THE ORGANIZATION OF SELF-HELP GROUPS FOR FAMILIES

OF CHILDREN WITH CANCER

Mark A. Chesler

and

Meg Yoak

University of Michigan

April 1983

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Mark A. Chesler
&
Meg Yoak[1]

This paper is a brief progress report of our ongoing study of self-help groups organized for families of children with cancer. The study is not complete, and the findings and conclusions reported here are tentative. However, we now can provide some feedback to the many people who participated in the study, and who shared with us their views and reactions.[2]

The focus of this study is on the ways in which self-help groups for families of children with cancer are organized, and the ways in which they operate. Our basic purpose is to understand what such groups do, how they do these things, and what environmental or organizational factors help or hinder them. We have not tried to focus upon why individuals become members of such groups, or what benefits and satisfactions they derive from them; such inquiry, while important and interesting in itself, addresses a different set of problems and requires different methods.

There are a number of theoretical issues in the development and utilization of coping resources and social support networks that the study of these particular self-help groups should clarify. Moreover, as examples of consumer-oriented or consumer-developed programs, these groups appear to have much in common with social movement organizations and many other forms of grass-roots and voluntarist acitivity in the human services and public sector of our society. Thus, we expect the results to be useful to scholars, practitioners and health care consumers. Moreover, when we piece together the many conversations we have had with self-help group members, facilitators, supporters and leaders we also hope to provide specific suggestions family members and professionals can use as they help each other deal with the psychosocial

issues involved in childhood cancer.

People who wish to read further on these matters, or to tie our findings and ideas to related work, may consult the footnotes and references at the end of this report. We would appreciate receiving any comments or suggestions readers may have regarding these issues and our interpretations of local groups' experiences.

The Background of Stress and Social Support for Families of Children with Cancer

People always have helped one another in times of adversity or crisis, and in the search to create better times and situations. The ability of people to find support from others, and to use this support to stabilize or enrich their lives, is an essential ingredient in maintaining or improving their quality of life and the quality of life in their community or society. Although mutual support is a central feature in any social system, its more formal organization appears to be a growing phenomenon in contemporary American life. Some observers have attributed such growth to popular reaction to the bureaucratization and depersonalization of life in our major institutions and communities, while others see it as a response to increasing stresses and crises of various sorts.[3] Important to most of us, at any time, help from others is especially critical in a crisis or stressful situation.

One circumstance readily identifiable as a crisis is a threat to the health and life of a beloved family member, particularly a child. Recent research on childhood cancer has documented the multiple and potent ways in which such a crisis produces stressful experiences for patients, parents and other family members.[4] As more children with cancer live longer and are "cured" at an increasing rate, patients and their families must deal with the illness, and potential recovery or relapse, over a long period of time and must discover how to manage long-term stress. Moreover, childhood cancer not only threatens the life of the young patient: it also challenges

parents' traditional roles as protectors of their young; normal family patterns created over years; individual and family plans and hopes for the future; role divisions between mothers and fathers, parents and children; and accustomed relationships with family members, friends and neighbors.[5]

Parents and patients cope with the stresses of childhood cancer in a variety of ways. Some try to attain "intellectual mastery" of the disease and treatment, reading much technical material. Others test and often reinforce their religious beliefs, calling upon these resources to provide existential and spiritual meaning to their new roles and/or situations. Some respond by becoming assertive partners in the care of their children, even to the point of intervening in traditional patterns of medical care. Some deny the illness and its seriousness. And some distance emotionally from family members and friends.[6]

In these coping efforts, some parents may seek help primarily from professionals within the medical care organization, such as doctors, nurses and social workers. Others seek help primarily from their family and friends, from the "kith and kin" that surround their daily lives, and that help establish a meaningful and responsive social world. The research on social support systems in general, and our own data from studies of families with childhood cancer, indicate that this process of helping (both giving and receiving help) is quite complex.[7] Not all parents find the support they desire and need from other family members, nor from their close friends or from health care professionals. While many helpful acts occur, parents of ill children often report, sometimes quite poignantly, the failure of some family members', friends' and professionals' well-intentioned efforts to be helpful to them.

One distinctive source of help and support some parents report utilizing during the crisis of childhood cancer is other parents of ill children. Especially where other families of children with cancer have organized a self-help or mutual support group,

this may be a particularly important resource for parents struggling to cope with their child's disease and the problems it presents.

The Nature/Role of Health Related Self-Help Groups

The scholarly literature on self-help groups in general has burgeoned over the past several years.[8]   Self-help groups have developed around human service systems of all sorts, and have become especially popular in the health care field. As human service systems continue to face cutbacks, people desiring such services will have to draw more on non-professional and voluntary sources.   And as more attention is paid to the relevance of social support in helping people to cope with medically related stress, such groups probably will continue to gain in popularity.[9]   People who share a common problem often can provide unique forms of information and support to one another. They also can provide a reference group, a means of comparing with and learning from others undergoing similar situations and problems.   By pooling their information and energy, they may even be able to have an impact on the medical system with which they interact.

A self-help group can be defined in different ways, but most literature focuses upon an identifiable group of people, in a similar stressful situation or with common needs, coming together on a voluntary basis, to "do for themselves" or to help each other cope with a chronic problem. In dealing with health concerns, members of self-help groups typically try to lessen the negative impacts or ramifications of a disease process. Obviously, the prevention or buffering of secondary effects is as much of a concern as is remediation or reduction of a primary disease process.   Within this definition there is still great variety, but some of the health-related groups most observers would agree on as fitting this prototype include: Reach for Recovery, Mended Hearts, Osto-mates, Make Today Count, Living One Day at a Time, etc.

Some scholars have suggested that the increasing bureacratization and high technology of modern medical care alienates clients or consumers from the providers of care. Thus, they explain self-help groups as one response to this depersonalization of care, and as a way of establishing intimate contact with professional and lay helpers. In this context, the mutuality of support and help generated in typical self-help groups may be an antidote or supplement to the one-way or non-reciprocal helping process practiced by most medical and social service professionals. Other scholars argue that disatisfaction with care is not related to self-help group membership, and that some people participate in self-help groups as a alternative form of social connection and mutual aid, not as a compensation for negative medical experiences.[10]

Regardless of one's position on this general debate, it appears that some of the traditional role relations established among medical service providers and consumers may not fit well in the case of chronic and serious illness. People dealing with serious illness over a long period of time, including an out-patient treatment regimen that disrupts family life, must learn a great deal of what physicians and nurses know, and must become active care-providers themselves. As individuals, and as members of an organized group, they may challenge some of the assumptions underlying traditional models of medical care (e.g., physician authority and impersonality, patient passivity and compliance, separation of medical issues from psychosocial issues, etc.).[11]

The potential roles of a self-help group as an aid, complement, or challenge to current forms of medical practice suggest a new form of partnership or collaboration between organized groups of family members and professionals concerned with effective care. As in any collaboration, conflicts may arise, and all parties may need to learn new roles and relationships. Reformation of some of the traditional norms

governing the physician-patient relationship even may lead to more effective care for patients, especially to more effective forms of psychosocial care.[12]

Self-help Groups for Families of Children with Cancer

There is relatively little research available on self-help groups organized for families of ill children, and even less on groups for families of children with cancer.[13] Informal reports indicate that self-help groups have been organized at many centers where children with cancer are treated; in fact, records of The Candlelighters Foundation (a national network of self-help and mutual suport groups for families of children with cancer) estimate over 200 such groups currently in existence. In the absence of detailed reports or direct observations, it is hard to distinguish among various kinds of self-help groups and professionally-led counselling or discussion groups, group therapy sessions, informal mutual support groups, etc. For example, in a recent study, Stolberg & Cunningham (1980) report that eighteen of the 21 children's cancer centers responding to their inquiry have some kind of parent support group, most of them initiated and staffed by professional social workers or nurses. Our experience (and reports from The Candlelighters Foundation) suggests that many other groups exist that are not initiated or led by professionals.[14]

Our pilot research project (Chesler et al., 1981) indicates some of the specific ways in which a self-help group can be useful and supportive to parents of children with cancer.[15] For instance, it can provide them with information of the sort that medical professionals may find difficult to communicate in everyday language. Moreover, it may provide them with an identification or sense of community with others, and emotional support at critical stages of their attempts to cope with the illness and treatment. As some parents in one group noted (Chesler, et al., 1981):

> I went to the SHARE meeting and shared my experiences with them. When I see someone else who is going through the same thing I am and they can handle it, then I can conquer it too.

> No one else knows what you're going through until they've been there. You can tell someone who's been through it how you feel and ask, should you or do you have the right to feel this way.

> SHARE meetings are really good. The first few tore me up when everyone was talking and I found out I was in the same boat as them. Then I thought I was lucky because some had it so bad.

In those instances where a hospital or medical center provides little information, support or counselling, the role of a self-help group may be even more critical in helping families deal with the illness and its consequences.

Other recent research discussing the positive benefits of self-help support groups interpret them as part of a "doing defense", as an expression of an active style of coping with stress and feelings of helplessness. In the same context, several authors draw attention to the "helper-therapist" principle, whereby people who give help to others gain strength themselves.[16] Indeed, parents who reach out to others, who can share or give a part of themselves, may be behaving in ways that indicate they have spare resources, and that they are not totally bereft of coping energy and skills. Acting "as if" they are potent, in the midst of an otherwise debilitating and disempowering experience, parents may overcome some of their feelings of helplessness and reestablish a sense of emotional and practical control of their lives. As parents share information, support and other resources with each other, they may all learn more about how to get their needs met -- in and out of the medical system.

Given the paucity of information available on self-help groups for families of children with cancer, and the need for more adequate information in this area, we attempted to develop a broader information base on such groups and their operations. In the next sections of this report we indicate what information we sought, how we

gathered it, and what appear to be some of the preliminary results.

## The Foci of This Study and Our Methods of Inquiry

In our attempt to learn about the organization of self-help groups for families of children with cancer, we decided to examine several related issues. On all the following dimensions, we also wanted to gather as much practical information as possible, the better to share information and advice with other groups around the country. At the outset, we wanted to know what kinds of activities different groups engaged in, and how they organized to conduct their business. The concern about groups' activities involved inquiry into the kinds of services groups provided to families and the kinds of events or programs they sponsored. Concern about how groups were organized led to a focus on groups' charters and by-laws, the degree of formality evident in meetings, and membership patterns and leadership functions. Of course, these activities and organizational patterns may change over the course of a group's existence, so we often asked about differences in the group over time.

We anticipated that two other factors in the self-help group's relationship with the external community or medical environment might be related to these internal organizational forms and activity patterns. First, we knew there existed a natural division between groups that were invented, initiated, "run" or facilitated by health care professionals and those that were initiated, run and controlled by family members themselves. Of course, divisions of this sort are never nice and neat, and many groups had and have a mix of professional and parent leadership, perhaps even shifting over time. Moreover, this is only one piece of a larger issue - the nature and degree of collaboration and support existing between a self-help group and the local medical staff and treatment facility. We anticipated that this distinction would be important in understanding the kind of program or activities a group sponsored and the kind of formal organizational structure they adopted. We also anticipated that

groups would differ to the extent they were organized around, or located near, a major medical center, perhaps one focusing on children's cancer treatment, as compared with others located in or near a smaller and more general community hospital. This distinction, we assumed, would affect the local patient load, and thus the size of the group and the kind and amount of medical and community resources it could draw upon. It, too, might have impact on a group's internal program and organizational structure.

In addition to these four major factors, we wished to understand how each group developed its own set of norms and common values. Although each group may be formed primarily by the combination of external factors noted above (relation to the medical staff and character of local facility) and its internal program and organizational structure, it also seems possible that active members may develop unique "rules" about what kind of people should or shouldn't be members, how people ought to cope, what behavior is appropriate in the group, etc.

Our general concerns can be illustrated in the following diagram:

External
Factors

Organizational
Factors
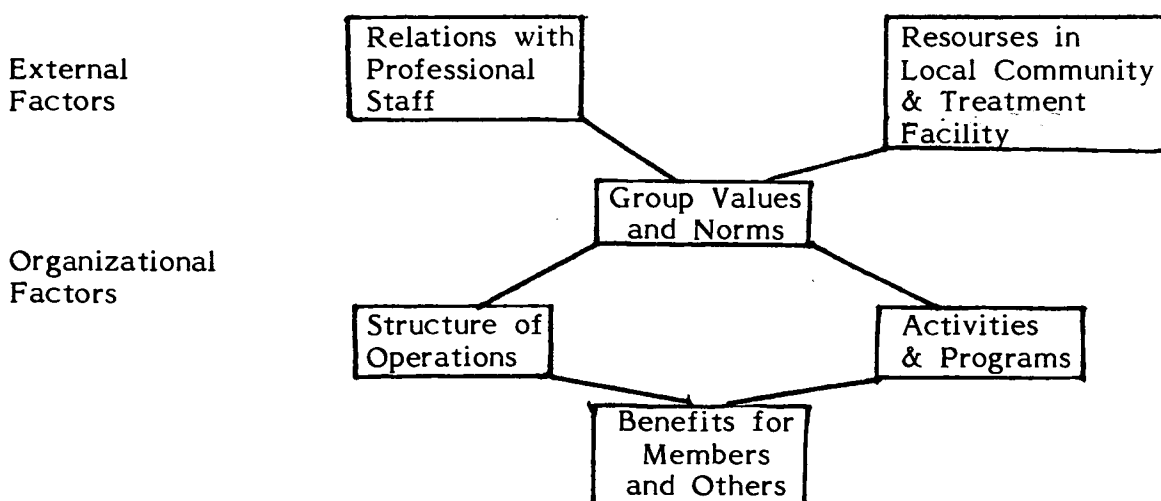
Our interest in learning about these issues in self-help groups for families of children with cancer required personal visits and conversations with people active in them. To date, we have visited with 30 such groups, in all parts of the nation. We have talked with (or interviewed) over 200 people, including approximately 150 parents currently or formerly active in these groups and 60 professionals working in or with them. We expect to complete data gathering visits by May 1983, adding perhaps 3-4 more groups and 30 people to this sample.

Groups we visited were identified first from lists provided by The Candlelighters Foundation, the Children's Leukemia Foundation of Michigan, and a number of other national and regional networks and treatment centers. As noted above, decisions about which groups to visit were made with an eye to varying certain characteristics: level of professional involvement in the group and type of community and treatment setting.

Our typical procedure was to send each group we were interested in visiting an informational letter, and to follow that up with a phone call identifying ourselves, describing the study, and a requesting information about the group's interest in a potential visit. At that time a local contact person was established in each group: in most cases this was an active parent, but sometimes a social worker or nurse was the prime contact.[17]

In most instances we conducted group interviews with active members of the local self-help group, and usually with some persons who had been active members once but were so no longer. In this way, we were assured of learning about the group's history, as well as its current operating procedures. Whenever possible, we also talked with health care professionals (social workers, nurses, physicians, child life workers) who were involved with the local group. All interviews were conducted in small group settings, with from 1-10 participants. In no cases were parents and

health care professionals interviewed together. Interviews were conducted in families'
homes, Ronald McDonald houses, hospital offices, and sometimes over lunch or dinner
in a restaurant. Almost all interviews were tape-recorded, with the permission of
participants, and with the assurance that all comments would be kept confidential and
anonymous. In addition, each person interviewed was asked to fill out two checklists:
one asked for a description of the activities of the local group; the other asked for
judgements of parental satisfaction with the health care services provided by the
treatment center(s) involved. The major topics covered in the interviews included:

1. history of the group and changes over time

2. current membership - size and characteristics '

3. activities or programs the group runs or sponsors

4. leadership patterns - who exerts leadership, for how long, and how

5. organizational structure - how formally incorporated the group is,
   how meetings are run

6. the group culture - norms and values about self-help, about what
   should go on in the groups, and beliefs about why certain
   families are involved and others not

7. linkages to other community groups

8. relations with the hospital and the medical staff

9. evaluation activities and advice to other groups

After completion of a visit, our staff at the Center for Research on Social
Organization listened to the tapes of each interview, and made copious notes that
reconstructed (not transcribed, but captured meaning and illustrative comments) the
interview session. Out of each set of interviews we created a profile and capsule
description of each local self-help group. These descriptions now are being compared
and the major themes are being analyzed across groups.

During some interviews and visits we were asked to share our growing knowledge of other self-help groups, and to help a local group reflect on its own activities or problems. We tried to respond to these requests, even though all the data had not been analyzed, because of our general commitment to sharing the results of this study with other people active in or concerned about such groups, and with the improvement of groups' operations.

Preliminary Findings: Issues or Dilemmas Faced
by Self-help Groups of Families of Children with Cancer

Although our analysis of these groups' experiences is not complete, some issues are becoming clear. There are several key problems most groups appear to face at some time during their history and development. While there is no single pattern of solving these issues, their particular solution undoubtedly affects other aspects of a group's development. Thus, it seems best to refer to a series of issues or dilemmas that most groups must deal with.

What kinds of activities or programs do groups undertake?

Different groups emphasize different activities, and undertake different programs they see as benefitting members. Five different kinds of activities seem to be most popular: information/education, emotional sharing, social support, fund-raising and making changes in the medical system.[18]

Informational and educational activities are most common, and appear to be undertaken by almost all groups, at least for some time during their history. The focus of these programs may be on the nature of childhood cancer, new treatment regimens, hospital procedures, ways of dealing with young children, etc. In some cases, parents educate each other in these settings: in other cases an outside speaker/expert addresses the group. The invitation of local physicians generally

represents a particularly popular option, one that often is used to attract previously non-active parents to a meeting. Moreover, such invitations may help link the treatment center and the medical staff more tightly with a larger group of parents.

Sharing feelings and supporting other parents emotionally also is a focus of many groups' activities. Here the objective 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. These problems may cover quite a range: dealing with spouses' and family members' feelings, preparing for death, fighting depression, coping with diagnosis and/or relapse, relating with the medical staff, being afraid of the future, "bringing up" an ill child, dealing with siblings, finding time for intimacy, etc. The topics of some of these meetings may be quite similar to the information/education sessions above, but the purpose and style is quite different: here the goal is for parents to share their experiences, feelings and suggestions with one another. In some cases, parents do this work with one another directly; in other cases a social worker, nurse or psychologist "facilitates" discussion and promotes openness and sharing among group members.

A third major focus of group activity is social support and friendship. Some groups feel their primary activity is to provide an arena within which people with a similar experience can gather and talk with one another. Groups do this by arranging picnics and holiday celebrations, pot-luck dinners, informal get-togethers and parties or special activities (movies, field trips, recreational events) for their children. By staying at a "lighter" level than the emotional sharing reported above, people may ask for help if they wish, but also can concentrate on keeping in touch and in having a good time with one another.

Fund-raising is a fourth major activity in which many groups are involved. It generally is a way of gathering resources in order to provide direct (and material)

service to families. However, fund-raising is not undertaken by all groups, and even those who do so may vary greatly in their approach. Some groups raise small amounts of money, in casual ways, mostly to support their own newsletters, coffee, social events, etc. Other groups may raise more substantial funds, primarily to purchase prostheses for children without adequate insurance, to buffer the high costs of transportation, parking or child-care for families, or to pay for in-room television for hospitalized patients. Still other groups raise considerable funds in order to aid families transporting children to specialty treatment centers, to build "parent houses", or to donate funds to support research at the medical center. For example, one group which sought facilitators for its parent sharing and co-counselling program decided they did not want to use a member of the hospital staff for this purpose. In order to protect their privacy and "get away" from the hospital, they raised funds to hire a psychologist to work directly with their group for a period of several months. Several other groups were faced with what they felt was a shortage of social workers available for their children and themselves (not an uncommon problem). They raised enough funds to support part of such a person's salary for a period of time, and offered to donate these funds to the hospital for that purpose if the hospital would pick up that salary in succeeding years. The hospitals involved agreed to this innovative funding pattern!

A fifth category of activity some groups engage in involves attempting to make changes in the operation of the medical staff or treatment center. Groups embarking on this agenda usually work in close collaboration with health care professionals as in the above example of expanding (or altering) staffing patterns. However, on occasion self-help group members advocate changes despite professional reluctance or resistance. In most instances of this sort, both professionals and parents report that they eventually are pleased with the collaboration such advocacy generates, and with

the outcomes of changed procedures. However, one of the dangers of these actions is that they may provoke negative reactions and fears among professionals, the same fears that make some professionals wary of active parent groups in the first place. Our observation is that serious alienation seldom ocurrs as a result of parents' change-oriented activities, but this fear and the resultant dilemma remains, nevertheless.

Which of these activities works best? Which are most important to undertake? What is the correct balance among them? Each of these activities respond to the different stresses associated with childhood cancer, and different ways in which parents of seriously and chronically ill children wish to cope with such stress. For instance, substantial research indicates that some parents of children with cancer cope with stress by seeking a great deal of information: for these parents information sessions may be most appropriate. Other parents have difficulty managing the many practical and instrumental tasks associated with the treatment of childhoood cancer, and with the attempt to normalize family life. For these parents, advice on how others have managed these processes, gained either from professionals or directly from parents, may be most appropriate. For some who find themselves or others in dire financial straights, fund-raising activities may be most important. Parents who wish to share, express, and reflect upon their feelings may be most desirous of group activities that promote emotional sharing and intimate engagement.

In addition, each activity may be more or less appropriate, or needed in greater or lesser amount, by parents in different treatment centers or in different kinds of communities. Depending upon the kinds of social services an institution provides, or the type and quality of available care, parents may generate or participate in a self-help group designed to "fill the gaps" in available psychosocial care, medical information or social services. Moreover, the availability of some kinds of community

services (e.g. Ronald McDonald Houses, American Cancer Society funds) may make fund-raising activities less important for parents who live in communities where they already have access to needed servcies.

Since different groups emphasize different kinds of activities, each may appeal most to parents who want or need those particular activities. For instance, if a parent's primary desire is to talk with others about the pain and stress of parenting a seriously and chronically ill child, and the local group is committed to casual conversation, socializing and fund-raising, that parent is not likely to become active in that group. By the same token, a parent who wants information about the disease and treatment, and who does not want to "get depressed" by talking about feelings, will not get his or her needs met in a group that focuses on sharing deep feelings. Aside from this self-selection process, a more subtle process of socialization or re-orientation may occur, whereby parents who enter a group for one purpose may learn from others to adopt new ways of coping. In addition to this process of peer-modeling, some parents may become quite interdependent with or "bonded" to other members and to the group, and as a result alter their needs or coping styles in order to fit with the dominant activity patterns in the group. Some parents, upon getting involved in a group and becoming committed to its activities and other members, may discover a need or desire for different activities. They may try to change or expand the range and priorities of group activities, either with the willing cooperation or against the resistance of group leaders and collaborating professionals. Some groups deal with this influence process simply by expanding and developing different specializations within the organization, while others make a formal division or radical changes in the way the group functions. The membership of a group may remain stable through any and all of these changes, or there may be a high turnover resulting in a newly constituted leadership and membership.

Some groups deal with the problem of attaining a balance among these activities by forming several different sub-groups, some of which meet (perhaps once a month) to receive information, some of which meet (every two weeks or so) to share feelings or problems, and some of which meet (once or twice a year) to socialize and have a holiday party or summer picnic. At a more formal level, some groups incorporate separate fund-raising organizations, parallel to but with different administrative structures than that part of the group that shares information and discusses feelings.

Who are these groups for? Who is not part of such groups?

In addition to the issue of matching coping styles and activity patterns, as above, it is clear that some parents do not wish to be involved in any self-help group. They may not want to "identify" themselves publicly as a parent of a child with cancer, may not feel comfortable dealing with these issues with strangers, or may be too isolated geographically to get to meetings, etc. Moreover, some may receive all the support they feel they want or need from other sources (family, friends, church, etc.).

Many groups wrestle with the question of whether or not parents of deceased children with cancer should be encouraged to be or to remain active. In some groups parents of deceased children are active alongside parents of living children. In other groups parents of deceased children dominate and set the tone for the group - and for members whose children may be living. In still other cases parents are not expected or encouraged to be active after their child dies (although they never are formally excluded). Arguments in favor of both sets of parents being part of the same self-help group include: parents of deceased children still have ties to the hospital and to other parents, and they would be sadder and lonelier if these ties were cut; parents of deceased children have organizational skills and energy that the group needs; parents of deceased children can help prepare others for the potential of

death; parents of living children can benefit from the model of parents of deceased children - that life continues even after the death of a child. The major arguments against such integrated groups appear to include: parents of newly diagnosed children, especially, may be frightened by meeting many parents of children who have died; parents of deceased children may be at different stages of their lives, and not interested in talking about the same things as parents of living children with cancer; it may be too painful for parents of deceased children to meet with and see parents of living children; and it may be too guilt-provoking for parents of living children to take joy in their situation in front of parents of deceased children. We do not know what the "best" answer to this question is. However, it is important that groups deal with this issue explicitly and not avoid it. When too many issues of this sort are swept under the rug informal norms are created that decide the group's fate - sometimes without the group ever being aware that such decisions have been made.

Our discussions with parents and professionals involved in these self-help groups also suggest that in very few cases are members of black or hispanic communities active. And, in very few cases are parents from very low income backgrounds involved. There are exceptions, to be sure, but this is a strong impression from the visits and interviews.[19] Why should this be the case? We do not know at present, but some possibilities do suggest themselves. One is that minority parents may elect different coping methods, ones that do not include sitting and talking with others (non-family members or strangers) about dealing with childhood cancer. Moreover, if one of the appeals of a self-help group is that people talk with "others like themselves", minority group members are certainly not "like" whites, although they are like all other parents of children with cancer in many respects. Another possibility is that these parents are not made to feel welcome by the white majority in most self-help groups. After all, racial separation and exclusion is a common

phenomenon in this society, and even people of good will may not be able to overcome the weight of this historic tradition. We are not suggesting deliberate acts of exclusion: indeed, our impression is quite the contrary. But despite people's best efforts, it simply may be too difficult to overcome these stereotypes and barriers, even in the face of the common crisis of childhood cancer. Other possibilities have been suggested: alternative forms of family, neighborhood, and church support may exist and be utilized in minority communities; low income people and minority people may have access to different hospitals, or may be excluded from some major treatment centers; they may live in different communities, too far from the group's meeting place; they may lack as much available time and energy, or the financial resources to make time and energy for group involvement available, etc. At this time we do not have the answer to this puzzle, and can do no more than acknowledge its existence and importance.

How formal should be the organization of a self-help group?

Different groups make different decisions about how formally organized they want to be. For instance, some groups are comprised of several parents who get together every other week to sit and talk. They meet informally over coffee or lunch, or in one of their homes, and don't rely on organizational tools such as minutes, reports and committee agendas. Other groups are semi-formally organized: they have regular meetings and notices of these meetings are sent out to other parents. Generally these meetings are held in a community center or the hospital, but sometimes they are in people's homes. In some cases they even have a charter. Still other groups are organized quite formally: they not only have a charter, but formal by-laws and even systematic membership criteria. Some have active committees which give regular reports at large group meetings. Meetings often are held in a hospital, and

are chaired by a designated or elected officer. Many of these groups also have applied for non-profit and tax-exempt status, an important issue whenever fund-raising activities are involved.[20]

The degree of formal organization of a group appears to be related to the nature of its activities. As noted, tax-exempt status and more formal procedures become especially important when fund-raising is involved. For groups that meet just to talk, especially if they are small, a very informal organization may be quite sufficient. One of the advantages of more formal organization is that it may help designate responsibility for certain tasks, and locate specific people who will do them and report back to others on a regular basis. On the other hand, most people feel there is little sense in investing time and energy in formal charters and bureaucratic procedures if they are not called for.

How does a group operate when potential members are spread over a large geographic area?

Self-help groups located in a limited geographic area generally can stay in touch with members and potential members on a phone or face-to-face basis. This is most likely in a large city or even in a small city with a community hospital. However, when a group is organized around a large teaching hospital or regional cancer treatment center, or when the area is very sparsely populated and rural, families may be spread over great distances. How then can people stay in touch with one another? Phone calls are expensive, and face-to-face meetings also require substantial travel time and expense.

Some groups are tied to treatment centers serving a large and diverse population, and have to face this problem directly. One innovative solution is to use a newsletter, and to mail monthly notices and reports to members living in widely

separated areas. Another important innovation is to establish an organization of organizations with a "wheel and spoke" design. For instance, in one case a central group near the major treatment facility, the hub of the wheel, generates a newsletter, serves as an information clearinghouse, and coordinates the activities of several outlying or satellite groups which form the spokes of the wheel. In one small town, fifty miles away from this center, there is a local group with 4 - 5 families as members. Another local group, fifty miles away in another direction, represents another spoke. And so on. In this way people who live near one another meet and care for one another, or participate in fund-raising programs, without travelling long distances. On the other hand they do not have to exist alone: they are tied to other groups by the central coordinating agency. On a regular basis, leaders of each of the satellite groups meet with the central cordinating group to make sure they all are working together. In the case of large fund-raising efforts, picnics, and major events at the hospital, large meetings are called once or twice a year, and everyone from all the satellite groups is invited.

How does a group sustain itself over time?

Many self-help groups, like small voluntary organizations in all sectors of our society, have a fairly short active life-span. They may start up with great energy, work actively for 2 or 3 years, and then slowly lose energy, cease generating large meetings, and slowly fade.[21] Sometimes active members watch or participate in this process with feelings of failure and guilt. Our visits with self-help groups indicate that most of them encountered a leadership crisis, and a crisis of continuation, approximately four or five years after initiation. Some of the early members who "grew up" together became tired and wanted to move on to other issues in their lives (indeed, some of their children died, and other children completed treatment, years

ago). At the same time, parents of children diagnosed more recently have not "taken over" these groups and made them theirs. Newer families sometimes report that they face a well-entrenched clique of older members who will not let go of the reins the group. In some cases newly diagnosed families have not bonded together tightly in the ways the older parents have; as such they can not rely on each other for support and organizational accountability as can the original members.

How do those groups that have existed for several years create a pattern of succession and continuation? Some groups deal with this transition by slowly integrating newer families into positions of responsibility and leadership, thus bridging the generational gap. Other groups help newer families organize and meet separately for a while, until parallel operating groups can meet together on a somewhat equal basis. Still other groups utilize the social worker or staff nurse as a linking agent between the "old" self-help group and the "new" self-help group. Still other groups do not deal well with this potential crisis, and falter for months or years, or even die off, perhaps to be born again when another new group of families feels the need to start a self-help group.[22]

Who should be responsible for the group, or lead it - parents or professionals?

Groups differ widely in the degree to which they operate with direction and leadership from parents, with leadership from professionals, or with some integrative mix. Thus, professionals' roles range from speakers or attenders at a parent-run group, to full participants, to "facilitators" of parents' discussions, to organizers and leaders of a hospital-run group established for parents.[23] In some cases, groups themselves make choices on these issues: in other cases, scarce resources or a lack of energy and imagination make few options available; then choices are made by whatever interested and skilled people are available.

The dilemma of the degree of professional involvement, collaboration and even control of consumer self-help or mutual support groups has been discussed in much prior literature. Many medical and social work professionals, and some parents, are cautious about self-help groups and prefer a strong professional presence. Some are concerned that parents might hurt each other - unintentionally of course. Some are concerned that parents might share misinformation, and/or generate support for current fads in the treatment of children with cancer. In addition, some professionals are concerned that parents might create a norm of anger and opposition to or criticism of the medical staff. In a very different vein some professionals suggest that on their own parent discussions may stay on a superficial level, offering social friendship and support instead of "meaningful emotional work". Obviously these different concerns reflect some very different agendas or programs people have in mind for these groups. Whatever the particular caution, many professionals and some parents feel that if professionals are in leadership roles in self-help group meetings, these problems can be prevented or dealt with before they get serious.[24]

On the other hand, many parents and some professionals feel that parental needs can be met well by parents conversing and sharing with one another, and that any realistic potential for harm is quite minimal Moreover, some feel that professionals' presence is likely to be intimidating or limiting, and that there are things parents might not feel comfortable in talking about with a professional present. Obviously this view is not a criticism of any particular professional but a statement about people's different roles and commitments. Some parents and professionals argue, moreover, that it is especially important for parents to run their own self-help group. One basis for this belief is that the diagnosis of childhood cancer is itself dis-empowering; that is, parents feel helpless in the face of serious illness to their child, are relatively helpless to create a cure, and are rendered passive by many of the

operations of the medical system. Under these conditions, it may be especially important for parents to regain their own sense of control, efficacy or empowerment. One way for this need to be expressed is through the ability to render helpful service to others (similar to the "helper-therapy" principle discussed earlier), and through their activity to build and direct a group of their own, on their own. Another major argument in support of groups operating without professionals is that the basic need of parents may be for support, and not for the deeply emotional counselling for which professionals are uniquely qualified. As one social worker we interviewed stated: "Parents know what they need, and it's support from other parents - not therapy."

The major differences in views about the relationship between professionals and self-help groups are not always between professionals and parents; some professionals and parents feel one way and some feel another way. There is substantial disagreement among parents, and among professionals, on these matters and they cause internal strife for some groups. Moreover, underlying any and all of these different views is the reality of what parents and professionals can do in any local situation, with a limited set of resources. Thus, while anyone - parent or health care professional - may have an ideological preference for or against professional involvement in self-help groups, or for or against any particular kind of professional involvement in a particular group, that ideology often is altered or suppressed when people actually try and build a group together, and deal with their reliance upon one another.

The Difference Professionals Can Make

It seems clear that there are some important roles professionals can and do play in the initiation and maintenance of parent self-help groups. In most locales, some degree of parent-professional partnership is critical, and professionals' attitudes and

actions make a difference in the operation and future of local self-help groups. A physician cannot literally keep parents who want to get together from getting together, but he or she can make it easier or more difficult for them to find and rely upon one another (Chesler & Barbarin, 1983). Indeed, some parents report that physicians and other health care professionals explicitly advise them against meetings and talking with other parents of children with cancer -- in clinics or in self-help groups. Medical staff members, especially physicians, are in very powerful positions with respect to patients and patient families. They are perceived (often rightly so) to have life and death power over children with cancer, and some parents report being afraid to challenge, confront or displease them, fearing recrimination to their child. Medical staff members also control key resources essential for self-help groups. These resources include access to lists of newly diagnosed patients, permission to utilize hospitals or medical facilities as meeting places, financial aid and human energy for a variety of tasks such as mailing materials, support for the general legitimacy or credibility of the self-help enterprise, and linkage to other medical and community agencies.

Some concrete examples from our interviews illustrate the key roles and behaviors involved in generating a collaborative approach among parents and professionals working in such groups. For instance, one parent with a close relationship with the medical staff secured support for a meeting between the staff and the self-help group to go through a list of parent grievances and complaints about the treatment center. Although parents' complaints threatened the medical staff, and many parents were nervous about expressing them, the heated exchange clarified some important issues. Both physicians and group members reported satisfaction with the results of the meeting, and with the feeling they could air their issues with one another openly. Other parents whose children were treated at this

facility began to attend the group's meetings, now more convinced that the group was a viable and credible agency.

In another major children's cancer center the social worker believed strongly that parent groups which operated without professional supervision were potentially dangerous to parents. As a result, he has designed and runs a series of mutual support groups and workshops for parents. Several parents attend these sessions, and there is no question of their positive value. However, no independent self-group has emerged in that treatment center, unlike other hospitals and clinical operations of that general size and mission. A physician in another center actively dissuaded parents of his patients from talking with parents of other children with cancer, on the basis that they would share misinformation and question either their treatment regimen or the staff's widsom. Although a self-help group has started with parents whose children are being treated by other doctors in that area, it has not been able to involve many parents whose children are treated by that physician.

These examples, and other information from groups we visited, indicate a variety of important roles professionals can play in assisting the development of parent self-help groups: providing parents with access to hospital facilities; developing and implementing an active and efficient referral system, wherein parents of newly diagnosed children are placed in direct contact with a veteran (and perhaps explicitly "matched") parent group member; legitimizing the group's existence, purpose and activities by recommending it actively to others; processing some parents' complaints at a low level of confrontation with the staff; publicizing the group's activities in the hospital and community; educating other health care professionals to the utility and importance of a self-help group for parents and family members; providing parents with access to medical and nursing students or trainees, so they may educate them directly; providing training in leadership skills to group members; educating group

members about the politics and structure of the medical care organization, so they may select their programs strategically; and helping the self-help group link its programmatic efforts to other relevant community agencies and organizations, such as schools, social service agencies, insurance companies, etc.

In some times and places professionals are most effective if they play these supportive roles actively and vigorously. In other situations it is most effective if professional provide support from the background, as low-key complements to the public activities of the self-help group. And in some circumstances parents are able to produce all these resources and play all these roles themselves, with only subtle support from their partners in the professional staff. In most cases where viable self-help groups exist, they have occurred because such roles have been played in unique combination by an active and charismatic parent leader(s) and a loving and outreaching health care professional(s).[25] The actions of professionals alone do not appear to be sufficient to catalyze parent activism, nor to sustain it over a long period of time. By the same token, even the most exciting and energetic parents, working without any support from local health care professionals, have a very difficult time making a group "go."

Next Steps in the Analysis of these Data

This brief description of our study of self-help groups for families of children with cancer leaves many stones unturned. We are only beginning to make sense out of the data, and out of the experiences of many groups and hundreds of parents and professionals with whom we talked. One of our next steps will be to gather more information from the people we have interviewed, including their responses to a questionnaire about the motivations and benefits associated with their involvement in

these self-help groups.

In terms of our future data analysis plans, we expect to provide more detail on each of these dilemmas or issues, illustrating them with the actual words of informants and concrete examples from newsletters, programs and other materials provided by local groups (although maintaining confidentiality and anonymity). In this manner we will share useful information with other parents and professionals working with such self-help groups. Another step in the analysis will be to create integrative case studies or "pictures" of each group's history, internal structure, activities and relationship with their environment. When the data have been organized in this manner we can compare groups with one another on a systematic basis. Groups can be clustered on the basis of characteristics such as "dominant type of activity", "kind of medical facility" or "formality of internal structure", and then examined for patterns of similarity or contrast among groups with different characteristics.

Then we will draw connections among these various issues, in order to understand the underlying themes and dynamics of self-help groups for families of children with cancer (and perhaps of self-help groups and grass roots organizations more broadly). For instance, some of the specific questions we will analyze in detail during the next few months include:

1. What factors determine the kinds of activities or programs a group undertakes?

    a. What is the relation between the amount of support (or control) from local professionals and a group's activities?

    b. What is the relation between the kind of community and treatment facility and a group's activities?

    c. What is the relation between a group's membership - parents of living children and/or parents of deceased children - and its activities?

    d.   What is the relation between the ideas or leadership styles of key parents and a group's activities?

    e.   What is the relation between a group's degree of formal organizational structure and its activities?

2. Does a group's degree of formal organizational structure have any relationship with its ability to gather resources and sustain itself over time?

    a.   Do more or less formally organized groups have different relations with medical professionals?

    b.   Do more or less formally organized groups have different relationships with community agencies?

    c.   Do more or less formally organized groups have different experiences with the "succession crisis"?

    d.   How do groups deal with leadership or succession crises?

3. What factors are related to parents' satisfaction (or dissatisfaction) with the medical and social services available at local treatment facilities?

    a.   What is the relationship between the level of professional involvement in a group and parents' satisfaction/dissatisfaction with services?

    b.   What is the relationsip between a self-help group's activities and programs and parents' satisfaction/dissatisfaction with services?

4. What are the dilemmas professionals face as they work with such groups?

    a.   How do they resolve these dilemmas?

When we have completed these and other analyses we will prepare reports for various audiences: parents and groups of parents of children with cancer and with other chronic and serious illnesses; professionals serving these families; and academic or scholarly researchers interested in the growth and development of such groups. We also expect to conduct regional conferences where the results can be shared with local parents and professionals, where all parties can share their information and experiences, where training in special skills can be provided, and where parents and professionals can learn to develop more effective partnerships in the delivery and improvement of health care.

3. See, for instance: Citizen Participation, 1982, 3(3); Journal of Applied Behavioral Sciences, 1976, 12(3); Katz & Bender, 1976; Robinson & Henry, 1977; Social Policy,1976, 7(2).

4. The experience of childhood cancer presents families with an unexpected and unpredictable "crisis," one quite different from the normal developmental crises of parenthood, adolescence, school transitions, etc. (Futterman & Hoffman, 1973; Pearlin & Lieberman, 1979). Family members must deal with new practical problems (child care, schooling, financial strains), intellectual problems (understanding medical jargon, learning about diagnosis and prognosis), interpersonal problems (relating in new ways to family members and friends and co-workers), emotional problems (wrestling with fear and anxiety and anger), and existential problems (making sense of this event, fitting it into a faith or world view). Some of these issues are delineated in greater detail in our earlier study (Chesler, et al., 1981), as well as in others' research.

5. Thus, some observers note that childhood cancer is a "family disease," one which disrupts normal family functioning and impacts on all members of the primary unit (Binger, et al., 1969; Cassileth & Hamilton, 1979; Fife, 1980).

6. For more detailed discussions of these and other coping styles among families of children with cancer, see: Chesler et al., 1981; Friedman, et al., 1963; Futterman & Hoffman, 1973; Hamburg & Adams, 1967; Kaplan, et al., 1973; Kupst, et al., 1982; Spinetta, et al., 1981.

7. For instance, see the problems and issues discussed in: Brickman, et al., 1982; Gottlieb, 1978; Gottlieb, 1981; Gourash, 1978; Wortman & Dunkel-Schetter, 1979.

8. Some excellent general treatments or summaries of the field include: Prevention in Human Services, 1982, 1(3); Caplan, 1974; Gartner & Reissman, 1977; Gottlieb, 1981; Journal of Applied Behavioral Sciences, 1976; Katz, 1981; Katz & Bender, 1976; Killilea, 1976; Lieberman & Borman, 1979.

9. However, some observers voice the fear that effective voluntary action by consumers might have the negative effect of releasing government agencies and health professionals from their own responsibility to provide extended care to citizens facing health crises (Checkoway & Blum, 1982; Crawford, 1981; Withorn, 1980).

10. Portions of this debate are captured and analyzed in: Back & Taylor, 1976; Banhoff, 1979; Katz, 1981; Kleinman, Mantell & Alexander, 1976; Lenrow & Burch, 1981; Lieberman, 1979; Tracy & Gussow, 1976; Traunstein & Steinman, 1976.

11. Traditional formulations of the doctor-patient relationship are based on Parson's (1951) functional analysis of the sick role and doctor-patient expectations and interactions. Others (Bloom & Wilson, 1979; Friedson, 1970; Szasz & Hollander, 1956) challenge this model, arguing that such role distinctions are in reality based upon the superior power of the medical establishment, on physicans' ability to say how patients should behave, on their power to define whether or not patients are sick, and on their more general and often irrelevant moral power, etc. With particular regard to the "management" of patients with serious and chronic illnesses, some scholars have argued that the traditional model may be quite counterproductive or unsatisfactory (Becker & Maiman, 1980; Chesler & Barbarin, 1983; DiMatteo, et al., 1979; Schulman, 1979).

12. See footnote 11. However, the gains may not be limited to improved health outcomes and satisfaction for patients . Such collaboration also may lead to more fulfilling work roles and relationships for health care workers. They, too, need help and support; while most discussions of these issues focus on colleagues and family members as supports for professionals working with childhood cancer (Gronseth, et al., 1981; Rothenberg, 1967; Sahler, et al., 1981), we see no reason why parents cannot provide professionals with such support as well.

13. The available evidence suggests great variety in self-help groups organized by people with different health problems or issues. Thus, groups organized around children's diseases, or childhood cancer more specifically, may differ considerably from others focused on different age groups or disease categories. Moreover, a sound analysis and understanding of self-help groups for families of children with cancer must start from systematic knowledge about the medical and psychosocial issues these families face. In addition to the sources cited in footnotes 4-6, the interested reader may consult several other excellent sources: Adams, 1979; Coping with Cancer, 1980; Kellerman, 1980; Koocher and O'Malley, 1980; Maintaining a Normal Life, 1980; Schulman and Kupst, 1980; Spinetta, et al., 1976; van Eys, 1977.

14. Although the Stolberg and Cunningham (1980) data are interesting, they also are somewhat suspect, since they were gathered by mail questionnaires directed to the chief medical officers of 25 major children's cancer centers. More broadly, the importance of self-help groups for families of children with cancer, whether initiated by parents or professionals, is stressed by many scholars and practitioners (Adams, 1979; Heffron, 1975; Knapp & Hansen, 1973; Martinson & Jorgens, 1976; Ross, 1979; Sachs, 1980). Most of the available literature on such groups discusses professionally-led varieties, partly because the literature is written by and for professionals.

15. In this prior research we conducted face-to-face interviews with parents and children from 55 midwestern families with children with cancer. See: pp. 61-68 in Chesler, et al., (1981), and Chesler, Barbarin & Lebo-Stein (forthcoming), as well as others' research or anecdotal commentary (Heffron, 1975; Lang & Oppenheimer, 1968). Similar benefits, for participants in a broader range of self-help groups, are reported by Gottlieb (1982).

16. See: Dory & Reissman, 1982; Gartner & Reissman, 1977; and Leiken & Hassakis, 1973.

17. In all cases, parents were enthusiastic about participating in this project. We were invited warmly into people's homes, and often asked to accept food, lodging and

transportation from group members. It appeared, however, that entry via an active parent was different than entry via a social worker or nurse, at least in the initial stages of a visit. Health care professionals were (understandably, given their roles) somewhat more protective of parents' time, energy and privacy than were parents themselves. Our dual roles as "outsider social scientists" and "insider member/advocates" of self-help groups for families of children with cancer certainly facilitated access and entry through various sources.

18. Similar kinds of activities are reported by scholars studying a wide variety of self-help or mutual support groups, although few reports indicate fund-raising activities. For instance: Katz (1959) identifies social support, sharing feelings, providing information and providing an arena for group action for change; Langton & Peterson (1982) identify education, fellowship, direct service and advocacy; Lipson (1982) identifies information, emotional support, reference processes, giving help and increased consciousness; Levy (1979) identifies education, aid in coping and making changes. Lieberman (1979) stresses the importance of social support, and Borman (n.d.) also emphasizes this activity in what he calls the "restaurant effect". With specific regard to groups formed for parents of children with cancer, most reports emphasize education/information (Adams, 1978; Belle-Isle & Conradt, 1979; Gilder, et al., 1976; Heffron, 1975; Kartha & Ertel, 1976; and Martinson, 1976), sharing of feelings (Adams, 1979; Belle-Isle & Conradt, 1979; Gilder et al., 1976; Heffron 1975; and Kartha & Ertel, 1976) and social support (Belle-Isle & Conradt, 1979; Martinson, 1976). Gilder et al., (1976), is one of the few reports that discusses in any detail parents' attempts to create changes in the medical system.

19. Gourash (1978), Lieberman & Berman (1979), and Wheat & Leiber (1979) also report, from a wide variety of studies on specific self-help groups, that parents with higher income statuses and educational backgrounds appear to be most prevalent and to dominate.

20. Even in the most formally organized settings, non-bureaucratic and participatory norms are present. This pattern is consistent with Traunstein & Steinman's (1973) report that self-help groups generally are non-bureaucratic, and even though Katz (1981) generates an informal-to-formal continuum on which to consider group structure, he acknowledges the skewed distribution of groups on this variable.

21. Stolberg & Cunningham (1980) report that most of the groups established by the medical centers they contacted evidently lasted 6 months or less. This is quite an extreme report, and is not supported by our discussions with groups established either by parents themselves or by professionals in other medical centers.

22. One perspective may be to envision these groups as "temporary groups" (Miles, 1964). Perhaps we should not expect them to behave like formal, bureaucratic and enduring agencies or organizations, with lives extending beyond those of active leaders. Perhaps we ought to expect them to be temporary in character, rising and falling with changes in local members' interest, energy, and involvement. Maybe a model of temporary organizations would fit better, and free us to think more creatively about "succession crises", membership changes, etc.

23. In fact, some scholars use the degree of professional involvement as a key criterion distinguishing between (autonomous) self-help groups and professional-led support or counselling groups (Katz & Bender, 1976; King & Meyers, 1981; Rodolfa & Hungerford, 1982). Reinharz (1981) provides an excellent discussion of alternative

roles professionals may play in self-help groups, concluding with the notion of a parent-professional "alliance" or "coalition".

24. See, for instance, professionals' fears or cautions regarding autonomous groups for parents of children with cancer as expressed by Belle-Isle & Conradt (1979), Binger, et al., (1969), and Kartha & Ertel (1976).

25. Thus, while we maintain an open mind on general debates about the basically pro-professional or anti-professional stance of such groups (Katz, 1981; Leiberman & Berman, 1979), and on the degree of desirable professional and parent involvement and control, we can assert that in the case of self-help groups for parents of children with cancer some degree of professional-parent collaboration is both commonplace and important. A further discussion of our own and others' views of the roles and role options of health care professionals with self-help groups can be found in Chesler & Yoak (forthcoming).

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