

CHARACTERISTICS OF POLIO SURVIVOR SELF-HELP ORGANIZATIONS

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ABSTRACT

While polio has been largely eliminated from the developed world, millions of survivors suffer not only the direct effects of this disease but many face new obstacles 20 to 40 years after "recovering" from the initial viral infection. With few of today's doctors familiar with how polio affects the body, survivors have created self-help groups for social support and to disseminate the most recent information on what is commonly referred to as "post polio syndrome" or "post polio sequelae." Post polio groups differ from other health focused groups like cancer and obesity, in that they do not have a new pool of potential members from which they can recruit. However, our survey of 83 polio self-help groups finds several similarities in organizational goals, structure, and services to other types of self-help organizations. The groups' focus was primarily on providing members with health related information and social support. Leaders tended to be well educated professional females. Many post polio self-help groups had alliances with other polio groups and with medical clinics and hospitals.

Polio reached epidemic proportions in the United States in the 1940s and early 1950s (Neus, 1999). Since then, however, in a review of major diseases, McKinlay and McKinlay (1990) reported polio to be one of the few diseases to have declined due to direct medical intervention. Indeed, Salk and Sabin were hailed as heroes for their work on polio vaccines. In the late 1980s work began to eradicate polio from the earth. Polio has been absent in the United States since 1979, from the

Americas since 1994, and from China since 1996. By 1999 only 41 of the world's 202 nations reported cases of polio with total number of cases falling from 40,000 in 1988 to 5,000 in 1998. Polio may become the second disease to be eliminated from the world, following smallpox in 1980 (Neus, 1999).

However, in recent decades, polio survivors of the epidemics of the 1940s and 1950s have begun to experience new medical problems. Indeed, of an estimated 1.63 million Americans who survived polio decades earlier, it is estimated that about 50% are re-experiencing medical symptoms (Kuehn & Winters, 1994). The terms "post polio syndrome," "post polio sequelae," and "polio late effects" have been coined to describe these problems.

In recent decades the number and type of self-help groups have also been increasing in industrialized nations. In 1990 it was estimated that as many people in the United States attended self-help/mutual aid groups as participated in professionally-led psychotherapy. In one year 7.1% of the U.S. population and 2.4% of the Canadian population attend self-help groups (Kessler, Mickelson, & Zhao, 1997 as cited in Borkman, 1999; Gottlieb & Peters, 1991 as cited in Borkman, 1999).

While bodies of research on self-help groups and on medical and psychological symptoms experienced by polio survivors have emerged, there is a lack of research on self-help groups for polio survivors. In this article we examine the characteristics of a sample of self-help organizations for polio survivors.

EMERGENCE OF SELF-HELP ORGANIZATIONS

A number of reasons for the emergence and growth of self-help groups have been suggested. First, Borkman (1999) noted that since the 1960s the pace of cultural and technological changes has increased. Consequently, new diseases were identified and life spans were lengthened, increasing the prevalence of chronic diseases. Because medical professionals lack effective remedies for new diseases and, thus, primarily treat symptoms, persons with new and/or chronic diseases may determine that they know more about their conditions than do medical professionals.

For example, polio survivors have claimed to be "medicine's lost generation," noting that since the 1960s there has been little training about polio in medical schools (Moffett, 1998). Foster, Berkman, Wellen, and Schuster (1993) reported that 54.8% of polio survivors in their study indicated they lacked access to physicians with knowledge of post-polio effects. Indeed, the term "post polio syndrome" was coined by polio survivors themselves rather than by medical professionals (Healy, 1992).

Second, during the 1960s and 1970s a consumer movement emerged. The movement resulted in a struggle for dominance between consumers and professionals (Borkman, 1999). As consumers became better educated, they became increasingly likely to question and to challenge professionals (Ritzer & Walczak, 1986). As noted by Foster et al. (1993), success in preventing polio has led to a

generation of medical professionals unfamiliar with acute cases of polio let alone late effects of the disease. Bruno and Frick (1991) reported that 23% of respondents in a national survey of polio survivors were told by physicians that they imagined their symptoms and 26% were told the symptoms were unrelated to polio. Others were told they had other diseases or that they were just getting old. It was not until the 1990s that medical practitioners accepted late effects as linked to polio. One response to the desire of consumers for greater knowledge and rights has been formation of self-help groups (Borkman, 1999).

Third, the earlier success of Alcoholics Anonymous provided a model for self-help groups. While many of these groups did not adopt AA's quasi religious format and 12-step program, its success demonstrated that volunteer self-help groups could impact individual lives (Wuthnow, 1994).

Fourth, Treanor (1998) aptly describes the long struggle for civil rights for persons with disabilities. The civil rights movements of the 1960s and 1970s increased awareness of cultural rights. These movements motivated persons who shared common problems and experiences to come together in groups where they could share their experiences and become experiential authorities with rights to defend themselves (Borkman, 1999).

Fifth, the women's movement of the 1970s and subsequent feminist scholarship has helped to validate experiential knowledge (Borkman, 1999). Feminists have emphasized the need for groups to speak in their own voices (Andersen, 2003).

Since the 1970s self-help resource centers or clearinghouses have emerged. These centers maintain lists of self-help groups and are able to act as referral agencies. They additionally may assist people who wish to establish new self-help groups. While self-help groups are most prevalent in developed nations, they are currently emerging in former communist areas as well. Some African nations are starting support groups for AIDS victims and their families (Borkman, 1999).

NAMES OF ORGANIZATIONS

Although self-help groups began in the 1930s with Alcoholics Anonymous, Borkman (1999) links momentum in emergence of self-help/mutual aid groups to a cultural emphasis on learning from peers and the younger generation. While she pinpoints the 1970s as the time this trend emerged in the United States, Litvak and Martin (1999/2000) cite 1980 as the time of the shift from a medical to a minority/civil rights/independent living model. Nonetheless, the 1970s was an important decade in the history of self-help groups in terms of the attention the groups received from researchers. In 1976 alone five journals in various disciplines published special issues or books devoted to such groups. It was during the 1970s that the groups were clearly named as self-help/mutual aid groups. Symbolic legitimation of the groups came about in 1987 when a national Workshop of Self-Help and Public Health was convened by Surgeon General Everett C. Koop. As a result of the workshop, some agreements were reached

regarding ways in which self-help is distinct from professionally-controlled support groups (Borkman, 1999).

Names carry important cues concerning the scope, ideology, and the nature of an organization's activities. As Borkman (1999) noted, terms used in names of self-help/mutual aid groups are controversial, reflecting the sensitive nature of the issues. Self-help/mutual aid participants often prefer to call themselves survivors, not victims. This has been an especially sensitive issue for polio survivors. Many have vivid recollections of the names of institutions in which they were treated for acute polio: The Home for the Incurables, The New York Society for the Ruptured and Crippled, and The Home for the Destitute Crippled Children (Hindley, 1997).

ORGANIZATIONAL SIZE AND TYPE

There is a lack of consensus regarding desirable size of self-help groups. On one hand, some groups actively seek ways to expand their membership. For example, Gaston and Meissen (1999/2000) reported that members of local chapters of the National Alliance for the Mentally Ill sought assistance from the state organization in attracting new members, in inspiring them to attend and become actively involved, and in retention of members. According to Borkman (1999), self-help groups may also receive assistance in recruiting new members from professionals associated with the group. Even with such help, however, retention poses particular problems in self-help groups. This is so because some participants harbor expectations of being "cured" through their participation and leave the group when no cure is forthcoming. Indeed, Borkman (1999) found that self-helpers who continue their participation over time tend more often to be active problem solvers than those who are not retained in the group. In fact, fewer than 18% of persons who are offered opportunities to participate in self-help groups and are told of the benefits attend even one meeting. Further, variability in world views of members may negatively impact retention (Borkman, 1999).

On the other hand, increasing size may negatively impact the ability of self-help groups to retain traits originally deemed desirable, i.e., egalitarian interactions, flexibility, and opportunities for participants to engage actively in the group. According to Borkman (1999), as size of a self-help group increases, so does bureaucratization. Thus, we would expect to see greater formalization of procedures in larger organizations for polio survivors than in smaller ones.

CHARACTERISTICS OF MEMBERS

According to Blumberg (1987), members of voluntary organizations often share a common identity such as race/ethnicity. For example, Borkman (1999) found there were few women in the first self-help group for persons who stutter. Nonetheless, she pointed out that self-help groups vary in the extent to which they

are open to participants of differing world views and varying demographic traits. Data on extent of homogeneity of self-help groups is limited and may be biased by researchers' choices of types of groups and geographic locations. Additionally, some self-help organizations, such as Alcoholics Anonymous, design groups for participants with particular traits, i.e., young people, nonsmokers, persons who require child care and the like (Borkman, 1999). However, while members of a self-help group may share some common traits, they may differ on others. Gaston and Meissen (1999/2000) reported characteristics of members of the National Alliance for the Mentally Ill, noting that a majority (76%) had attended college. However, ages of members ranged from 33-82 with a median age of 64. Incomes ranged from \$10,000 to over \$100,000 with a median of \$30,000-40,000. Just over half (55%) were employed either full or part time.

SERVICES: INFORMATION AND ACTIVITIES

Because most participants in voluntary organizations do not obtain incomes as a result of their participation, many participate only episodically and their interest may be only passive (Hall, 1999). Consequently, internal environments of voluntary organizations, including self-help/mutual aid groups, tend to be unpredictable as few participants are involved in all dimensions of the group's operations. For example, some may exchange ideas and support at local meetings while avoiding advocacy and public education (Gaston & Meissen, 1999/2000).

Despite this, all organizations need the involvement of participants. In general, involvement tends to be greater when motivation is both moral and material. Moral motivation can be created by sharing stories (Blumberg, 1987). On the other hand, because typical functions of self-help groups are to provide current information to members and to educate the public regarding their condition, self-helpers cannot be totally colloquial. Meeting activities often include education by professionals in addition to experiential education and social advocacy (Borkman, 1999).

While there is little research on meeting activities of polio survivors' groups, Foster et al. (1993) noted mutual psychological support to be of high importance to members of self-help groups generally. Borkman (1999) reported that among groups for persons who stutter, the least popular meeting activity overall was organizational matters, though attendance was also apt to be low if there was no planned topic or if the presentation conflicted with the group's meaning system. Once a majority of members have attained survivor or thrivor statuses, attendance of meetings tends to decline if professionals take charge and/or advocated approaches are incompatible with the group's meaning system. On the other hand, repeated discussions of the same topics tend to lead to declining attendance as well. Satisfaction, and thus participation, is more apt to remain high when members are actively engaged.

Madara (1999/2000) discussed the role of computer technology in reducing barriers among persons desiring mutual aid. For example, those who are home-based are now able to converse with others sharing their problems. On-line self-help/mutual aid has been found to provide benefits similar to face-to-face aid. Indeed, currently a majority of the 100 largest self-help/mutual aid groups have Web sites and/or e-mail addresses. Barriers that have been overcome through online self-help include: lack of an existing local group, which is a common problem in rural areas; need for round the clock rather than monthly help; transportation problems; and reluctance to participate due to shyness or desire to hide such limitations as braces. In addition, online sources of information can reduce medical costs. On-line self-help can overcome problems of hierarchy and inequality because on-line self-help is less structured and no formal leadership exists online. Thus, on-line communication is an equalizer, for there are no visual distractions, i.e., signs of social status, age, dress, weight, race, and disabilities.

CHARACTERISTICS OF LEADERS

According to Levin (1999/2000), locus of control is a major issue within self-help/mutual aid groups. Self-help/mutual aid processes require that control of learning content and methods shift from professionals to laypersons because groups controlled by professionals are by nature hierarchical.

Self-help organizations, however, are rarely leaderless. As Blumberg (1987) notes, it is difficult to maintain non-bureaucratic egalitarian groups when society as a whole is bureaucratic and hierarchical. Although there is a lack of past research on characteristics of leaders of polio survivors' groups, Medvene, Wituk, and Luke (1999/2000) found that among the leadership of the local chapters of the National Scoliosis Association 85% were female, 69% were married, 73% had at least some college work, and 70% were employed part or full time. Average age was 54. Thirty-three percent had founded their local chapters and average tenure as leader was 4.5 years. Twenty-seven percent of the leaders held professional positions, ranging from physician to nurse, social worker, and educator.

A number of researchers (Blumberg, 1987; Gaston & Meissen, 1999/2000; Hall, 1999) noted that characteristics deemed desirable for leaders of self-help/mutual aid groups may differ from those in bureaucratic groups. In voluntary organizations administrative ability is less important than an ability to represent the needs of members and to run the organization democratically. Because of this, voluntary organizations are less likely than bureaucratic organizations to set criteria for leader characteristics in advance of selection. Variation in leadership performance is greater in voluntary organizations and serves to generate new ideas, preventing trends toward bureaucratization (Hall, 1999). A major function of self-help groups—to combat stigmatization—is better achieved in collectives than within hierarchies (Borkman, 1999).

In the case of polio survivors Backman (cited by Foster et al., 1993) noted high levels of distrust of medical authorities due to negative experiences during the acute phase of polio. These past negative experiences may heighten the wariness of polio survivors to become involved in groups or organizations led by professionals.

While Wollert (1999/2000) agreed that professional involvement violates a core value of self-help groups, he also saw benefits to professional participation. Specifically, Wollert argued that professionals who participate in self-help groups gain better clinical understandings of issues faced by self-help members and thus become more effective in helping patients who come to them for treatment. While Borkman (1999) notes dehumanizing treatment by medical personnel to be a major impetus for self-help/mutual aid movements, Wollert (1999/2000) believes that by learning from self-help participants, professionals will in the future be able to improve human services and medical delivery systems.

Medvene et al. (1999/2000) reported that in their sample of leaders of local chapters of the National Scoliosis Association, leaders typically performed the following 10 activities for their groups: conducting meetings, notifying members of meetings, arranging programs, answering letters and phone calls, keeping membership lists, arranging for meeting rooms, maintaining contact with professionals, and keeping a library of information. Thirty-five percent of the respondents reported that leaders were responsible for all of the group's activities.

ALLIANCES AND FINANCES

There are two general categories of organizations with which self-help/mutual aid groups tend to establish relationships. First, the effectiveness of local self-help/mutual aid groups can be improved when they are linked to more formalized state or national organizations (Gaston & Meissen, 1999/2000). The benefits of such ties are mutual in that the local groups and the larger organization use each other as resources (Blumberg, 1987).

Second, some self-help groups are linked to hospitals or social services agencies. These self-help groups tend to be more structured than those that lack these linkages. In yet other cases self-help/mutual aid groups are created in order to sever ties with formal organizations like hospitals, thereby escaping restrictive rules imposed by professionals (Borkman, 1999).

Self-help/mutual aid groups vary in extent and sources of funding. Although budgets tend to be small in groups without paid staff, it is rarely possible for self-help groups to be totally independent in terms of resources (Borkman, 1999). One reason for this is that qualification as a self-help group requires that contributions be voluntary and thus that no membership fees are charged (Medvene et al., 1999/2000). Because of this, some groups obtain at least part of their funding from mainstream organizations. Mainstream organizations that provide funding for self-help groups vary in the extent to which they attempt to control

rather than facilitate self-help/mutual aid processes. Nonprofit status can also affect level of bureaucratization of self-help/mutual aid groups. Groups that are legally incorporated as nonprofit organizations must conform to legally mandated procedures and rules and thus are by necessity bureaucratized to some degree (Borkman, 1999).

At the height of the polio epidemics of the 1940s and 1950s, the March of Dimes emerged as a grassroots effort to raise funds to aid those stricken with polio (Hindley, 1997). However, there is a lack of current research on alliances and funding for polio survivors' groups.

THE SAMPLE

The sample of organizations was obtained through a list compiled by *The International Polio Network Directory—2000*. Questionnaires were sent to a total of 220 organizations—200 in the United States and 20 organizations in four other English-speaking nations. Fifteen were returned by the post office and seven by the recipient because the organization no longer existed, leaving a final sample of 198 organizations. A total of 83 usable questionnaires were returned—the United States (74), England (3), Australia (3), and New Zealand (3)—for a return rate of 42%.

The questionnaire included questions about the organizations' membership, leadership, activities, finances, and alliances with other organizations. The questionnaires were filled out primarily by the organizations' presidents, coordinators, or secretaries.

WHEN FOUNDED?

The oldest organization in our sample was founded in 1939 in England. The next oldest was founded in 1975 in California, followed by a Kansas organization in 1976, and another California group in 1978. Half the organizations were founded in the 1980s with 1985 (11) and 1986 (8) reported as the most frequent years the organizations were founded. In fact, the two years of 1985 and 1986 account for nearly one-fourth of the organizations. The newest organization in our sample was started in 2001 in Florida. The Australian organizations started between 1989 and 1992, about the same years as the New Zealand organizations (1986-89). The second United Kingdom organization in the sample started in 1996 (see Table 1).

Our sample included organizations in 35 of the 50 states. California had the most with six. Florida, Louisiana, and Texas each had four organizations. There were organizations in every region of the country including Hawaii, but not Alaska.

The rise of polio organizations in the middle 1980s is consistent with both the increase in self-help groups in the United States and with the rise in post polio

Table 1. Year Organizations were Founded

Year	<i>N</i>	Percent	Year	<i>N</i>	Percent
1939	1	1.2	1990	3	3.6
1975	1	1.2	1991	5	6.0
1976	1	1.2	1992	1	1.2
1978	1	1.2	1993	8	9.6
1980	1	1.2	1994	3	3.6
1982	2	2.4	1995	2	2.4
1983	1	1.2	1996	2	2.4
1984	3	3.6	1997	2	2.4
1985	11	13.3	1998	3	3.6
1986	8	9.6	1999	2	2.4
1987	5	6.0	2001	1	1.2
1988	6	7.2	Total	81	97.6
1989	8	9.6	Missing	2	2.4
			Total	83	100.0

syndrome symptoms experienced by polio victims of the 1940s and 1950s (Bruno, 2002; Gould, 1995; Halstead, 1998).

WHAT'S IN A NAME?

One way an organization presents an identity to the public is through its name. It is not surprising that all but two organizations included “polio” somewhere in the organization’s name. Two of three organizations used “post-polio,” indicating the disease has passed even though most of these groups are clearly designed to help members deal with the after-effects of their disease and the possible onset of post-polio syndrome. One in six includes “survivor” in the name with one organization using “heroes” to refer to the members’ valiant struggles (see Table 2—left columns). This is consistent with Borkman’s (1999) observations that self-help/mutual aid groups want to disown the “victim” role and engage in activities that destigmatize their condition.

Organizations frequently use their names to indicate the type of organization. Jerry Lewis’s telethon, which is primarily a fund-raising organization, is very different from a self-help organization even though both kinds of organizations might be organized around muscular dystrophy. Over half (56.6%) of the polio

Table 2. Type of Names

Polio reference	Percent	N	Type of organization	Percent	N	Named after	Percent	N
Post-polio	66.3	55	Support group	56.6	47	Geographic	80.7	67
Survivor	18.1	15	Network	8.4	7	Person	2.4	2
Heroes	1.2	1	Other	14.5	12	Sponsor	4.8	4
Polio only	10.8	9	Association	8.4	7	Other	12.0	10
Other	3.6	3	Connection	2.4	2	Total	99.9	83
Total	100.0	83	None	9.6	8			
			Total	99.9	83			

organizations included “support group” in their official names (see Table 2—center columns). Nearly 20% used “network,” “association,” or “connection” in their name.

A third way we classified organization names was to indicate for whom or what they were named. Four of five organizations include a geographic designation (region, city, or state) in which they are located (see Table 2—right columns). Four included their sponsor (e.g., Easter Seals) in their name and one in Warm Springs, Georgia used FDR in its name.

ORGANIZATIONAL SIZE AND TYPE

Half the organizations have filed as non-profit organizations and half have an official mission statement. The organizations ranged in size from 7 to 9,000 members. The mean size was 367 with a much lower median of 110. When the organization with 9,000 was removed, the largest organization was 1,700 with a mean of 249 and median of 106. One-fourth of the organizations have 36 or fewer members.

Membership is not well defined. Since many of these organizations don’t charge dues (or are lax in collecting them), some define their membership by those on their mailing list.

The average meeting attendance falls far short of the organizations’ membership/ mailing lists. Meeting attendance ranges from 4 to 110. The mean is 25 with a median of 18.

The sample was divided into two types of organizations—support groups and networks. Organizations with “support” in their names were put in one group ($N = 47$) while those with network, association, or connection were another group ($N = 16$). Bivariate analysis revealed several differences between the two groups. On average, the networks were larger than the support groups with a mean size of 430 compared to 158 and with larger meeting attendances of 34 for networks compared to 19 for support groups. On average, networks charged more for dues (\$8 vs. \$4) and were more likely to report non-profit status (73% vs. 31%).

Networks were more likely than support groups to publish newsletters (94% vs. 66%) and have Web sites (56% vs. 19%). Of those that printed newsletters, it is not surprising that the networks, which had more members, printed on average more newsletters than support groups (587 vs. 268). The newsletters of networks also had, on average, more pages (9.2 vs. 7.0) but fewer issues per year (5.5 vs 7.4).

The two types of organizations did not differ in the demographic characteristics of their presidents/coordinators, sex or age of members, affiliations with hospitals, clinics, or other polio organizations, likelihood of having mission statements, or time of meetings. Even the meeting activities were very similar.

MEMBERSHIP CHARACTERISTICS

As we would expect, this is an older population. Only about a third of the organizations report any members below age 40 and only one organization had more than 10% of its membership in this age group. One in four organizations reports no members under 50 years of age. On the other hand, every organization reported having members in the 51 to 61 age group and all but one reported they had members in the 66 to 79 age group. Over half reported members in their 80s or older.

No organization has more males than females. Female percentages ranged from 50 to 100% with measures of centrality in the 60s—mean (67), median (65), mode (60). One in four organizations reported female percentages of 75% or greater. The female bias is, in part, reflective of the female bias found in older populations.

The organizations report their membership racial make-up ranges from 75 to 100% Caucasian. Over two-thirds of the organizations report white membership of 95% or above. Like the gender differences, this could be, in part, due to the longer life expectancies of whites compared to blacks, but there is also some evidence that whites are more susceptible to polio than are blacks (Bruno, 2002).

ORGANIZATIONAL SERVICES: MEETINGS AND NEWSLETTERS

People join organizations because they perceive the organization will provide them with some benefits. For members of polio self-help organizations, these benefits include information and socialization.

Over half of the organizations hold meetings on a monthly basis with another third having either quarterly or bimonthly schedules. Only two meet more frequently (twice monthly) with three meeting less than quarterly.

Over half the organizations hold their meetings on Saturday. Overall, Saturday morning is the most common time (29.6%) with Saturday afternoon (22.2%) a close second. The next most popular days are Sunday and Monday with only one organization having Friday meetings. Mornings and afternoons were the most popular times for the weekends with evenings being more popular on weekdays.

Weather considerations are used by some organizations to plan their meeting schedules. Litvak and Martin (1999/2000) noted that among disabled persons transportation is a major problem, especially in non-urban areas. This helps explain why some of the organizations reported they do not schedule meetings for months when inclement weather is expected. For example, one organization in a northern state suspends meetings in January and February. Additionally, several organizations explained that they suspended meetings in either the summer or winter because many of their members seasonally migrate.

Medical/health care speakers and sharing experiences are the most common meeting activities. Two-thirds of the organizations report that medical speakers increase attendance at meetings. This preference for meetings with medical speakers and sharing experiences is consistent with the self-help philosophy of education and support (Medvene et al., 1999/2000).

While sharing personal experiences is the second most preferred activity, one in five organizations report that meeting attendance is down when discussions are the primary or only activity. We are aware of a new post-polio organization (not in our sample) that formed explicitly to avoid meetings that focus on “sharing experiences.”

Speakers on technical aids, social services benefits, and working to change laws are uncommon meeting activities. We are somewhat surprised that there is such little interest in changing laws or learning about social service benefits.

Nearly a third of the organizations hold meetings at hospitals and clinics. Community buildings, social services facilities, and churches are used by a over half the organizations. Restaurants and members’ homes are also used as meeting sites.

The polio organizations use a variety of communication channels to announce their meetings. Three of four use newsletters. Other direct communication channels include post cards, phone calls, and e-mail. Newspapers are the most used media source with half the organizations using this method. Web pages, radio, and TV are used less frequently.

Seventy percent of the organizations publish newsletters. Publication frequencies range from two to twelve issues each year with the most common schedule being four issues per year. The organizations in our sample report printing from 20 to 1,850 copies of each newsletter with the size of newsletters ranging from one to twenty-four pages.

A number of organizations sent us copies of their newsletters when they returned their questionnaires. These newsletters included health tips for exercise, drugs, and therapy. There were personal stories about clinics, treatments, and travel. There were also reviews of books and Web sites. And there were announcements for meeting and activities of interest to members.

Like the rest of society, a number of the organizations are moving into Cyberspace. Nearly half the organizations have e-mail addresses and 30% have Web sites. As discussed earlier, Madara (1999/2000) found that self-help organizations are increasingly using Web pages to reduce barriers that previously kept persons desiring mutual aid apart.

CHARACTERISTICS OF LEADERS

On our questionnaire we asked for information on the “president” of the organization. While most completed this section without comment, several noted that they did not have a president. Four said they had no officers of any kind and

supplied no information for this portion of the questionnaire. Twelve crossed out "president" and wrote in coordinator, facilitator, or leader. One respondent referred us to the G.I.N.I. guidelines. Two identified themselves as founders and one as a chairman. Of those who reported no officers or wrote in coordinator, facilitator, or leader, all were support groups. These comments, which reflect anti-hierarchical philosophies and structures, are consistent with the self-help and support movements generally (Charleston, 1998; Gaston & Meissen, 1999/2000; Levin, 1999/2000; Wollert, 1999/2000).

All but one of the leaders were Caucasian, the other being Asian. Two of three were female with an average age of 61. Two-thirds of the leaders were married at some time. Most reported past or present employment in the paid labor market. Three of four worked as professionals, semi-professionals, managers, or executives. Two-thirds of those responding hold a college degree, over 85% have some college, and all have completed high school (see Table 3).

While the educational and occupational levels might appear high for a population of this age, the physical disabilities associated with polio likely ruled out employment in areas requiring sustained physical labor. Additionally, leaders frequently utilize communicative and management skills acquired in educational and white-collar environments.

Leaders of polio organizations are similar to those found in other self-help groups. Medvene et al. (1999/2000) studied characteristics of leaders of a range of

Table 3. Characteristics of President/Coordinator

Characteristic	<i>N</i>	Percent	Characteristic	<i>N</i>	Percent
Sex (<i>N</i> = 76)			Marital status (<i>N</i> = 77)		
Male	31.6	24	Married	64.9	50
Female	68.4	52	Widowed	6.5	5
			Divorced	11.7	9
Occupation (<i>N</i> = 75)			Never married	16.9	13
Professional	16.0	12	Education (<i>N</i> = 72)		
Semi-professional	42.7	32	High school	13.9	10
Manager/executive	18.7	14	Associate/Jr. college	23.6	17
Clerical/sales	12.0	9	Bachelors	31.9	23
Skilled crafts	2.7	2	Masters	22.2	16
Operative	1.3	1	Doctorate	8.3	6
Never employed	5.3	4	Age		
Retired	1.3	1	Mean	60.7	
Race (<i>N</i> = 77)			Range	39-88	
Asian	1.3	1			
Caucasian	98.7	76			

self-help groups. They reported the following demographic characteristics of the group leaders: 85% were female, 69% were married, 73% had some college education, and 70% worked full or part time. The average age was 54. The relatively high rates for marriage and educational attainment are consistent with previous research on polio survivors (Bruno & Frick, 1991; French & Sloss, 1996).

The gender of the president/coordinator had no impact on organizational characteristics. There were no statistical differences in the type of organization (e.g., support group, network), whether the organization had non-profit status or a mission statement, affiliations with hospitals, clinics, or other polio organizations, or whether the organization had an e-mail address or Web site. There were no differences in the size of membership, meeting attendance, time of day for meetings, persons planning the meetings, meeting activities (e.g., speakers, sharing experiences), amount of dues or size of budget, newsletter characteristics, average age of members, or even the sex of members.

With a few exceptions, a similar lack of pattern emerged for educational characteristics of the president/coordinator. Organizations headed by individuals with less education were more likely to have non-profit status and to be associated with polio clinics. However, those headed by individuals with associate/junior college or Ph.D. degrees were more likely to have mission statements. Organizations headed by individuals with high school diplomas were most likely to have e-mail addresses (80%) but least likely to have Web sites (20%). Organizations with Web sites were headed most often by individuals with associate/junior college degrees (53%) or Ph.D.s (83%).

One task of leadership is planning meetings (Medvene et al., 1999/2000). In nearly half (46%) the organizations, the president/coordinator is solely responsible for planning the meetings. Fifteen percent of the organizations have a formal planning committee. In the remaining 40% a combination of people, often including the president, plan meetings.

ALLIANCES AND FINANCES

The organizations raised money in a variety of ways. Half the organizations had dues but they tended to be minimal. Of the half that had dues, none charged more than \$20 per year with most charging \$10 or less.

Over half the organizations report receiving donations, some solicited directly from members and businesses. Nearly one in five (18.5%) report receiving grants, 11% engage in fund-raising, and 7% charged for their newsletters.

Half of the organizations have budgets of \$500 or less. Several wrote that they had no expenses. Of those organizations with expenses, newsletters and informational literature are their largest expense. Some organizations incur expenses for members attending conferences. A few reported paying for meeting room rental and refreshments, renting or buying videos, speaker expenses, and awards

(plaques or gifts) to recognize the support of individuals or other organizations. Few organizations were financially sound enough to maintain offices or have paid staff.

These organizations appear to be surviving with little financial support through their alliances with other organizations. Numerous organizations reported meeting rooms and often meeting refreshments were provided for them by other organizations. Some even had the printing and/or mailing of their newsletters provided by another organization.

Inter-organizational relationships abound within the polio community. Seven in ten are affiliated with another polio organization (69.9%), one in four (25.3%) are affiliated with a hospital, and one in six (15.7%) with a polio clinic.

The hospital and clinic associations are to be expected. Polio left many of its survivors with various disabilities and health problems. In recent years, many of the survivors have started experiencing additional health problems, referred to by such terms as "post polio syndrome" and "post polio sequelae" (Bruno, 2002, 1991; Bruno & Frick, 1991; Halstead, 1998; Jubelt & Cashman, 1987).

SUMMARY AND CONCLUSIONS

We report on a sample of 83 polio organizations from English-speaking nations, the majority (74) from the United States. The organizations were founded between the years of 1939 and 2001 with most founded in the mid-1980s. The size of the organizations range from 7 to 9,000 with a median size of about 110. Support groups were smaller than networks but other differences were minimal.

On most characteristics, the organizations and activities of these self-help organizations were similar to what others have found to be characteristic of self-help volunteer organizations in general. Most members were white, female, and between the ages of 51 and 79. Meeting attendance, on average, ranged from 4 to 110 with a mean of 25 and median of 18.

The most popular meeting activity was medical speakers who addressed the medical problems members were facing. Sharing common experiences by members was the second most common meeting activity. Learning about their health risks and possible therapies and socializing with people in similar situations seem to be the motivating factors for most members.

Most organizations operated on minimal budgets and charged no or minimal dues. Many were associated with other health care organizations (e.g., hospitals, clinics) and with other polio organizations. These affiliates often provided meeting space, speakers, and financial support either directly or indirectly (e.g., print and mail newsletters).

Because post polio syndrome has only recently been recognized and continues to be questioned by some practitioners, few physicians have adequate knowledge to diagnose and treat it (Fish, 1993). Indeed, some survivors have become more knowledgeable about post polio syndrome than their physicians and

find themselves in a position of paying office fees to educate their health care providers (Foster et al., 1993). Obviously these organizations play a role in generating experiential expertise among their members.

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