SELF-HELP GROUP STRUCTURES AND ACTIVITIES:
IMPLICATIONS FOR PROFESSIONAL ROLES

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Introduction

The self-help group is a growing phenomenon on the American scene, and is becoming a new focus for inquiry in the social sciences and social services. In this report we describe and analyze organizational and leadership dynamics in a sample of self-help groups of parents of children with cancer. Groups with this particular focus are exemplars of the larger variety of self-help groups in the health field, and perhaps of such groups more widely. In turn, self-help groups of various sorts are examples of the more general phenomena of voluntary organization and social support. In this report we are particularly interested in what self-help groups can teach us generally about voluntary social support and change organizations, as well as how they function in the case of parents of children with cancer.

Self-help groups are generally defined as "voluntary, small group structures for mutual aid and the accomplishment of a special purpose" (Katz & Bender, 1977: 9). In a broader perspective, self-help groups may be viewed as a "special form of voluntary association formed by particular populations to accomplish specific common purposes" (Katz, 1981: 151). As such, these groups share many characteristics of the general class of small voluntary associations; they are often locally based, somewhat formalized in nature, and have an identifiable membership and purpose. They must confront issues of leadership, internal regulation and policy, and articulation with other organizations and institutions in their locale. Thus, self-help groups provide a natural laboratory in which to examine dynamics of the broader class of local voluntary organizations.

1

Some researchers have gone so far as to see self-help groups as part of a social movement, or an organized expression of changing values and orientations in Western society, and as part of a challenge to technological and bureaucratic control over human services (Smith and Pillemer, 1983; Katz, 1981; Back and Taylor, 1976; Steinman and Traunstein, 1976). Others see them as a way to make resources go farther in a time of scarce resources and high demand. Thus from various perspectives, interest in self-help groups is on the rise.

Self-help groups, organized around individuals' common experience with life problems, exist on the margins of organized service-provision. They fill gaps, counteract effects perceived as negative, and sometimes support existing professional services. Professional service-providers often become involved with self-help groups in a variety of ways. They may actually play the role of initiator, bringing potential members together to create a group. Ongoing roles include collaborating with members, acting as organizational consultants, presenting programs, facilitating group discussions, and referring new members to the group. Professionals may be very closely or only distantly involved in the day-to-day activities of the group. Their relations with these groups may be collaborative (Borman, 1979) or confrontational (Kleiman, Mantell, and Alexander, 1976), or may resemble an uneasy truce. In spite of the close relationship between professionals and self-help groups, the role of the professional in this situation often is ill-defined and unclear. One approach to clarifying professional options and their ramifications for self-help groups is through an improved understanding of how these groups work and what they do, and their different forms of leadership and articulation with professions and with institutional systems.

Unfortunately, research on self-help groups is fairly new, and the knowledge base, relying primarily on individual case-studies and anecdotal

evidence (Katz, 1981), is scant and idiosyncratic. Much of the research seems to result in typologies, most of which display an "ad hoc and unsystematic quality" (Smith and Pillemer, 1983: 207). Older studies focused on gaining a greater understanding of what self-help groups were, and so descriptive typologies were developed around the groups' goals and activities (Katz and Bender, 1976; Levy, 1976, Killilea, 1976). More recent efforts have included a focus on such organizational aspects as leadership, membership, formal structure, and institutional affiliation (Smith and Pillemer, 1983; Pillisuk and Parks, 1980). Beyond description, there has been little systematic analysis to guide us toward a more generalizable understanding of self-help groups and their distinctive dynamics. This paper will take a step in the direction of such analysis, examining the range and variation of group structures and operations, and relating them to leadership patterns and professional involvement in a sample of self-help groups. A comparative case-study analysis of these groups' organizational commonalities and divergences should begin to provide tentative generalizations regarding the way self-help groups work.

The study: a brief description of methods

A primary aim of this research is the creation of a systematic and in-depth study of self-help groups sharing some basic characteristics, and the analysis of the variations within that sample. The groups in this sample share a common problem orientation: the family effects of childhood cancer. This particular type of group is experiencing substantial growth in the last decade, especially as the improved treatment of childhood cancer increases both treatment duration and survival rates, with attendant long-term uncertainties. A sample of over 30 groups was identified from a national pool of over 200 such groups made available by the Candlelighters Foundation (a national network of self-help groups of parents of children with cancer), childrens' medical centers, and other state and national

3

organizations and programs.[1] Groups were selected for the study based on our goals of achieving some variation with regard to geography, characteristics of independent or professional leadership, and characteristics of the treatment center or community base with which groups are associated (insofar as these could be determined from available records). Although there is no way to verify whether this sample is representative of the numerical distribution of such groups across a variety of dimensions, our experience has convinced us that this sample does represent the range and variety of parent groups organized around the issues of childhood cancer.

The research team was composed of a social psychologist from the University of Michigan who is also a parent of an adolescent with cancer and founder of a self-help group, and a sociologist at that university who has previous experience in community development and health service organization. As interviewers, we made prior arrangements with local contact people (parents and/or professionals) by mail and phone, and then entered the site for a series of intensive individual and group interviews (tape-recorded) with group members and the professionals working with them. Group interviews were considered appropriate in this instance, since we were looking for group-level rather than individual-level data. Each interview lasted an average of 1-1/2 hours, and overall contact time for each group was one to two days. To date, 218 persons have been interviewed: 155 parent/members; 18 social workers, 20 nurses, 10 doctors, and 15 "others," usually people in related helping professions who have worked with the group. Additional information was collected through several written instruments: an individual checklist administered on-site regarding group activities and medical-system relations; and a mailed follow-up package gathering both additional group-level information and a series of individual responses regarding group participation and benefits.

4

The researchers and trained student coders reviewed all tapes of group interviews and reconstructed these interviews in written form. The informants' responses to individual questions were combined with group documents and materials and reorganized into a group composite. Then the general data were coded to highlight key themes, such as group structure, activities, relations to community and medical systems, professional roles and role dilemmas, and other aspects of group operations. Individual variables were created out of these general themes, and coded in such a fashion as to provide categorical measures appropriate for quantitative manipulation.

The remainder of this paper is divided into three sections: (1) a summary of some of our findings regarding the range and diversity in groups' formal structure, age, size, operating procedures, activity focus and professional/member leadership pattern; (2) an analysis of the relationships between professional/member leadership patterns and aspects of group structures and operations; and (3) implications of these findings for understanding and approaching the dilemmas professionals face in working with self-help groups.

Diversity in group structures, operations, and activities

Descriptions of group structures and operations are based primarily on information from the on-site interviews with group members and associated professionals, as well as on analysis of printed materials such as brochures, newsletters and by-laws. The information presented below is summarized in Table 1.

Formalized structure. These groups run the gamut in terms of structural configurations. Twenty-nine percent (9 groups) are informal gatherings, with no formal structural features at all (no by-laws, officers, etc). Another 29% have "intermediate" levels of formalization, with such features as informal steering committees, officers or boards of directors (without committees) or perhaps adjunct advisory boards. Another 42% of the groups are quite highly formalized, having elected officers, boards of directors, functioning internal committees (internal division of labor). In fact, four of these highly formalized groups have delegated organizational tasks to the point of running support activities separate from the business activities of the group.

Size. These groups are predominantly small. Forty-eight percent (15 groups) have under 20 people attending meetings and a mailing list (our measure of "total defined membership") under 100. Another 16% of the groups are quite large, with over 30 people attending regular meetings, and over 200 people on the mailing list. Thirty-six percent (11 groups) have a small "active core" of members (under 20 people attending meetings), and a relatively large mailing list (over 100). This "active-core" pattern, with a large nominal membership and a relatively small number of active members, is similar to a participation pattern that often develops in voluntary associations over time (Tsouderos, 1955: 209).

Age. The groups tend to be relatively young; 55% (17 groups) are in what we have labelled as "Stage 1," from 6 months to 4 years old. 39% are at "Stage 2," 4-1/2 to 8 years old; while only 2 groups (6%) are "Stage 3," over 8 years old. The stages were defined by the natural clustering observed in the sample.

Membership definition. Thirty-two percent (10 groups) define their membership on an experiential basis: parents, children, or extended-family who are directly affected by the experience of childhood cancer (6 as parents-only, 2 as nuclear family, 2 as extended family). The other 68% (21 groups) define their membership based on peoples' interest in being helpful or in combatting childhood cancer (8 as family-and-professionals, 13 as "anyone interested"). Our assignment of groups to these categories is based on verbal statements in the interviews regarding group membership and on formal definitions of membership in group by-laws and written materials. These statements may or may not accurately reflect the group's actual operation in defining membership; however, they are the most standard available representation of a group's definition of its membership boundaries.

Member retention. One unique issue encountered in these self-help groups is whether the parents of children who have died will become or remain active. Sixty-five percent of the groups retain the parents of deceased children as group members, while in 35% of the groups parents drop out immediately upon or soon after their child's death. This situation is virtually never subject to an explicit rule, but is rather a matter of group norms or "culture."

Referral source. Access or recruitment patterns are an interesting aspect of self-help group operations; Borman (1979) reported that most self-help groups recruit primarily through media or word-of-mouth, seldom relying on professional referrals. In this sample of groups, however, the

7

opposite is true: only one group out of 31 reported not using medical-system referrals as a principal access mechanism. In response to the question, "How do people learn about the group?", 48% (15 groups) report utilizing principally or solely referrals from the medical system, while another 48% combine referrals with direct contact or outreach by parents or group volunteers. The remaining group uses direct contact only, and is included for our analysis in the latter category (personal contact).

Activities. Information regarding the activities or programs of this sample of self-help groups comes from on-site interviews and written materials provided by groups. Based on our previous experience and understanding of these groups, we initially defined activities within six major categories: (1) information-education, (2) sharing-emotional support, (3) social-friendship, (4) business/group maintenance, (5) fundraising, and (6) attempting to make changes in the system of medical or social-service care. We also inquired about any other activities, including those occurring outside of meetings, such as parents' visiting newly diagnosed families in the hospital or contacting each other to provide support outside the formal context of meetings.

In groups' written materials a clear dominant theme emerged. Statements of purpose indicated a universally high concern with emotional and social support for families of children with cancer. This was true even among groups where the primary activity focus was actually a task such as raising funds for medical research. Other activity categories that emerged were: providing direct aid to families (money or goods); general public education/awareness; educating medical trainees; and funding research or medical care programs in the fight against childhood cancer.

Responses in on-site interviews regarding activities provided the following breakdown about what these groups actually do:

Information and education at meetings - 74%. This activity usually consists of an outside speaker/expert addressing the group regarding some specialized aspect of diagnosis, treatment, or effects of cancer on the child; local or visiting physicians, researchers or psychologists are among the most popular speakers for such programs. Occasionally, this task is performed by parents who share experiences and educate each other.

Formal emotional support activities - 68%. The objective here is to provide an arena within which parents can share their joys and pains, their hopes and despairs, and discuss the problems they experience in dealing with childhood cancer. In some cases parents work with each other directly; in other cases a social worker, nurse or psychologist facilitates the discussion and promotes openness and sharing among group members.

Business - 65%. Groups may conduct a variety of activities related to projects or tasks, or to general group maintenance, either during regular meetings or at special board or business meetings; they discuss committee activities, social or recruiting efforts, relations with the medical system, fundraising projects, etc.

Social events - 81%. Groups often provide a setting within which people can gather informally and talk to one another, enjoy a sheltered relaxed time for both children and parents where cancer is not perceived as a stigma, and receive informal support from friends in a similar situation. Such events usually draw a wider participation than do regular meetings, and are often for the entire family — picnics, holiday parties, zoo trips, and pot-lucks are common examples.

Fundraising - 77%. Three-quarters of the groups that do raise funds do so on a relatively small scale, with budgets of $200-$1500; they may seek internal donations, establish memorial funds, hold a bake sale or perhaps do

door-to-door sales. Other groups engage in major fundraising, organizing community-wide events and getting corporate donations or sponsorship; group budgets run as high as $60,000 annually.

Working to effect changes in the medical system - 36%. Some groups work in collaboration with health care professionals in efforts to make the system more responsive to family needs, while other groups advocate changes despite professional reluctance or resistance. The scope of such changes ranges from getting better facilities for parents staying overnight with ill children, to changing hospital policies regarding visitation and family participation in care.

Visiting newly diagnosed patients and families in the hospital - 36%. Some groups take on the role of reaching out to offer support to families in the first crucial days after the child's diagnosis, feeling that other parents can do the best job of providing understanding and support at that sensitive time. In other groups, these initial contacts are left up to medical and social-service professionals, and parents visit when asked to or referred.

One-to-one networking outside meetings - 87%. Parents often establish a practice of calling each other between meetings, or getting together for coffee, in order to provide day-to-day support or to be available in time of crisis. Some parents become closely bonded through their common experience and almost part of the family, even sitting with a hospitalized or dying child to relieve the parents for a few hours.

Table 1
Range and Diversity in Self-Help Group
Structure, Operations, and Activities

		(N=31)
STRUCTURE		
Formalized	High (incorporated, differentiated)	42%
Structure	Intermed (semi-formal)	29%
	Low (informal gatherings)	29%
Size	Large (large attendance and mailing list)	16%
	Active Core (small attendance, large mailing)	36%
	Small (small attendance and mailing list)	48%
Age	Stage 1 (4.5 years or less)	55%
	Stage 2 (4.5 - 8 years)	39%
	Stage 3 (over 8 years)	6%
OPERATIONS		
Member	Direct experience with childhood cancer	32%
Def.	Interest in helping	68%
Retaining parents as members	Yes	65%
after child dies	No	35%
Referral	Med System referrals only	48%
Source	Personal contact/outreach by parents	48%
ACTIVITIES		
Formalized emotional suppport at	Yes	68%
meetings	No	32%
Information and Education:	Yes	74%
speakers, movies, etc	No	26%
Business: organizational maintenance,	Yes	65%
committee reports, etc.	No	35%
Fundraising for org. maintenance,	Yes	77%
services, or large projects	No	23%
Socializing: parties, picnics,	Yes	81%
holiday events, for kids or parents	No	19%
Efforts to make changes in medical	Yes	36%
system to meet needs of families	No	64%
Parent visiting newly diagnosed	Yes	36%
families in the hospital	No	64%
1-to-1 Network: contact among parents	Yes	87%
outside meetings (telephone, personal)	No	13%

Leadership patterns: parent, professional, shared

The following descriptions will focus on leadership patterns and the role of professionals in this sample of self-help groups. Specifically, we have divided the groups into 3 categories; those in which parent/members are the leaders, those in which professionals provide key leadership, and those in which members and professionals work closely together and share leadershp functions. Information for assigning groups to these categories came from responses in the on-site interviews to several questions regarding group participation and leadership: "Who attends meetings? Who runs meetings? Who sets the agenda and plans meetings? What roles do professionals play? Do professionals set agendas and plan meetings? Do they attend meetings?" The duplication of information provided by these closely related questions in different sections of the interview enabled us to verify individual responses and to fill in gaps where responses were incomplete. During the process of sifting through and coding this information, the three basic ways in which group functions are performed became apparent.

Independent or parent-led groups are those in which the members themselves (parents of children with cancer) organize, set agendas, and preside over group meetings. Forty-nine percent (15 of the groups in our sample) are "independent" groups, in which parent/members constitute the leadership and the most active membership. In 6 of these groups professionals take virtually no consistent role in group operations and activities; in the other 7 professionals attend but do not plan or run meetings. Professionals may offer support to these groups in a variety of ways: referring parents to the group, providing liaison to the medical system, working with individual families to help meet their material or emotional needs, or helping secure resources for the group. However, they are not part of the central leadership and decision-making structure of the group. In some cases, groups are independent because professionals are

resistant to or simply not interested in parent groups; however, those cases are a small minority in the groups we have observed. In most cases in this category professionals are supportive but not very involved.

Shared-leadership groups are those in which parents are most central as leaders, but professionals also are actively involved and central to the group's leadership. These professionals perceive themselves and are perceived as a support system to the parent leadership. Thirty-two percent (10 groups) evidence this shared or cooperative parent/professional leadership. In these groups, parents and professionals may collaborate in planning for and setting up meetings, keeping track of organizational business, and sharing in key decisions. In some groups a new type of leadership has emerged in which parents of children with cancer assume professional roles in relating to and participating in the group, either by having been inoprofessional positions before their child's illness or by entering into or being accorded the professional role subsequent to their child's having cancer (eg., as formal group advocates, nurses, social workers, child life workers, etc.). These groups also are categorized as having shared parent-professional leadership, since the effects of close parent-professional collaboration accrue whether or not the professional is also a parent or the parent a professional.

Professionally-led groups are those in which the primary leadership functions of organizing, planning, and running or facilitating the group are performed by a professional, usually a member of the health-care system (social worker, nurse or psychologist). Nineteen percent of the groups in our sample (6 groups) are led or run by professionals who exercise the most active leadership, organize the group, and run or facilitate the meetings. In some cases, the professional evidences a desire to see parents take over more of the active group leadership; however, in most instances, professionals feel that their control is beneficial to parents, providing

13

them with advantages of group participation while relieving them of the responsibility for group maintenance or facilitation. Occasionally, parents in these groups voice a concern over their lack of control, but in most cases they likewise seem satisfied with the status quo.

Relationship between parent/professional leadership pattern and self-help group structure and activities

After documenting the diversity of ways in which these parent groups are structured, operate and carry out activities, we analyzed group characteristics according to the leadership categories described above. Results of this analysis are presented in Table 2 and briefly described below.

Structure. Professionally-led groups are uniformly low in formalized structure, small in size, and predominantly young. About 47% of the independent parent-led groups are high and 47% intermediate on formalized structure, and only one has low structural formalization. About 87% of the independent groups have a small or active-core size, and they also are predominantly young. The shared-leadership groups are about 60% highly formalized, 20% intermediate, 20% low; similarly to the independent groups, their size is 70% small or active-core. They are generally somewhat older than groups in the other two categories.

Operations. There is no relationship between leadership pattern and the way membership is defined at a formal level; about 1/3 of all groups across categories define members based on direct experience with childhood cancer, and 2/3 define members based on the broader category of either interest or experience.

However, professionally-led groups tend not to involve parents of children who have died (83%), while only about half (47%) of the independent groups and none of the shared-leadership groups fail to include parents whose children have died as members.

In terms of recruitment patterns (responding to "How do people learn about this group?"), all the professionally-led groups use medical-system referrals only, while 60% of the independent and 70% of the shared-leadership groups combine medical-system contacts with personal and word-of-mouth outreach to recruit members.

Activities: Professionally-led groups, in comparison with independent and shared-leadership groups, do more formalized emotional support activities in meetings, and less of all other activities: information and education, business, fundraising, socializing, advocating medical-system changes, hospital visiting of newly diagnosed families — and even less one-to-one networking among group members than the independent or shared-leadership groups.

Table 2
Self-Help Group Characteristics in Relation to Professional, Independent, and Shared Leadership

		PROF (N=6)	INDEP (N=15)	SHAR (N=10)
STRUCTURE				
Formalized Structure*	High	Ø	46.7%	60.0%
	Intermed	Ø	46.7%	20.0%
	Low	100%	6.7%	20.0%
Size*	Large	Ø	13.3%	30.0%
	Active Core	Ø	40.0%	50.0%
	Small	100%	46.7%	20.0%
Age	Stage 1	83.3%	60.0%	30.0%
	Stage 2	16.7%	33.3%	60.0%
	Stage 3	Ø	6.7%	10.0%
OPERATIONS				
Member Definition	Experience	33.3%	33.3%	30.0%
	Interest	66.7%	66.7%	70.0%
Retaining PDC*	Yes	16.7%	53.3%	100%
	No	83.3%	46.7%	Ø
Referral Source*	Med System	100%	40.0%	30.0%
	Pers Contact	Ø	60.0%	70.0%
ACTIVITIES				
Support	Yes	100%	60.0%	60.0%
	No	Ø	40.0%	40.0%
Info & Educ	Yes	50.0%	86.7%	70.0%
	No	50.0%	13.3%	30.0%
Business*	Yes	Ø	86.7%	80.0%
	No	100%	13.3%	20.0%
Fundraising*	Yes	16.7%	93.3%	90.0%
	No	83.3%	6.7%	10.0%
Socializing	Yes	50.0%	86.7%	90.0%
	No	50.0%	13.3%	10.0%
Making Changes	Yes	16.7%	33.3%	50.0%
	No	83.3%	66.7%	50.0%
Hosp Visiting	Yes	16.7%	33.3%	50.0%
	No	83.3%	66.7%	50.0%
1-to-1 Network	Yes	66.7%	100%	80.0%
	No	33.3%	Ø	20.0%

*Statistically significant at P<.Ø5. (The small sample in this study, resulting in some cells having very few cases, calls for caution in imputing significance and in generalizing from these results.)

Discussion: A comparison of professional and parent leadership in self-help groups

Some noteworthy patterns emerge from our analysis of the relationship between leadership patterns and the structure, operations, and activity choices of these groups of parents of children with cancer. The most striking differences are those between the professionally-led groups and the general category of parent-led groups (both independent and shared-leadership forms, which are very similar to each other). Professionally-led groups are less formal, smaller, younger, do not as often involve parents of deceased children, and stress emotional support activities, even to the exclusion of other activities engaged in by the member-led groups. Moreover, the professionally-led groups are not as often engaged in pro-active activities such as promoting changes in the system of medical care or doing direct parent outreach to newly diagnosed families. We will pose two approaches to explain the differences in the characteristics of groups which have different leadership patterns, and some of the implications of each. These two explanatory schemes are, respectively, an individual-level explanation and a structural or institutional-level explanation for the origins of organizational characteristics.

At the individual level, we approach organizational issues by looking at personal characteristics, beliefs, values, and backgrounds of those in influential positions. These personal attributes, whether the result of individual psychological needs or of professional norms and training, then can be used to explain the characteristics of the organizations those individuals lead. At an institutional or structural level, we focus more on institutional resources and constraints in shaping behaviors, and see these structural factors as the forces that establish the basis and limits for organizational structure and activities.

17

In the case of self-help groups an individual-level explanation suggests that their structures and activities reflect the definitions, priorities, and values of those in leadership positions. Professionally-led groups thus may reflect the way professionals define the needs of families whose children have cancer; a focus on emotional support, sharing and ventilating feelings to aid in coping with the stresses of their child's cancer. The more diverse, and often more task-oriented, activities of the parent-led groups may reflect the wider range of needs and priorities parents themselves see — perhaps a need to have an impact on the fight against childhood cancer, or to make the medical system more humane, or to reach out to other parents and families in their own times of crisis.[3] Some professionals may claim that these parents' emphasis on external activities reflects their denial of emotional stress, and an unwillingness to deal with the deeper psychological issues in their lives. These real differences in perspective between professionals and patients or clients may lead to different priorities and decisions in these different types of groups.

An alternate explanation for the differences between professionally-led and parent-led groups might emphasize the institutional constraints faced by professionals working in the medical system. The institutional definition of the professional's role may be limited to the provision of support to patients and patient families during the period of their active treatment. If that is the case, assistance with task activities such as fundraising may be beyond the institutional definition of the professional role. This explanation has to do not so much with the values of individual doctors, social workers or nurses, but with the bounds set by the institutions within which all must survive and work. Such a situation may lead to some hard choices for the professional who wishes to respond to a broader range of patient and family needs.

The younger age of the professionally-led groups (all 5 years or less) also is open to various interpretations. An individual-level explanation would argue that professionals who are sustaining the support group may simply run out of energy to keep such a group going single-handed. When there is parent leadership to complement professionals' efforts, the required energy level may be easier to sustain. An explanation stressing the institutional aspect of professionals' responsibility would suggest that if services extend only to families in active treatment, and if new families are not constantly recruited and integrated into the group, a support group may dissolve when the cohort of families who went through diagnosis and treatment about the same time is no longer in need of intensive emotional support. We have seen several instances of groups in which parents of children who have died, or who have achieved a long-term recovery, move from support-oriented groups to more task-oriented organizations; for instance, many become involved in fundraising for Ronald McDonald Houses. The phenomenon of parents' feeling a need to move on to other activities, but having nothing within the group to which they can move, may contribute to the tendency for professionally-led groups not to survive that 4-5 year period.

One approach to understanding the lower retention rate for parents of deceased children in professionally-led groups again stresses the dominant value orientation of leadership. Several professionals who were facilitating support groups noted that they felt it was "too sad" or "too threatening to parents of newly diagnosed children" when they were asked whether the group involved parents whose children had died. Some also registered their feeling that it might be inappropriate for parents to go on focusing on childhood cancer for very long after the death of their child. However, members of parent-led groups often responded that involving parents of deceased children served for other parents as assurance that

"life can go on after the death of a child;" "that you <u>can</u> survive the worst that could happen;" and that "these parents are part of our group, and we can't abandon them when they need support most!" Alternately, from an institutional perspective, the health care system may classify the parents of deceased children outside the professional's case-load or sphere of duty, or may limit that responsibility to one consultation following the death of the child. Such restrictions would naturally influence the composition of the support group offered as a professional service by the hospital.

Professional leadership may also be related to parent/member feelings of investment in the group, and their motivation to take an active role: there is less personal outreach for recruitment into professionally-led groups, and less one-to-one networking. If parents do not take responsibility for organizing and maintaining the group, and see themselves as recipients of services in a group context, it stands to reason that they will also be more likely to define recruitment and the provision of person-to-person support as part of the professional's job. This concept could also help explain the lower age of these groups, as less "invested" parents would be less likely to remain active in a group beyond the 4-5 year period of intense involvement in their child's illness and treatment. The professionally-led group, and other forms of professional support, are being provided <u>to</u> and <u>for</u> parents, and only incidentally <u>by</u> them. This approach to giving and receiving support may be most appropriate for meeting the needs of some parents, while more active group involvement may respond to other parents' coping and support needs.

Shared leadership: the parent-professional coalition

Another approach to interpreting leadership functions in these groups involves highlighting the patterns in the shared-leadership groups — those groups in which parents are the effective leaders, but in which professionals are also very active and supportive. Such a leadership pattern indicates a very close articulation between the medical/social service system and the parent group, yet the maintenance of autonomy and parent direction. Because this represents an alternative to the polar formulations of professional vs. member leadership that have dominated the literature, this integrated and collaborative form may highlight elements of either or both traditional forms.

In comparison to the independent groups, the shared-leadership groups are more varied in structure, show about the same distribution in size, and have a slight tendency to be older. While 60% of the shared-leadership groups are highly formalized (much like the independent groups in that regard), another 20% are in the "low" or unstructured category. They are even more likely than independent groups to include parents of deceased children, and slightly more likely to use personal contact in recruiting members. The shared-leadership groups are not very different from independent groups in most activities; they engage in system-change activities and hospital visiting more than independent groups, and do only slightly less one-to-one networking outside meetings.

In our sample of groups, the varied approaches to organizational structure and activities represented in the shared-leadership groups may reflect the most creative efforts of innovative parent-professional teams. The greater tendency to include parents of deceased children as members may speak to a greater stability of membership, and a more open approach to reaching out to parents with a variety of needs, at different stages of the process of coping with childhood cancer. And the surprising fact that the

21

proportion of shared-leadership groups involved in working for changes in the system of medical and social-service care is equal to that in independent groups may open a new perspective on the potentials for a fruitful articulation between self-help groups and institutional systems. Though Smith and Pillemer (1983) cite the literature as providing evidence that ". . .groups that exhibit strong ties to professionals are more likely to focus on individual change, and less on institutional or societal change (p. 225)," the data from this study may provide a basis for challenging that assumption. The context within which those professional-member ties are forged may have a significant impact on the nature of the self-help group.

Our findings speak to a theme that is often a focus of academic argument regarding self-help groups: that of new roles for professionals. Borman (1979) makes the point that work with self-help groups calls for a new conceptualization of the professional role, one that is less controlling, moving "from a principal and solo role to a collaborative one " (29):

> . . . professionals . . .[supporting self-help groups] .
> . . were apparently a new breed, not succumbing to traditional professional models. They may be representing a "paradigm shift" for many human service professionals (41).

An influence of the growth of self-help groups on professional systems can be a re-definition of the professional-client relationship:

> Both parties . . . must search for a new balance. Clients have expertise in their own experience of the problem; professionals have special supporting knowledge in the medical or welfare sphere. Relations between clients and social workers are redefined in the direction of equality in rights and status, more input by the client, and a restriction of "expert" domination (Bakker and Karel, 1983: 176, 179-80).

Though the extent to which we can generalize from this data set is limited, the results are certainly suggestive of the options for new professional approaches to self-help and support groups, and of the opportunities for exciting and creative professional-member partnerships. The most constructive partnerships between professionals and self-help group members seem to be those in which professionals reconceptualize their helping role into that of "resource" to the indigenous member leadership of the group; where they foster independence rather than dependence, and where they are willing to "let go" when members are ready to take over. New professional role opportunities include involvement or leadership in helping self-help groups get established, providing support and consultation on organizational matters, and performing ongoing service roles such as sponsor, referral source, and advocate-mediator with institutional systems (Wollert and Barron, 1983). The professional who supports member leadership will also need to be open to a potentially heterogeneous membership, and to the variety of activity foci that may be generated by such an organization.

Self-help group members and leaders, in turn, have a part to play in supporting the new professional role. Group leaders must sometimes take the initiative in reaching out to professionals in the social-service and medical institutions, and in helping them learn to be a valuable resource-person for that group. New channels of communication will need to be established across the different experiences and perspectives of group members and professionals, and effort and flexibility on both sides may be necessary to keep those lines open over time.

Together, professionals may learn new ways of interpreting their role in working with self-help and support groups while group members may learn to exercise constructive leadership and to cultivate positive relationships with supportive professionals. Both parties can move in these directions only if the health care systems that integrate them also become more

flexible in defining the roles of professionals and of parents, and professionals' relationships with member-led groups. Then we may experience the benefits of more innovative and adaptive organizations meeting the needs of people in a time of personal and family crisis.

FOOTNOTES

1. At the time of this writing, the study is in progress and new groups are still being added to the sample. Sample size in this study was constrained by the limited funding under which the research was carried out, and by the intensive nature of the data-collection process.

2. For a more detailed discussion of stress, social support and parental coping with childhood cancer, see: Chesler and Yoak, 1983b; Coping with Cancer, 1980; Futterman and Hoffman, 1971; Kellerman, 1980; Ross, 1978; Ross, 1980; Schulman and Kupst, 1980; Spinetta and Spinetta, 1981.

BIBLIOGRAPHY

Back, K. and R. Taylor
1976. "Self-Help Groups: Tool or Symbol?" Journal of Applied
Behavioral Science. V. 12 No. 3 295-309.

Bakker, B. and M. Karel
1983. "Self-Help: Wolf or Lamb?" Rediscovering Self-Help: Its Role
in Social Care Vol. 6 of Social Service Delivery Systems: An
International Annual. Ed. by D. Pancoast, P. Parker and C.
Froland. Sage Publications, Beverly Hills

Borman, L.
1979. "Characteristics of Development and Growth." Self-Help Groups
for Coping with Crisis: Origins, Members, Processes and Impact.
Ed. by M. Lieberman and L. Borman. Jossey-Bass Publishers, San
Francisco.

Chesler, M., and M.Yoak
1983a. "The Organization of Self-help Groups for Families of
Children with Cancer," C.R.S.O. Working Paper 285. Center for
Research on Social Organization, The University of Michigan.

Chesler, M. and M. Yoak
1983b. "Self-Help Groups for Parents of Children with Cancer."
Group Intervention for Medical-Surgical Patients and Their
Families. Ed. by H. Roback. Jossey-Bass Publishers, San Francisco
(forthcoming). Also pre-printed in modified form as C.R.S.O.
Working Paper 290, Center for Research on Social Organization, The
University of Michigan.

Coping with Cancer
1980. U.S. Department of Health and Human Services (National Cancer
Institute). Bethesda, Md.

Futterman, E. and I. Hoffman
1973. "Crisis and Adaptation in the Families of Fatally Ill
Children." The Child in his Family: The Impact of Death and
Disease, Vol. 2. Ed. by J. Anthony and C. Koupernick. Wiley
Publishers, New York.

Katz, A.
1981. "Self-Help and Mutual Aid: An Emerging Social Movement?"
Annual Review of Sociology. V. 7, 129-155.

Katz, A., and E. Bender
1976. "Self-Help Groups in Western Society: History and Prospects."
Journal of Applied Behavioral Science. V. 12, 265-282.

Kellerman,J. (Ed.)
1980. Psychological Aspects of Childhood Cancer. C.C. Thomas,
Springfield.

Killilea, M.
   1976. "Mutual-Help Organizations: Interpretations in the
   Literature." Support Systems and Mutual Help: Multidisciplinary
   Explorations. Ed. by G. Caplan and M. Killilea. Grune and
   Stratton, New York.

Kleiman, M., J. Mantell and E. Alexander
   1976. "Collaboration and Its Discontents: The Perils of
   Partnership." Journal of Applied Behavioral Science. V. 12,
   403-410.

Levy, L.
   1976. "Self-Help Groups: Types and Psychological Processes."
   Journal of Applied Behavioral Science. V. 12, 310-322.

Pillisuk, M. and S. Parks
   1980. "Structural Dimensions of Social Support Groups." The Journal
   of Psychology. V. 106, 157-177.

 Ross, J.
   1978. "Social Work Intervention with Families of Children with
   Cancer: The Changing Critical Phases." Social Work in Health Care.
   V. 3, 257-272.

Ross, J.
   1980. "Childhood Cancer: The Parents, the Patients, the
   Professional." Issues in Comprehensive Pediatric Nursing. V. 4,
   7-16.

Schulman, J. and M. Kupst
   1980. The Child with Cancer. C.C. Thomas, Springfield.

Smith, D. and K. Pillemer
   1983. "Self-Help Groups as Social Movement Organizations: Social
   Structure and Social Change." Research in Social Movements,
   Conflicts and Change. V. 5. Ed. by L. Kriesberg. JAI Press, Inc.,
   Greenwich, Conn.

Spinetta, J. and P. Deasy-Spinetta
   1981. Living with Childhood Cancer. C. Mosely, St. Louis.

Steinman, R. and D. Traunstein
   1976. "Redefining Deviance: The Self-Help Challenge to the Human
   Services." Journal of Applied Behavioral Science. V. 12, 347-361.

Tsouderos, J.
   1955. "Organizational Change in Terms of A Series of Selected
   Variables." American Sociological Review. V. 20, 206-210.

Wollert, R. and N. Barron
   1983. "Avenues of Collaboration." Rediscovering Self-Help: Its
   Role in Social Care Vol. 6 of Social Service Delivery Systems: An
   International Annual Ed. by D. Pancoast, P. Parker and C. Froland.
   Sage Publications, Beverly Hills.