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The Self-Help Movement: Evolution of a Dystonia Chapter

BETSY M. COHEN and HANOCH LIVNEH, Ph.D.

ABSTRACT: The self-help movement has evolved during the last 50 years from a group of parents and friends promoting the improvement of services for disabled persons to individuals with disabilities advocating for their own needs. The Dystonia Medical Research Foundation was established in 1975 to support research of dystonia, a rare neurological disorder that causes the body's muscles to twist and to posture. Within the Dystonia Medical Research Foundation, the local chapters have grown to reflect the trends within the self-help movement. After a brief review of the history of the Dystonia Foundation and the self-help movement, the New England Chapter's model of self-help is presented to illustrate this evolving process.

THE SELF-HELP MOVEMENT began in the 1930s as a response to several factors that were making general counseling services unavailable or unresponsive to those who needed them.^{8,12} Depersonalization, dehumanization of the system, size and complexity of the facilities, as well as the alienation of individuals caused by technological advancements were all major contributions to this trend.

Early groups were initiated by parents whose children had disabling conditions.⁵ Other self-help organizations started as a cooperative effort against unemployment throughout the depression era. During the decade following World War II survivors of concentration camps formed groups to help newcomers adjust to life in the United States.¹

Today, the self-help movement is geared toward not only the encouragement of the parents or families of people with disabilities to promote advocacy, but toward the person with a disability as well.^{6,14} Peer counseling programs have appeared for those affected by alcoholism, heart disease, neurological disorders, and many other disabling conditions. Such programs have appeal because they offer more direct and effective intervention without the stigma often attached to seeking outside professional assistance. With the change in emphasis on the person with a disability promoting his or her own advocacy, organizations with a peer counseling orientation, or self-help programs, afford the individual with a disability a chance at a rightful and equal role in society.

History of the Dystonia Medical Research Foundation

The Dystonia Medical Research Foundation was established in 1975 to promote and support research efforts to find a cure for this condition. During the last decade, four local chapters of the Dystonia Foundation were started by families who had children affected by dystonia (New York, Chicago, Southern California, and Delaware Valley, Pa.). In 1983, the establishment

of the fifth local chapter in New England reflected the trend of self-help organizations, as it was the first chapter to be initiated not by parents or family members of a person with dystonia, but by a young woman living with the disorder. Since that time, a Montreal Chapter has been formed and is the second subsidiary chapter of the Dystonia Medical Research Foundation to be organized and managed by an individual with dystonia.

Dystonia

Dystonia is a rare neurological disorder characterized by repeated and uninterrupted movements that can affect one muscle, a group of muscles, or the entire body musculature. The cause, control, and cure are as of yet unknown.⁴

There are several different forms of dystonia, all of which can occur at any time throughout the person's life cycle. Generalized dystonia affects all or most of the musculoskeletal system. The segmental type involves more than one major muscle group, whereas focal dystonias are limited to one specific site (e.g., oromandibular—affecting the jaw muscles; blepharospasm—affecting the muscles of the eye; or torticollis—affecting the muscles of the neck). Paroxysmal dystonia can appear in any of these forms, although it most often affects several or more muscle groups and is characterized by fluctuations in the presentation of symptoms and in the manifestation of the disorder itself.

Dystonia tends to affect ethnic groups in a differential manner; however, its prevalence in the general population of North America is estimated at 3 per million individuals. Within the black community, the incidence is considerably less (0.3 per million). Jewish individuals with an Eastern European background have an increased prevalence of dystonia (25 per million).³ The etiology of dystonia is often traced to trauma or insult to the brain, hereditary factors (the exact genetic transmission, however, is presently not well

understood), or idiopathic (cause is undetermined). Research has demonstrated that 40 percent of the individuals affected by dystonia have been misdiagnosed at least once.⁷ In general, the earlier the age of onset of symptoms, the greater the possibility of progression of dystonia and the severity of its symptoms.³

Treatment presently follows a trial-and-error pharmacotherapeutic approach. Investigations⁴ have proven several drugs to be beneficial to certain individuals, but the type of medication and therapeutic dosage differ significantly from one person to another. In extreme situations when all conservative methods have been exhausted, some individuals require a surgical procedure known as cryothalamectomy. This surgical intervention involves creating a lesion in the assumed-to-be-affected area of the brain. None of these treatment modalities, whether pharmacological or surgical, carry a guarantee for success. Dystonia is suspected to be a disease of the basal ganglia, but no gross or microscopic changes have yet been determined.⁴

The New England Dystonia Chapter

The New England Dystonia Chapter, Inc. was established in 1983. Its goals and processes as a self-help organization are presented as one example of the growing importance and trend within the self-help movement. The goals of the New England Chapter are:

- (a) to provide peer counseling and support services to individuals with dystonia and their families;
- (b) to establish educational programs about dystonia for the medical and lay communities, utilizing reprinted journal articles, films, information distributed by the Dystonia Medical Research Foundation, and providing a speakers' bureau;
- (c) to serve as advocating and liaison body for chapter members regarding the availability of medical, legal, and social services; and
- (d) to participate in a network of services with other dystonia chapters and the National Foundation, in order to represent the concerns, ideas, needs, and recommendations of the chapter's membership.

The Self-Help Process

The self-help process is comprised of several major phases:

1. The process is initiated when the individual contacts the organization or when a written referral from a physician is received by the chapter. Local neurologists, psychiatrists, internists, and pediatricians who are familiar with the chapter's services—either from the chapter's Medical Advisory Board or from its

active educational outreach program—often refer individuals to the organization. Self-referrals are made as a result of individuals learning of the existence of the New England Dystonia Chapter through the media. Several newspaper articles and appearances on television interview shows have increased the public's awareness of the organization and its efforts. In addition, the chapter has a speakers' bureau that has reached a wide audience of medical and lay people over the last two years.

2. Once a referral, self or otherwise, has been made and contact is established, the chapter president telephones each person to explain the nature, function, and role of the organization. Since the entire New England region is served by this chapter based in Providence, Rhode Island, a home visit is made by a peer counselor. Such a visit allows the person to make contact with the organization and to meet not only a peer counselor, but a resource person as well. For the majority of members, this association with the New England Dystonia Chapter and a peer counselor, whether by telephone or personal meeting, is their first contact with another person with dystonia. If a meeting is not possible, then this initial exchange of information is made by telephone and is followed up by additional telephone contacts. The New England Dystonia Chapter has a 24-hour telephone service that allows continued contact with the organization for all members in the event of an emergency. Even though this chapter covers only the New England region, calls are often received from people who recently learned they had dystonia and from their family members, from other parts of the country where there is no established local affiliate. The 24-hour telephone service is especially helpful to those whose time zones differ and who are unable to reach the chapter's office during business hours. This telephone number is listed in the yellow pages of the telephone directory under social service agencies, and is given to all members, as well as to area hospital departments of neurology.

3. Following the initial referral, issues that are most often in need of attention for new members are discussed. These include issues relating to diagnosis, medical treatment, prognosis, and psychosocial adjustment to the disorder. Peer counseling plays an important role during this period. Many of the individuals have experienced misdiagnosis prior to this recent experience and have mixed feelings surrounding the medical community on whom they must now depend. Fear, anger, and confusion regarding past treatment are not uncommon, nor are questions about incidence, severity, and prognosis of this disability.

Peer counselors are individuals with disabling conditions who use their related experiences to help other persons with disabilities improve and utilize their coping skills to adjust to their impairment.^{10,11} Peer

counselors involved with the New England Dystonia Chapter live with dystonia or have a family member who is affected by dystonia. These individuals either hold degrees in psychology, counseling, or related fields, or have been trained professionally by counselors for the purposes of this peer counseling program. The primary counseling model is Rogers' person-centered therapy at the start of the process, emphasizing attending to clients' needs and concerns with empathic understanding and genuineness. A more direct counseling approach, including cognitive and behavioral techniques, is utilized later on focusing the reinforcement and rewarding of appropriate attitudes and behaviors, mild confrontation, and developing problem-solving and decision-making skills.

4. Since dystonia is a relatively rare and poorly understood disorder, the issues raised as most pertinent by those affected often include those having few answers. The success of treatments is individually determined. There is no accurate method for determining the extent of control of dystonia or of the progression of its symptoms. For most of the chapter's members, the only certainty is that of indefiniteness. The hereditary mechanisms of dystonia are poorly understood, making the decision of whether or not to have children of one's own difficult at best, even following a referral to a genetic counselor. Fear, concern, and anger regarding the "why" and "how" an individual is affected by dystonia seem to be quickly replaced by the practicalities of living and coping, on a daily basis, with an unpredictable disorder.

Interestingly, those individuals who achieve a good level of control fairly soon after diagnosis do not tend to be involved with the efforts of the New England Dystonia Chapter. Many of them fear vocational, educational, or social reprisal and prefer to "pass" as non-impaired persons. Those involved with the efforts of the New England Chapter are the individuals who are most severely affected by dystonia. Such persons may discuss fantasies of returning to work or of furthering their education; however, the majority of the information they seek surrounds new treatments, issues related to disability insurance, and support services.^{2,13}

Discussion

Mathews¹⁰ cites support, friendship, and assistance in problem-solving as the most common reasons given for seeking peer counseling. For the members of the New England Dystonia Chapter, experienced advice, support services, and advocacy would be the reasons most frequently given for initiating contact with this organization. Often people who contact the chapter are not trustful of medical personnel. Some allow contact with the organization but refuse medical attention. All options are carefully explored and outlined

with each person, and a listing of neurologists trained to treat dystonia is available upon request. Counselors are advised not to suggest nor promote a specific medication or surgical procedure that has been helpful to a relative, friend, or one's self. Neurologists are the best source of information regarding treatment. However, peer counselors have been very helpful in providing the necessary support during the difficult transition time from diagnosis to effective treatment.

The peer counselor is in many instances the only individual with whom individuals with dystonia discuss issues relating to their disorder and how the disability affects their life. On occasion, members comment that they feel uncomfortable burdening their physicians with questions regarding daily living with dystonia. Many physicians will not refer people with dystonia to rehabilitation centers for physical, occupational, or speech therapy unless the individual impresses upon the physician that he or she requires such assistance. Since the emphasis is on the medical model, treatment is usually confined to medication in an effort to completely control the symptoms associated with the disorder. This is often the desired goal of the person living with dystonia—to ultimately have total symptom control or cure. However, little, if any, time is spent with physicians planning a safe and satisfying way for the affected individual to live until this desired goal is achieved. Although peer counselors stress the importance of open communication between the doctor and patient, there is still a reluctance on the patient's part to question the doctor, often for fear of creating increased tension with the medical personnel. When requested, the chapter president or peer counselor will serve as a liaison person between the patient and the physician. This type of communication intervention or support is also available to chapter members when sensitive school- or work-related negotiations are required.

Vocational and educational planning often become a source of frustration for the individual who is moderately or severely impaired with dystonia. If the dystonia is stabilized, the problems associated with school or work adjustment center mostly around negative attitudes by peers, co-workers, or employers, much like the problems faced by individuals having other types of physical disabilities. Progressive and paroxysmal forms of dystonia, however, create an even greater challenge for the person with respect to future career and school plans.

Interruption of the traditional educational and vocational process is frequent and the time frame within which the progression occurs is indefinite. Few employers can afford to tolerate erratic work schedules. Often disability insurance of some type is the best temporary solution, although as a source of income such funds are rarely adequate. In instances where

chapter members are denied disability insurance or other health care benefits due to a lack of awareness regarding the nature of dystonia, the New England Dystonia Chapter intervenes by sending the necessary information and published medical facts concerning dystonia to the appropriate lawyers and court officials to ensure the continuation of these deserved benefits. Chapter members have stressed the importance of these advocacy-related and psychosocial support services. Many of the clients have stated that these programs have significantly helped in their adjustment to living with dystonia.

Several months following a referral, most crisis situations have usually been managed and the individual no longer requires continuous intervention. This process is then followed with a telephone call, approximately every eight weeks, to note any change in the member's needs. Each member is encouraged at that time to contact the chapter and its peer counselors whenever the need arises.

Summary

The New England Dystonia Chapter was established to provide psychosocial support services to persons with dystonia and their families in addition to educational programs regarding dystonia for the medical and lay communities. As a subsidiary of the Dystonia Medical Research Foundation, it maintains a nonprofit status with all of its medical and lay advisors, as well as peer counseling services provided on a voluntary basis. The New England Chapter presently provides services for approximately 35 individuals who live with dystonia, as well as their families. The chapter has a mailing membership list of well over 200 individuals. In addition to the peer counseling and educational programs that are supported and conducted by the chapter, there is a group-sponsored meeting, open to all members, at which time guest speakers are invited to present information regarding new research findings or treatment efforts for dystonia or concerning topics related to coping and living with dystonia. Advocacy, peer counseling, and education are the primary programs and services that the New England Dystonia Chapter offers its members in order to assist them in the adjustment process of living with dystonia.

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