or chronic physical condition. Of the 188 people, 73 were men (39%) and 114 were women (61%). Ages ranged from 17 to 80 with a mean of 37.4 years. Seventy-six percent of the participants were Anglo and married (54%). Most had attended college or held a college degree (80%). Seventy-nine percent were employed. In comparison to 1980 census data for the city in which the health fair was held this group was slightly older by a few years, female, and better educated than the general population.

The second group consisted of 117 individuals who returned questionnaires that had been mailed to members of a statewide disability advocacy group. This group was 88% Anglo, 54% male, and had an average age of 44 years. Eighty-three percent had attended college and 46% were employed full time. People from this group reported 22 different disabilities, with the most common being paralysis, cerebral palsy, and post-polio syndrome. Forty-six percent reported needing mechanical assistance "all of the time", but only 15% needed personal assistance "most" or "all of the time. Fifty-four percent indicated they had adequate financial resources.

Instruments

The Self-Rated Abilities Scale is a 28-item, summated rating scale, designed to measure self-efficacy specific to health promotion. Respondents indicate the extent to which they are able to perform each health behavior on a 4-pt. scale. Items cover the content areas of exercise, nutrition, health responsibility, and psychological well-being. Becker, et al. (1993) reported a Cronbach alpha of .94, and a test/retest correlation coefficient of .75 over a two-week period. Scores have been shown to be positively correlated with scores on Walker, Sechrist, and Pender's (1987) Health Promoting Lifestyle Profile, a widely used measure of the frequency with which individuals report engaging in activities directed toward increasing their level of health and well-being.

The Perceived Health Status Scale is a 4-item summated rating scale designed to measure beliefs about current health status. *The higher the score, the lower the self-rated health.* Lawton, Moss, Fucomer, and Kleban (1982) have reported a test/retest correlation of .92 over three weeks, internal consistency, measured by Cronbach Alpha, of .76, and correlations of .63 with clinicians' ratings of health status. Originally used in a study with geriatric consumers, it has also been used with people with disabilities.

Perceived General Self-Efficacy Scale measures beliefs regarding personal ability to affect outcomes in varied situations and was measured by the Sherer General Self-Efficacy Scale (1982). Sherer et al. (1982) have reported a Cronbach Alpha

coefficient of .86 and significant correlations between this scale and success in vocational, educational, and military settings. The 17-item summated rating scale asks respondents to indicate their agreement with items such as "If I can't do a job the first time, I keep trying until I can." The alpha coefficient reliabilities for all instruments was acceptable (above .80), and similar to what was observed in previous studies.

Respondents were asked to indicate basic demographic information, the amount of personal and mechanical assistance needed, and how long they have been living in the community. Finally, there was a question asking participants if there was anything else that they wanted to tell us about what helps or prevents them from promoting their health. Eleven individuals responded to this question.

Results

In reference to research questions 1 and 4, when compared with other groups (i.e., city-wide Health Fair attendees from the same community and individuals from a statewide disability advocacy group) the participants with cerebral palsy scored lower on all subscales of the Self-Rated Abilities Scale and the Perceived General Self-Efficacy Scale (see Table 1). The standard deviation on many scales was much higher for those with cerebral palsy, possibly suggesting a greater range of perceived self-efficacy, or perhaps simply a reflection of the smaller sample size in this group. The average self-efficacy rating was highest for the Health Responsibility Subscale and lowest for Exercise, which is consistent with the pattern observed among the statewide disability advocacy group.

In reference to research questions 2 and 3, the pattern of correlations among attitude measures is shown in Table 2. High scores on the Exercise scale was related to less need for personal assistance. Surprisingly, however, those needing more mechanical assistance rated themselves higher on the self-efficacy measures. The more adequate the perceived financial resources, the higher the scores on all self-efficacy measures. Those participants with higher self-efficacy ratings also tended to be more highly educated, although only the correlation between nutrition and educational level was statistically significant. Perceived General Self-Efficacy was most strongly related to the Nutrition and Health Responsibility subscales of the Self-Rated Abilities Scale, followed by the Exercise and Psychological Well-Being subscales. Higher ratings of health were associated with higher self-efficacy ratings, although the correlations were statistically not significant. There did not appear to be a relationship between attitudinal measures and years living in the community, or percent of life lived in the community.

The responses of the 11 individuals who answered the question asking if there was anything else that they wanted to tell us about what helped or prevented them in promoting their health varied. Of the three people who responded to what helps them promote their health, two individuals provided specific information. One person said that he swam, scuba dived, and was on the "quad rugby team. "The other person said that "knowing when I need one whole day of rest" helped them. The other person asked for more information, specifically "what kind of exercises can I do by myself and with my attendant. More information to pass along to other people I know."

Eight individuals provided information about what prevented them in promoting their health. Responses included attitudes of employers and professionals, mobility issues, and not having a job. A couple of participants commented, "When so-called providers and employers are not wheelchair accessible and refuse to be so; when the above and doctors and health care and dentists will not cooperate with transportation limitations that deny services it is so frustrating to maintain a good attitude!" and "Dentists who specialize in treating adults with severe cerebral palsy are difficult to find. They should also have sensitivity and attitudinal training. Patronizing is not acceptable". Other responses included "It is hard to make myself exercise when I can ride the scooter" for transportation, and "I would like to get out of the house more, but I would need a van with a wheelchair lift".

Discussion

The results of this study are consistent with findings from the first investigator's previous research suggesting that self-efficacy is related to financial, educational, and functional status. It is interesting to note that those participants who most frequently needed mechanical assistance had the highest self-efficacy ratings, while there was essentially the opposite relationship between self-efficacy and the need for personal assistance. Perhaps if people can operate an assistive device they perceive themselves as more independent than individuals who require assistance from other people.

The lack of observed relationship between years living in the community and the health variables studied here suggests that the impact of institutional experience on health self-efficacy is more complex than originally thought. It may not be the number of years, per se, but the timing and nature of the institutional experience that affect self-efficacy expectations. Future research should address the relationship between self-efficacy and community experience in more depth, perhaps employing a qualitative approach to better understand the relationship from the consumers' perspective.

It should be noted that generalizability of these findings are limited by the fact that this is a small convenience sample, drawn from one geographic area, and the exploratory nature of the design. It should also be noted that a number of the questionnaires were completed on behalf of the respondent with a disability by another individual. In studies with people with severe disabilities it may not be an uncommon practice for another individual to assist in responding; it is not known what potential bias this practice may introduce into the data collection.

We chose not to perform statistical tests of the differences among the means of the three groups because of the disparity in sample sizes and the exploratory nature of the data collection. An examination of the means and standard deviations for the three groups suggests that the individuals with cerebral palsy rated themselves substantially lower than the other two groups on the health specific self-efficacy measures. *Should the trends we observed in this study be confirmed in future studies of health among persons with cerebral palsy, then particular efforts should be directed at building their competencies in health promoting behaviors.*

The fact that the average ratings of ability to perform exercise behaviors is much lower than self-perceived abilities to carry out other health promoting behaviors (e.g., health responsibility, nutrition, and psychological well-being) suggests that there is a

	Mech	Pers	Finan	Nutri	Psych	Exerx	Hresp	Hlth	Effic	Reside	Live
Educate	.24	.09	.17	.46*	.27	.32	.17	-.16	.31	-.05	-.10
Mechanic		.34	.09	-.28	-.45*	-.23	-.60*	.16	-.45	-.12	.16
Personal			-.10	.10	.11	.37	.05	-.01	.03	-.15	.05
Financial				-.58*	-.51*	-.45*	-.42*	.21	-.38	.22	-.11
Nutrition					.58*	.61*	.63*	-.16	.68*	.01	-.07
Psych						.62*	.69*	.03	.46*	.06	-.13
Exercise							.54*	-.13	.50*	.09	-.18
Hlth Resp								-.29	.64*	-.10	.06
Health									-.31	-.10	.11
Efficacy										.13	-.11
Reside											.92*

* Correlation significant at $p < .05$

The higher the value, the **less** the reported need for mechanical and/or personal assistance.
The higher the value, the **less adequate** the reported financial resources.
The higher the value, the **poorer** the self-rated health.
The higher the value, the more years institutionalized (LIVING), and higher percentage time living in the community (RESIDE).

KEY:
Educate = Educational Level
Mechanic = Amount of mechanical assistance needed
Personal = Amount of personal assistance needed
Financial = Perceived adequacy of financial resources
Nutrition = Subscale score from the Self-Rated Abilities Scale (7 items)
Psych = Subscale score from the Self-Rated Abilities Scale (7 items)
Exercise= Subscale score from the Self-Rated Abilities Scale (7 items)
Hlth Resp= Subscale score from the Self-Rated Abilities Scale (7 items)
Health= Perceived Health Status Scale score (4 items)
Efficacy= Perceived General Self-Efficacy Scale score (17 items)

Table 2

Correlations of Health Attitude and Background Characteristics Among 28 Individuals with Cerebral Palsy

particular need for health promoting interventions aimed at assisting people find ways to exercise that are feasible. Comments from many of the participants further illustrate barriers many individuals with severe disabilities encounter as they attempt to take care of their health.

Implications for Rehabilitation Professionals

The fact that over three-fourths of these respondents rated their health as good or excellent supports Pender's contention that health and illness or disability are separate constructs, and may exist concurrently. *Rehabilitation counselors should take the lead in making health care providers and other professionals aware that people with disabilities see themselves as essentially healthy individuals with the same needs for health promotion as all other persons.*

There are both external and internal factors that contribute to people's ability to take care of their health (Melnyk, 1988). External factors include accessible exercise facilities with staff who are knowledgeable about accommodations needed in providing services for people with severe disabilities. For example, many exercise facilities require that individuals be able to change themselves. For persons with severe disabilities this may mean hiring attendants to come with them to help them change, wait while they exercise, and then assist them again. Changing areas available at many facilities have benches that are not usable by people who use wheelchairs, and changing mats may be needed so people don't find themselves on cold, wet cement floors (Dawidczyk, personal communication, January 25, 1994). Good nutrition may be dependent upon easy access to nutritious foods, which can be problematic for people on limited incomes or those without accessible transportation. The moderate correlations in this study underscore the importance of adequate finances for health promotion.

Another important aspect of taking care of one's health is routine primary health care. However, finding doctors, nurses, and dentists who work effectively with individuals with spasticity, for example, may be difficult. Moreover, many individuals with severe disabilities rely on Medicaid to pay for health care, and many private physicians and clinics don't want to take patients on Medicaid because of reduced rates. In addition, Medicaid does not pay for maintenance health care needs, which are at the heart of preventive health care.

Internal factors include knowledge and motivation. While we are bombarded with health promotion suggestions in the mass media, this information is not tailored to the needs of people with severe disabilities. In fact, one of the respondents specifically requested more information about exercises he could do with himself and his attendant. An individual may be aware of the benefits of exercise (Turk, 1993), but may not be able to exercise or stretch at home without someone assisting who is also knowledgeable about proper methods of exercising and stretching.

Motivation issues are also important. One of the participants pointed out that it is difficult to maintain a good attitude in the

face of transportation limitations (which may cause him to be late for an appointment, requiring him to wait if he will still be seen) and negative attitudes of health care providers, while another participant indicated the difficulty of staying motivated to exercise when she can ride a scooter. It is less motivating to engage in activities that are consistently difficult or frustrating. In addition, the time and energy invested in activities of daily living necessary to live independently in the community may leave less time available to put into health promoting activities.

Rehabilitation counselors can assist people with severe disabilities in health promotion. *The first step for both counselors and the consumers with whom they work is to become aware of the importance of health promotion. Although health promotion may not regularly be incorporated into rehabilitation planning, health promotion activities may prevent secondary disabilities, preserve functional capacity, reduce treatment costs, thus contributing to quality of life for persons with disabilities (Marge, 1988; Wong & Neulicht, 1994). Both the number and intensity of the comments made by many participants in this study suggest that people often need to talk about issues of health promotion as a means of sharing information, feelings, and concerns. Rehabilitation counselors should recognize the importance of giving the consumers with whom they work the opportunities to voice their health concerns.*

Rehabilitation counselors need to build collaborative relationships with advocacy groups around health issues. For example, advocacy groups may have lists of health care providers in their area who are knowledgeable and willing to work with people with severe disabilities. They may also sponsor support groups that can assist people in coping effectively with the stressors they experience in life and teach them strategies for taking responsibility in health issues.

Bandura argued that vicarious learning is one of the most effective ways of building self-efficacy. Rehabilitation counselors need to identify local "role models" such as a wheelchair athlete who teaches at, or directs, a local fitness center and look for opportunities to link consumers up with such role-models.

Counselors should be informed about supports in the community that facilitate health promoting activities, such as exercise facilities and hospitals that provide accessible pools and exercise rooms with knowledgeable staff. Information about resources for accurate assessments of seating and positioning will also be important for many consumers. *Finally, counselors should note that the passage of the Americans with Disabilities Act (1990) may impact on businesses that offer health promotion programs for employees as Title 1 employment prohibits discrimination of qualified persons with disabilities in all employment practices, including fringe benefits and privileges of employment such as employee wellness programs (Wong & Neulicht, 1994).*

More people with severe disabilities are moving successfully to the community and health maintenance and promotion are important considerations for rehabilitation planning (Roessler & Rubin, 1992). By being aware of local barriers and resources rehabilitation counselors can assist consumers with severe disabilities in maintaining and promoting their health.

Acknowledgement

The authors wish to thank Joyce Dawidczyk for her helpful comments and Florence Falola for her assistance in data analysis. This study was supported by BRSG and UAP grants. We also with to acknowledge the assistance of the United Cerebral Palsy Association of the Capitol Area for their support.

Partial funding provided by seed money from Biomedical Research Support Grant #2SO7RR 05991-04 and the Texas University Affiliated Program, made possible by a core grant from the Administration of Developmental Disabilities, U. S. Department of Health and Human Services.

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Received:	April 1994
Revision:	August 1994
Acceptance:	September 1994