
SELF-HELP GROUPS OF FAMILIES OF CHILDREN WITH CANCER:
PATTERNS OF STRESS AND SOCIAL SUPPORT

Mark A. Chesler
&
Meg Yoak
University of Michigan

June 1983

CRSO Working Paper #290

Copies available through:
Center for Research on Social
Organization
University of Michigan
330 Packard Street
Ann Arbor, Michigan 48109

June, 1983.

Self-Help Groups of Families of Children with Cancer:
Patterns of Stress and Social Support

Mark A. Chesler
&
Meg Yoak

Center for Research on Social Organization
University of Michigan

For: H. Roback (Ed.) Group Interventions for Medical-Surgical Patients
and their Families. San Francisco, Jossey-Bass.

1

Self-help groups concerned with health care have grown rapidly in the past decade. These groups represent "targets of opportunity" for professionals and consumers concerned about the quality of psychosocial care and extended treatment, as well as mechanisms for pioneering changes in the delivery of health care. At the same time, such groups often present a challenge to the local medical establishment, to traditional professional roles and to typical parent-professional relationships. The response of health care professionals and active medical consumers to this opportunity and challenge defines the nature of a new partnership in health care.

Numerous treatises exist regarding health-related self-help groups, but few discuss groups formed around children's illnesses. In this chapter we examine self-help groups formed by/for families of children with cancer. We first discuss the range of stresses experienced by families of children with cancer and the kinds of social support they seem to need and want. Then we examine the specific resources and activities of self-help groups, and how they help people deal with these stresses and provide this support. Self-help groups established to help people deal with health-related stresses must be seen in the context of particular stresses and the coping patterns and support systems people utilize in dealing with stress. The chapter concludes with a discussion of some useful roles health care professionals may adopt with such groups. In order to illuminate the interactions among these variables, we have included reports from our studies with families of children with cancer and with self-help groups formed by/for them (Chesler, Barbarin, Chesler, Hughes & Lebo, 1981; Chesler and Yoak, 1983).1

The Stresses Of Childhood Cancer

Several recent reports from the National Cancer Institute (1981) and the American Cancer Society (1982) indicate rapid rises over the past two decades in the

percentages of children with cancer who are surviving several years beyond diagnosis. In 1979 the National Conference on the Care of the Child with Cancer projected a "cure" rate of 40-50% for children with Acute Lymphocytic Leukemia, and from 30-90% for the other most common forms of childhood cancer (D'Angio, 1980; see also, Siegel, 1980; Simone, Aur, Hustu, Verzosa and Pinkel, 1979). Thus, what was once an almost universally fatal childhood disease is so no more. For instance, Wilbur notes that (1975, p. 809):

Many people...treat children with cancer as though they will all have a fatal outcome. Out of this has evolved a particular emphasis on helping families and children prepare for their expected death. The expectation of a frequently successful outcome with eradication of disease, and a recognition of the importance of rehabilitation, has just begun to emerge.

Whether preparing for chronic illness and death, or now more often preparing for long-term treatment and potential recovery or rehabilitation, families of children with cancer encounter many stresses in the care and management of the child and family. In particular, many more families and the medical community itself are concerned with enhancing the "quality of life" of those affected by childhood cancer. Such enhancement requires dealing with a series of stresses, beginning with diagnosis and continuing after death or after all treatment has ceased and recovery or "cure" is evident.

Diagnosis: First Encounters with a Long-Term Cycle of Stress

The major stresses associated with childhood cancer usually begin with the formal diagnosis. At this point, whether in an instant or over a period of hours and days, life is ripped from its normal context. Parents' prior reality is shattered and

they enter a new reality, with new definitions of their children, themselves and their world. From whatever level of consciousness they respond, these parents "know" they are embarking on a long and difficult struggle. They may hope for a good outcome, and perhaps a rapid return to a "normal" existence, while recognizing that their life can never return to what it was before.

A number of research studies emphasize the shock accompanying this diagnostic period (Adams, 1979; Binger, Ablin, Feuerstein, Kushner, Zoger and Mikelsen, 1969; Hamburg and Adams, 1967; Knapp and Hanson, 1973; Koch, Hermann and Donaldson, 1974; McCollum and Schwartz, 1972; Ross, 1978). A review of some parents' comments provides direct personal evidence of their trauma, sense of unreality and often despair:

For a while I didn't deal with it; nothing they told me sunk in. They had to tell me three times before I was grasping it. They told me things and two minutes later I couldn't tell you what they told me in terms of medicine, treatment and stuff.

When I heard the diagnosis I left the room, I ran. I don't know where I went. I know I ended up on the 7th floor. I know that I was trying to dial numbers and couldn't see the phone. I know I must have called four people before I was aware of what I was doing. I was so totally alone I didn't know how to function. I was going up and down the stairs of the hospital. It certainly was the worst day of my life. I thought the day that my Dad fell dead was the worst experience of my life, but this was the worst.

These feelings continue. They may abate over time and 'be moderated by

experience, hope and recovery, but they return throughout the course of treatment. After all, cancer in children is not a one-time event; it is a chronically life-threatening disease. Chesler and his colleagues (1981) asked a sample of parents of children with cancer to fill out a self-anchored scale indicating the times/events of greatest stress during their experience. The precise nature of this question, and composite representations of parents' answers, are presented in Figure 1. Although the data indicate that the diagnosis is one of the greatest stress periods for parents, other events also were reported as potent (Coping with Cancer, 1980; Futterman and Hoffman, 1973; Ross, 1978). The dotted lines in Figure 1 indicate that while not very many parents mentioned that their child experienced surgery or relapse, for those who did these events were more stressful than the diagnosis. Parents of children who died indicated that the relapse was even more potent and took on continuing importance, since it generally was the start of a downward trend. The parents of deceased children also identified deterioration or the terminal phase, and anniversaries such as birthdays and important family events, as potent stresses (Lascari and Stehbens, 1973). The rise and fall of these stress points reflect portions of what Adams has called the typical "illness cycle" (1979, pp.17-21). Some observers, noting a rhythm to families' stress at different phases of illness or adjustment to illness, suggest providing different kinds of help or social services at various points along such a stress-line (Kaplan, Smith, Grobstein and Fishman, 1973; Obetz, Swenson, McCarthy, Gilchrist and Burgert, 1980; Ross, 1978).

(Figure 1 about here)

Categories of Stress

The medical situation of the child with cancer clearly is the major generator of personal and family stress, but it is by no means the only problem requiring

resolution. Nor does it take a singular form; many different stresses are created by the medical and social complexities of this chronic and serious illness. One set of stressors is intellectual in nature and requires parents to understand and master massive amounts of new and complex information surrounding their child's condition. A second set of stressors is instrumental or practical in nature, and involves parents in finding or generating solutions to the day-to-day problems of arranging their personal and family life around the treatment of a child with cancer. There is also a range of interpersonal stresses parents experience, as old relationships are disrupted and tested and new relationships created, in response to their child's illness. In addition, there is a variety of personal emotional stresses, psychological and psychosomatic pressures parents experience when faced with this threat to their child's life and their own normal living pattern. Finally, parents often experience existential stresses, challenges to their understanding or evaluation of the meaning of their careers and lives as the "normal" order of life and death is cast into doubt.

Intellectual Stressors. Part of what is difficult and even shocking for parents of children with cancer is the need to assimilate a great deal of new information and to learn their way around an unfamiliar organization. If parents are to be involved in the long-term care of chronically and seriously ill children they must have adequate and detailed information about symptoms, disease progress, danger signals and treatment procedures and options. Gathering and understanding information may be critical to the child's survival, as well as to parents' own emotional stability and integrity. Futterman and Hoffman emphasize the latter issue as they note that some parents "use intellectual mastery to gain some sense of control, as though knowledge actually were power" (1973, p.133).

As parents try to cope with and act upon intellectual stress, they sometimes encounter a medical system that exacerbates the information gap. Their tasks are

made more difficult when medical information is withheld from them or when it is presented in ways that are incongruent with a lay life-style and culture. Thus, parents of chronically and seriously ill children are faced with the need to make a rapid entry into a different culture, with new rules, roles and language. The particular vocabulary, jargon and even style of the medical system often makes it more difficult for parents to understand what is happening to them and their child. Consider the following parental reports:

As parents try to cope with intellectual stress, they sometimes encounter a medical staff that exacerbates this information gap. Consider the following parental reports:

There was a communication gap between the doctor and us parents. The hematology staff would tell the residents who would tell the medical students who would tell the residents again. By funnelling the information through in this way sometimes it is not all gotten, and there is a chance it will get muddled. Therefore, a more direct communication and relationship between parents and doctor would be helpful.

When I brought a book on hematology and wanted to discuss something in it with a nurse, she tended to discourage rather than encourage my reading from other sources. None of them could understand why I wanted second opinions on some of the treatments.

Instrumental Stresses. As the child with cancer is treated or perhaps hospitalized for chemotherapy or surgery, parents often must establish new patterns of family life and new divisions of labor that permit them to care for the ill child, as well as to care for other family members, continue their jobs, manage transportation to the hospital and insure that household chores are accomplished.

Parents who must deal with the medical system on a long term basis begin to develop an awareness of medical records, hospital billing procedures and insurance forms. They often monitor the daily care of their child.

Doctors keep changing, and many come in without having even bothered to sit down and read the records, and don't know what's going on. You have to keep constantly telling them things over and over. You feel you have to be there or she won't get taken care of.

As children with cancer are treated on an outpatient basis, only occasionally coming to a clinic, parents become front-line caregivers. Then they must become proficient in using information to recognize symptoms, monitor dosages and compliance, and provide care which traditionally has been defined as a medical prerogative (Futterman and Hoffman, 1973).

Current regimens for the treatment of childhood cancer do not leave many reasonable decisions in parents' hands, at least not in the beginning of treatment; relatively "proven" treatment modes which have provided the medical advances reported earlier lay out standard courses of initial treatment. But parents may be asked to participate in research studies or experimental treatment programs and may need to select a treatment facility before they have mastered the intellectual challenges just posed. And later, if the child's situation should deteriorate, parents often become involved in making instrumental choices about whether or when to cease treatment, where and how their child may die, and so on.

For some parents, managing the financial stress of childhood cancer also represents a major practical problem. Parents who report the financial impact of the disease as "somewhat serious" or "serious" tend to be concentrated disproportionately

in lower income groups, and some report that they have to make major changes in their living style in order to cope with new financial problems.

We had to sell our house because he went through most of my health insurance policy in 6 months. Recently, my husband's been laid off again, and we're going through the financial strain again.

The bills are bad. I work, but I'm still in debt.

We know enough about the meaning of socio-economic status in American life to know that people's lives are affected by these factors in a variety of subtle ways. Financial resources make a difference in the life experiences of all families, and they establish a context for living and for dealing with a myriad of problems. Several studies of stressful life events suggest that lower income families are exposed to more unfavorable living conditions and stress of all sorts in our society (Dohrenwend, 1970; Myers, Lindenthal and Pepper, 1974; Pearlin and Schooler, 1978). The addition of childhood cancer exacerbates an already unequal life situation and escalates many of the practical problems of everyday living.

Interpersonal Relationships as Stressors. Relating to the child, dealing with his or her adjustment to the disease and treatment and to the many new or altered life situations it brings creates many stressful family situations (Kaplan, Smith, Grobstein and Fishman, 1973). For instance, although most parents report that their spouse is very supportive during this time, new divisions of labor and new family roles may create stress. If mothers and fathers have very different contact with doctors and other sources of medical information, they may experience an imbalance in normal family expertise and roles. Parents who are quite depressed or angry may be unable

to create intimate time and space with their partners, stretching the marital bond considerably. It also is typical for siblings to develop feelings of curiosity and concern about their brother or sister's illness, to question why this person was selected for this fate, and to experience jealousy or anger about changes in the way time and attention are reallocated in the family (Gogan, Koocher, Foster and O'Malley, 1977; Sourkes, 1980; Spinetta, Spinetta, Kung and Schwartz, 1976). In some families siblings act as "safety valves," acting out or blowing off when internal family tension becomes too great. In other instances they act as "reality challengers," indicating to parents when they really are paying too much attention to the ill child. If childhood cancer and its associated stresses disturb the family's prior patterns, it can threaten the interpersonal relationships between the ill child and his or her siblings, and between parents and all their children.

One of the critical tasks the parents of a chronically ill child must face is "going public;" sharing the new reality, and as much of its meaning as they wish, with their extended family and friends. This is a self-redefining act; in its accomplishment parents inform themselves and others of a life-changing status they have just assumed. Uncertainty about the social rules governing the behavior of seriously ill children, concern about how others will react and a desire to give the "right" impression to others all create awkward social situations. As Goffman (1968) notes, people who are close to a stigmatized person often are treated by others as stigmatized themselves. Moreover, they often internalize the same reaction to stigma. No one likes being labelled or stigmatized, and parental denial or silence with friends about their child's illness may be a way to avoid further social stress.

As parents turn their attention to the other people and relationships in their lives each person or group of persons become potential stressors; sometimes their reactions increase the stress parents already experience (Cassileth and Hamilton, 1979;

Hymovich, 1976; Kaplan, Smith, Grobstein and Fishman, 1973; Katz, 1980; Voysey, 1972; Wortman and Dunkel-Schetter, 1979). Thus, despite many reports of increased closeness to friends, some parents report stress and distress associated with friends' responses and reactions to their child's illness.

You go back to work and everything's pretty calm for a while. And people at work don't know what to say. So they're afraid to say anything.

Some of the people who we thought would be our best friends never showed up for at least a couple of months after. That was particularly tough at the time, because you expected them to be right there at your doorstep. As you get through this stage, the crisis stage, you find out that the reason they weren't there is because they couldn't handle it themselves.

In addition to managing relationships with friends and co-workers, parents also must deal with representatives of other social institutions. Parents of school age children sometimes experience difficulty in creating effective partnerships between the medical staff and the school as their child reenters the educational environment (Barbarin and Chesler, 1982). If principals, teachers and parents of classmates are frightened or awkward in dealing with the child with cancer in school, classmates also are likely to be uncomfortable. Any of these situations can add social stress and strain to the existing medical stresses of childhood cancer.

Emotional Stress. As prior quotes from parents and the data in Figure 1 indicate, the diagnostic encounter often has an overwhelming emotional impact. Even after this initial period, and even as the child "recovers," every symptom, every side-effect, every checkup may carry a dangerous message. Parents continue to be concerned

about the uncertain progress of the disease because there seldom is a time in the near future when certainty of any sort can be provided or anticipated. For most, the uncertain waiting, hoping that a relapse will not occur, lasts for years. As several parents note:

I worry when he says, "Mom my stomach hurts." And I worry what's going on there, "Oh no!" But as time goes on you learn what to worry about and what not to.

Regular CAT scans worry me, because they show potential progress of the disease, and each subsequent scan has been stressful. It is hard for me to wait for the results from the tests because they could show evidence of the disease.

The fact that a child's life is threatened, and that this threat will exist for a long period of time, undoubtedly creates chronic emotional stress. Constant alertness to small signs of recurrent disease, constant adaptation to new treatments and their side effects, and the prolonged effects of constant worry tax the mind and heart and body. Many parents report signs of personal psychosomatic illness, as in their own aches and pains, sleeplessness, fatigue, loss or gain of weight and so on. Some become easily irritable, provoked by otherwise minor events in their lives; others become depressed and anxious.

Parents cope with the personal and emotional impacts of childhood cancer in a variety of ways: some undertake active problem-solving while others become passive and reactive. Some try to ward off worry by denying potential ill effects for their child:

I try to keep my mind off it. I don't watch TV shows or anything pertaining to

it. I shut them right off. For instance, my brother called and started telling me about "Brian's Song." He'd seen it and it made him cry, and he asked if I had watched it. I said, "No." He said, "Don't you want to hear about it?," and I said, "No." So he shut up. Why hurt yourself by watching that garbage?

I deny the possibility of a relapse. I refuse to believe it's possible.

Other parents try to "think positively":

I think positively. I think in terms of her growing up and going to school and getting better and doing the things that a normal child would do. We're preparing for her future.

Since parents often are "front line caregivers" and know that their own reactions are transmitted to their child, their management of their own internal feelings is critical. It may affect the eventual mental health of their child with cancer as well as other children and adults in the family.

Existential Stress. Many parents find it stressful to fit the experience of childhood cancer into their prior understanding of life and death. Serious and chronic childhood illness is, after all, a challenge to the ways in which most people understand and organize their views of the world as well as their patterns of daily living (Spinetta, Swarner and Sheposh, 1981). Death is conceived of as occurring mostly to the elderly, perhaps to the evil or warlike, certainly not to the young and innocent. That it happens, and happens personally, may disrupt one's images of normal existence and one's faith in an orderly and just world.

For some people, this experience is attributed to environmental or hereditary factors, although those factors seldom are specified with much clarity or confidence.

I think one of the problems is that our technology has developed so much, and I think the private sector has been using contaminants irresponsibly.

It's hereditary, because there is a lot of cancer in our family.

Others feel it is due to an act of God or of Fate (Kushner, 1982):

We feel that our lives are controlled by God, and that he allowed this for a learning process.

For a while I thought the Man upstairs was punishing me for something I've done.

And some people give up trying to discover meaning in what appears to be a meaningless event or situation.

These efforts try to "make sense" out of an experience that denies the normal sense of the world and represent efforts to grapple with the meaning of one's own existence. Attempts to resolve these issues within the realms of normal experience seem quite difficult and often challenge prior religious or spiritual commitments. Some parents report altering their religious beliefs and practices and others indicate considering major changes in their career patterns, personal priorities and goals for the future. Dealing with this confusion or disorder in one's understanding of life and death and the meaning of life itself can be stressful.

Coping And The Search For Social Support

Parents experience these stresses of childhood cancer in different ways and

measures; moreover they come to this experience with different backgrounds, values and skills. Thus, they cope in a variety of ways. The general literature on coping with stress suggests a wide variety of options, including active and passive styles (Lazarus, 1966) and attempts to reduce the source of stress or to provide a buffer against the effects of stress (Lazarus and Launier, 1981; Pearlin and Schooler, 1978). Some literature emphasizes a transactional approach, suggesting that coping patterns are related to (fit with) and should be seen in the context of the specific nature of the stress experienced (Coyne and Holroyd, 1983). With particular reference to the five categories of stress emanating from childhood cancer, some parents respond by seeking "intellectual mastery;" by gaining information and understanding about the disease and its treatment (Adams, 1979; Friedman, Chodoff, Mason and Hamburg, 1963; Hamovitch, 1964; Lascari and Stehens, 1973; Hamburg and Adams, 1967). Such information may help them cope with their own anxieties, loss of control and sense of shock. Other parents report trying to solve the immediate practical problems with which they are faced, arranging transportation and child care, finding substitutes for themselves at work or becoming alert and active participants in the medical care of their children. Still others, not necessarily excluding those above, respond to interpersonal stress by altering social relationships or seeking help from their family and friends who can be part of a supportive social structure. In the same context, some try to establish personally meaningful relations with health care practitioners, extending themselves to physicians, nurses and social workers, and seeking help and support from them. Many respond to their potential emotional imbalance by attending to their psychological or physical needs, being alert to their eating and sleeping habits, making sure they stay healthy and deliberately trying to maintain control of despair and optimism, realism and fantasy, hope and terror. In this effort some parents seek professional counselling or therapy, availing themselves of social

workers' or psychologists' professional services on an individual or family basis. Still others deal with existential stresses by testing and often reinforcing their religious beliefs, or redefining their purpose in life, marshalling new spiritual or worldly resources to provide meaning to their new roles and situations.

Regardless of the specific stresses involved, and the particular coping styles preferred by any person, almost all of these stresses and coping patterns involve the use of some form of social support. In the first two columns of Figure 2 we list the five major classes of stress and coping tasks involved in childhood cancer. The third and fourth columns in Figure 2 identify some of the forms and agents of social support that may be relevant for each major category of stress and coping task. The research in general indicates that social support can aid in buffering individuals from the full impact of stress, and in helping them recover from the effects of unavoidable stress (Bloom, Ross and Burnell, 1978; DiMatteo and Hays, 1981; Gottlieb, 1981; Hirsch, 1980; Pilisuk and Froland, 1978). However, the process of giving and receiving support is quite complex, and many persons indicate that they do not find what they need when they feel they need it (Sontag, 1979; Wagner, 1981). Moreover, several observers discuss how the stigma of cancer may make it even more difficult for friends and family members to offer effective support (Wortman and Dunkel-Schetter, 1979; Sontag, 1979).

(Figure 2 about here)

One way in which social support is relevant for parents dealing with the stresses

associated with childhood cancer is in providing information. For instance, although several parents indicate that they did not receive enough information from the medical staff, others report how helpful the medical staff is in supporting them intellectually.

What impressed me most was the time they took to answer my dumb, stupid questions. Whatever it might be, they took that time.

On my request, one doctor told a nurse to xerox information from a Pediatric Oncology book for me. The nurse did it and I received great information. That doctor was a help.

On some occasions, non-medical personnel, friends and acquaintances also are able to provide helpful information.

Another family of a child with cancer was over one day and I told them about my son's strange behavior and pains. They said it happened to their child, too, and that it was one of the drugs. Then we knew what to do.

A second kind of social support may be quite specific and responsive to particular instrumental needs or tasks. For instance, parents report that many family members and friends help with key household or caretaking tasks, such as cleaning the house, cooking dinner while they are at the hospital, providing transportation, entertaining siblings, visiting the ill child, filling in for an employed parent, etc.

His side of the family was helpful with the practical things like babysitting,

cleaning the house, taking us out.

Our friends and neighbors brought over food for the kids. Our kids spent the night with neighbors lots of times. The neighbors took them places.

Neighbors would come over and spend the night with our sick child so we could get some sleep.

A third kind of support, sometimes the most important kind, is quite non-specific, and responds to the stresses created by unstable or unresponsive interpersonal relationships. For instance, many parents report being grateful that some people were "just there" and that an interpersonal network existed. This kind of help may be especially difficult to provide, for the well-intentioned giver may feel that he or she is not really "doing much", but it is important nevertheless.

They called and inquired about how he was doing. If we needed their help in any way, we just had to let them know. They didn't want to keep pestering us, but if we needed them all we had to do was to pick up the phone and they'd get it done.

A fourth form of support, also non-specific, appears to be responsive to the problems of maintaining balance and control of emotions. House refers to this kind of support as oriented either toward love and caring, or to empathic feedback and appraisals to people on "how well they are doing" (House, 1981). Family members and close friends, especially, may be able to help parents identify the extent to which they are not "going crazy," are doing well, or are keeping things in

perspective. Parents report such support in the form of reassurance and outlets for a variety of emotions as follows:

They gave me a shoulder to lean on, they cried with me and were very understanding...stayed by my side.

One friend would go out for coffee with me and just talk. Mostly this guy just listened. He was somebody I could talk to and he'd sit and listen. Knowing he was there great.

I did talk to a social worker and you need that to keep a perspective. A lot of times I could get insight this way.

A final form of social support responds to the existential stresses parents report. Often the agents of such support are the clergy, friends or even the ill child.

I had more success with the pastor at the church than I did with any medical professional.

Clergy helped us deal with why God let this happen to our child. But my daughter, before she died, helped us more than any doctor, clergy or reading.

Most of these sources and forms of social support are available in the medical, family and community environment immediately surrounding families of children with cancer. Recently, however, we have seen the emergence of a new way of organizing

social support which has direct relevance for many parents' efforts to cope with these particular stresses. Self-help and mutual support groups can play a unique role in providing forms of social support that are particularly relevant to the stresses and coping patterns reported by parents of children with cancer. We now turn to an examination of these groups' roles and functioning.

The Unique Resources And Activities Of Self-Help Groups

Groups of people in similar situations, or coping with similar stresses, sometimes organize mutual support or self-help groups (Collins and Pancoast, 1976; Gartner and Riessman, 1977; Journal of Applied Behavioral Science, 1976; Katz, 1981; Katz and Bender, 1976; Killilea, 1976; Lieberman and Borman, 1979; Powell, 1975; Tracy and Gussow, 1976). These organized groups develop as an innovative social mechanism to aid people coping with prolonged and serious stresses which affect their own social identity and role or those of other family members.

Self-help groups have been defined in different ways, but most literature focuses upon an identifiable group of people, in a similar 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. The focus on doing for themselves distinguishes self-help groups from other support groups run or guided by professionals. As Horton and Pillemer note, there are many support and service groups which "involve people not suffering from an alterable, pressing personal problem attempting to help those who do suffer from such a problem" (1983, p. 206). In the case of pure self-help groups the people with the problem are the ones helping the people who suffer from the problem. Within this loose definition there still is great variety, but some of the health-related groups which most observers would agree this prototype include: Reach for Recovery, Mended Hearts, Osto-mates, Make Today Count, Living One Day at a

Time, etc.

Some scholars argue that dissatisfaction with the bureaucratic and technologic paradigms and practices of modern medicine alienates consumers and helps generate self-help groups (Back and Taylor, 1976). Indeed, the active posture and the reflexivity of support generated in typical self-help groups may be an antidote or supplement to the non-reciprocal and passive roles forced on patients by most medical and social service professionals (Gartner and Riessman, 1977). Other scholars find no link between such dissatisfaction and active membership in self-help groups, suggesting instead that some people seek self-help groups as an alternate form of social connection and mutual aid, not necessarily as a compensation for negative feelings about current medical practice (Banhoff, 1979; Lieberman, 1979; Tracy and Gussow, 1976).

There is relatively little available research on self-help groups for families of ill children, and even less on children with cancer. The self-help anthologies referred to earlier discuss only one group related to these concerns, and that group serves parents of children who have died from a variety of causes (Society of Compassionate Friends). Informal reports indicate that self-help groups have been organized at many children's cancer centers. In fact, The Candlelighters Foundation, a national clearinghouse of self-help groups of families of children with cancer, estimates over 200 such groups currently in existence. In the absence of detailed reports or direct observation it is hard to know much about the nature of these local groups, and to distinguish among various kinds of self-help groups and professionally-led discussion groups, support groups, group therapy sessions, and so on. However, Stolberg and Cunningham (1980) do establish several important realities: eighteen of the 21 children's cancer centers responding to their inquiry reported some kind of parent support group, most initiated and staffed by professional social service workers.

Several other discussions of groups for families of children with cancer focus on groups organized by medical or social service professionals (Adams, 1979; Bell-Isle and Conradt, 1979; Heffron, 1975; Kartha and Ertel, 1976; Knapp and Hansen, 1973; Martinson and Jorgens, 1976; Ross, 1979; Sachs, 1980). The dominance of professionally-led groups in the literature is explained partly by the professional authorship and readership of these articles and journals. Many other groups of families of children with cancer exist that are not initiated or led by professionals. There probably are key differences between groups organized and led by parents themselves (not necessarily without professionals, but not as dependent upon them) and those organized by professionals, but as yet little systematic research is available on this point. The groups we examined include some that are very much run by parents themselves (pure self-help), some very much run or guided by professionals (pure support) and many with a mixture of professional or parental leadership and control. Unless otherwise noted, for the purposes of this chapter, we refer to all of these groups as engaged in self-help activities.

What do parent self-help groups do?

The literature and our own study of self-help groups of families of children with cancer (Chesler & Yoak, 1983) suggest that there are several different kinds of group foci, and thus different kinds of help parents provide to and receive from one another. Five different kinds of activities seem to be most popular: each of these forms of social support appears to respond to different stresses and coping strategies.

One focus of activity, and one kind of group, is educational or informational in nature, helping to inform parents about the disease and its side-effects, potential child-rearing and discipline issues and the specific nature of the hospital and hospital staff (Adams, 1978; Belle-Isle and Conradt, 1979; Gilder, Buschman, Sitarz and Wolff, 1976; Heffron, 1975; Kartha and Ertel, 1976; Martinson, 1976). For instance, as

several parents note:

Other people are going to be experiencing processes that us "advanced parents" have gone through. The whole concept is to prepare them, to get them to ask questions and learn more about the disease and treatment and understand it better.

It's a good idea for families to get together and to answer questions. The doctor helped, but I still had a lot of questions. Talking to another parent of an amputee helped.

Informational and educational activities are the most common group focus and appear to be undertaken by almost all groups at some time during their history. In some cases, parents educate each other about these matters; in other cases an outside speaker/expert addresses the group. The invitation of local physicians to speak to the group often represents a particularly attractive option, one that may help recruit previously inactive parents. Moreover, such an invitation may help link the treatment center and medical staff more tightly with a larger group of parents. Some self-help groups publish regular newsletters with medical information and others produce handbooks oriented to parents of newly diagnosed or newly hospitalized children.

A second major focus of some groups is instrumental aid to parents. By helping to solve problems of transportation and child care, for instance, self-help groups provide some of the same material assistance offered by friends and family members. Personpower is the most readily available resource for such services, but many groups also become involved in raising funds to support their activities. Some raise small amounts of money, in casual ways, mostly to support their own newsletters and social

events. Other groups 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 undertake major fundraising efforts in order to aid families transporting children to specialty treatment centers, to subsidize or construct low-cost lodging near the treatment center or to support research at the medical center.

Another form of instrumental support is reflected in those group activities which try to make changes in the operation of the staff or treatment center (Gilder, Buschman, Sitarz and Wolff, 1976). For instance, some groups try to solve problems in the local delivery of health services by suggesting or demanding modification in the policies or staffing structure of clinics and wards, providing feedback to the medical system on services to families, helping the hospital improve its services, funding special medical programs or holding certain services accountable to consumer scrutiny. Groups embarking on this agenda usually work in close collaboration with health care professionals, but on occasion they advocate changes despite professional resistance. In most instances of this sort (but by no means in all), both professionals and parents report that they eventually experience satisfaction with the collaboration such advocacy generates and with the outcomes of changed procedures.

A third major focus of group activity is interpersonal networks, friendship and social relations. 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 (Belle-Isle and Conrardt, 1979; Martinson, 1976). Staying at a "light" level, people may ask for help if they wish but also concentrate on keeping in touch and in having a good time with one another. Groups of this sort may provide a more subtle kind of support as well; parents may serve as referents for one another, as points of

comparison for defining or understanding appropriate behavior in a new situation (Powell, 1975; Silverman, 1976). According to one parent, for instance:

It helps to talk to people. Knowing that other people have gone through it, helps. Sometimes I think I felt isolated, like this was only happening to me.

And another parent indicates the way in which a newsletter may act as an interpersonal linkage to others as well as a source of medical information:

The newsletter is a great form of communication for people going through what I did, especially for some families who are from out of town and don't have friends nearby to help.

Sharing feelings and emotional support with other parents is a fourth major 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 their personal emotional responses to childhood cancer. The problems may cover quite a range: dealing with spouse's and family members' feelings, preparing for death, fighting depression, coping with diagnosis and/or relapse, understanding the medical staff, getting ready to come off treatment, being afraid, "bringing up" an ill child, dealing with siblings, and so on. (Adams, 1979; Belle-Isle and Conradt, 1979; Gilder, Buschman, Sitarz and Wolff, 1976; Heffron, 1975; Kartha and Ertel, 1976). The topics of these meetings may be quite similar to the information/education sessions, but the purpose and style is quite different: here the goal is for parents to share their experiences and feelings with one another. As several parents note:

I went to the 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.

It would be helpful to have someone who has been through this at the very beginning. 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 that way.

The two-way street of giving/receiving help to/from parents of children with cancer is a vital part of self-help groups. For instance, Leiken and Hassakis (1973) explain this aspect of self-help groups in terms of their report that "the most frequently used helpful coping mechanism was the 'doing defense' (p.55)." One example of this mechanism involves people helping other children and parents with similar problems; Riessman and his colleagues (Dory & Riessman, 1982; Gartner & Riessman, 1977; Riessman, 1965) refer to this as the "helper-therapy principle." As one parent notes:

The leukemia group which I am working with gives me something positive to do. I feel I am helping someone down the road, and changing things in a positive constructive manner.

Other authors have indicated the ways in which helping others may enable people to work through some of their own difficulties (Silverman, 1976) or to announce and act on the assumption that they are "doing okay" and have extra energy and resources to share with others. In some cases, parents provide such active emotional support to one another directly; in other cases a social worker, nurse or other staff member

facilitates these discussions and promotes openness and sharing among group members.

A fifth focus of some groups is the existential challenge referred to earlier. Although this is seldom the major activity of any group, it is an activity that arises, some time or another, within most groups. In this context, parents share their understanding of the role their struggle with childhood cancer plays in their lives. For some, especially for parents of terminally ill or deceased children, exploration centers around the meaning of life after death, and testaments to their own spiritual faith and commitment. For others, discussion focuses on their secular philosophy and the way it has changed as a result of their experiences. As parents see how others have incorporated the meaning of these events into their own lives, they may be aided to discover more effective answers for themselves.

Each of these major foci of activities may be appropriate, in greater or lesser fashion, for parents who cope in various ways or whose children are at different stages of the illness/treatment cycle. For instance, parents who are trying to cope with intellectual stress by seeking a great deal of information may find information sessions and activities most appropriate. Others, who have difficulty managing the many practical and instrumental tasks associated with the treatment of childhood cancer may want help or advice on how others have dealt with these matters. For some, in dire financial straits, the benefits provided by fund-raising activities may be most important. Parents who wish to share, express and reflect upon their feelings may be most desirous of groups and activities that promote emotional sharing and intimate engagement. Parents who wish to know and meet others "in the same boat" may be most interested in a group that talks easily and comfortably with one another, or "plays," has picnics and potlucks together. 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 to these families, parents may generate a group, or participate in one, designed to "fill the gaps" in available care. By the same token, the availability of certain community services (American Cancer Society support, Ronald McDonald Houses, The Society of Compassionate Friends) make some activities more or less important for parents who already have access to such resources.

Although many groups undertake several of these different activities, most emphasize one or two in particular. Thus, different groups appeal most to parents who want or need these particular activities. Parents are not likely to become active in groups where a match does not occur between their own stresses, coping styles or needs for support and the major activities of the group. Aside from this self-selection, a more subtle process of socialization may occur, whereby parents who enter a group for one purpose may become "bonded" to other members and alter their needs or coping styles in order to fit with the dominant activity patterns in the group. In this manner, parents who enter seeking information may become comfortable and active in a group emphasizing feelings, and parents originally not committed to fund-raising may engage in such activities when the group with close friends and comrades in it decides to move in this direction. In addition, some parents who want to participate in a group currently not oriented to their needs and styles may exert influence on other members to change the current focus of the group. The potential interaction or "fit" between the activities of self-help groups and parents' major stresses, coping patterns and social support mechanisms in dealing with childhood cancer are illustrated in the last column of Figure 2.

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 and share information, some of which meet (every two weeks or so) to

share feelings or emotional problems and some of which meet (once or twice a year) to socialize and have a holiday party, summer picnic or child-centered activity. At a more formal level, some groups have developed parallel structures, separating incorporated fund-raising activities from sub-groups where they share information and discuss feelings. And some groups have leadership struggles among the persons or sub-groups committed to different activities and activity priorities. As a result of such struggles, some people and activities may dominate the life of the group and other people may leave or become inactive.

Are self-help groups for all parents of children with cancer?

Despite the range of social support found in self-help groups, and their relevance for different coping styles, not all parents search for such support nor find it useful and helpful to them. Thus, self-help groups are not "for everyone," and people decide to become active or non-active through various patterns of self-selection and socialization. One reason parents may elect not to participate in a self-help group is simply time and energy. Coping with stresses of childhood cancer, particularly at certain stages (e.g., diagnosis, relapse, terminal), may be too time consuming to allow for time spent meeting with others; the priority might be to be with one's child as much as possible. While interpersonal support may still be sought, regular meetings and a participative role in an organized group may be a low priority. In addition, families living a substantial distance from the self-help group's meeting place may find it difficult or costly to travel to attend meetings. Parents who cannot be available during regular meeting times also may select themselves out.

In addition to these time and energy considerations, some parents find that their own preferred personal style of coping is not compatible with any of the various activities or forms of social support available in self-help groups. For instance, two parents quoted below note their unwillingness to "go public with strangers" or to talk

with others about these issues. Another indicates her general unwillingness to take the risks of thinking about and talking about (or hearing others talk about) painful issues.

I've never been a "go to meeting person", so I never went. I do like to run my mouth, but not in groups, especially with people I don't know.

Personally I don't feel the need to get together with other people in the same boat and get reassurance. I'm a loner.

It would bring back things that I'd really rather not even try to remember.

A common issue faced by many groups is whether or not parents of deceased children with cancer should be encouraged to be or remain an active part of the same group as parents of living children. 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 might be sadder and lonelier if these ties were cut; parents of deceased children have organizational skills and energy groups need; 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: new parents, 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. Of course, no one but each parent of a deceased child, or of a living child, knows the answers to these personal dilemmas of whether they should or shouldn't be involved, and whether or not they can benefit.

Roles Of Professionals In/With Self-Help Groups

One of the key issues affecting self-help groups is their relationship with the medical system and with health care professionals. We have already indicated various observers' views of how consumers' orientations toward the modern health care bureaucracy may affect self-help group activity. In addition, other scholars have discussed the perils and potentials of collaboration with professionals (Gartner and Riessman, 1977; Klienman, Mantel and Alexander, 1976). It is clear that the needs and orientations of parents are not the only important variables in understanding groups' relationships with medical systems. Tracy and Gussow (1976) indicate the importance of professionals' attitudes as well, noting that many physicians worry about self-help groups sharing misinformation or superstitions, pressuring group members unwisely, raising patients' expectations, or just plain intruding into the carefully controlled physician-patient relationship. For instance, with particular regard to support groups for parents of children with cancer, Belle-Isle and Conrath warn that (1979, p.49):

The danger of parents inappropriately sharing their concerns and unwittingly increasing each other's emotional burdens is a constant threat. With professional guidance this danger should be significantly less as staff participants are present to correct misinformation and control inappropriate exchanges.

Almost the same language is used by Binger, Ablin, Feuerstein, Kushner, Zoger and Mikkelson (1969) and Kartha and Ertel (1976). Although many of the professionals we interviewed expressed similar concerns, few of them (and very few parents) actually had seen or experienced such dangers in organized groups, whether those groups were led by parents or by professionals. Moreover, several reports indicate that many staff members recognize and support the value of even relatively autonomous (from professionals) self-help groups. Thus, the issues go beyond a simplistic dichotomization of conflict v. collaboration or trust v. non-trust, and require a better understanding of how such groups "work out an articulation with institutionalized medicine" (Tracy & Gussow, 1976, p. 396).

It seems obvious that professionals' attitudes and their resulting actions make a difference for the future of local self-help groups. Depending upon their attitudes and prior experiences, professionals can engage in actions that provide or fail to provide important resources to self-help groups. Some of these important resources are quite tangible (access to members, meeting rooms), while others are relatively intangible (reputation, credibility); all may affect a group's ability to recruit members, provide resources, have impact in the hospital or community and otherwise sustain operations. For instance, physicians cannot literally keep parents who want to get together from getting together, but they can make it easier or more difficult for them to find and rely upon one another. Medical staff members, especially nurses and 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 recriminations to their child. In addition, staff members' status and authority in the medical system provides them with control over key resources essential for self-help groups. How they use their power and make these

resources available determines how they can help families respond to stress, meet coping tasks and otherwise gain the social support they require. While these stresses, coping tasks and social support mechanisms may differ for each family, and indeed for each family member, certain classes of resources are especially relevant for the operations of family self-help groups.

One set of resources to which medical staff members have special access is informational or intellectual in character. These resources are particularly relevant for families responding to the intellectual stresses of childhood cancer and for self-help groups trying to develop educational/informational activities. Nurses and physicians, especially, have technical information about cancer and its treatment and linkages to materials and/or libraries where such materials are stored. In the attempt to provide this information in ways lay people can understand more easily, professionals have written articles for group newsletters and presented lectures, discussions and panels at meetings. In addition to information about the disease and its treatment, professionals (perhaps especially psychologists and social workers) have special expertise in family coping mechanisms and have shared information in personal or written form about the coping tasks families may face and the ways they have resolved these tasks. Finally, a key aspect of information shared by professionals is their special knowledge about the staff and operations of the local treatment facility. Social workers also often have information about financial and social services that may be available in the community and/or school system. Groups trying to help members get services, or trying to improve service availability, need such information.

A second set of resources the professional staff has may be particularly relevant to assisting in meeting some of the practical or instrumental needs of parents and the related activities of self-help groups. The problem of identifying one's own

needs, either ahead of time or as they are occurring, is a serious issue for many families. Professionals have been helpful in identifying these needs and in providing special programs training group members to aid each other. The staff also may have access to financial support for the family or to agencies and services that may be able to provide such support. In some cases, where self-help groups have raised funds to support wigs, prostheses, and incidental expenses for families, the professional staff has been involved in helping to identify needy families and distribute these funds. Groups that anticipate raising large amounts of money often must have collaboration from the medical staff to legitimize their effort, gain tax-exemption and help tap major local sources of funds. In some facilities, the professional staff also has helped establish good working relations between parent groups and local educational agencies, especially for parents of school-aged children with cancer. In a number of cases medical staff members even have aided self-help groups' efforts to conduct in-service training sessions or conferences for school staffs. Thus, the staff's links to other resources in the hospital and the community can make additional sets of resources available to local groups.

Professionals also often have the resources to help groups deal with some of their own practical problems in gaining recognition, running good meetings and keeping their records in order. For instance, if some parents are fearful or cautious about joining a group of "non-experts", expert professionals may be helpful in allaying their fears and ensuring them that the self-help group is a credible and valuable source of support. The establishment of an effective and vigorous referral system by which parents of newly diagnosed children are acquainted with and placed into contact with self-help group members is another example of practical help provided by professionals. Some groups, especially those led by parents who do not have skills in organizational leadership, have found social workers' skills in group processes very

helpful in their own search for sound electoral procedures, effective ways to run meetings, successful efforts to gain tax exemption, and so on.

The professional staff generally has resources available to help deal with the interpersonal stresses family members face and related programs the self-help group generates. Staff access to hospital or clinic records enables them to put parents who can help each other in touch with one another. This is an especially useful function when the group wants to establish a one-to-one visitation program among parents who have faced similar problems (by age of child, diagnosis, treatment). By encouraging parents to attend self-help group meetings, and thus making them accessible to other parents' resources, professionals strengthen the person, the family and the self-help group simultaneously. Parents who have not clarified their interpersonal needs, or who have not thought seriously about the stigma and problems of "going public", may need such encouragement. The staff's resources for aiding parents to deal with their emotional stress also has taken the form of group therapy or counselling sessions, either within the formal apparatus of the self-help group or at special meetings designed explicitly for this purpose. Some professionals have encouraged self-help groups to provide such counselling as part of their meetings and activities. In these instances professionals also have provided parent group members with special training in counselling and responding to others' emotional needs.

Finally, professional staff members may have resources that help parents deal with the existential stresses associated with childhood cancer. Their contacts with clergypeople, and with physicians who can identify causes of cancer, have helped groups develop programs that offer new perspectives on questions of fate and the meaning of illness. To the extent that all group members can share their experiences on this dimension, parents may be able to see their unique dilemmas in broader perspective. As a result they may be able to overcome feelings of isolation and feel

part of a larger community of people suffering or struggling with chronic and serious illness.

The role dilemmas of pediatric/oncology staff members.

In most cases where a health care professional takes a lead role in developing or working with a parent self-help group that person is the staff social worker. In some cases it is a nurse or clinical nurse practitioner. Whichever staff member provides this linkage, it is a role fraught with tension and difficulty, and interviews with these staff members highlight several issues worthy of attention. Adequate understanding of these issues, by parents as well as other staff members, might facilitate the process of collaboration.

Some observers emphasize a complementarity of interests between self-help groups and the medical professionals who work with them (Lenrow & Burch, 1981; Lieberman & Borman, 1979). These researchers document consumers' positive views of health care systems, professionals' positive outlook on self-help groups and the ways in which providers and consumers can collaborate harmoniously. For instance, Lenrow & Burch argue that collaborative relations can be developed when both professional helpers and their clients understand they each have "equally important resources to contribute to their common task (1981, p. 234)". Of course, disagreement about evaluations of "equally important resources" and about "their common task" may lead to conflict. When Klienman, Mantel and Alexander (1976) examines these issues in the context of a case study of a particular self-help group and a particular agency, they not only conclude that conflicts exist, but that the differences in power and values between professionals and self-help volunteers are irreconcilable. If, as some scholars argue, we anticipate that self-help groups are composed of persons dissatisfied with modern medical care, or who consider traditional services a failure, conflict between parents and professionals should be the

norm (Katz, 1981). If the following differences and ensuing conflicts are understood and dealt with by all parties, the results may be quite positive. If such differences and conflicts are denied or ignored, everyone involved may miss the opportunity (and challenge) to work through important issues with honesty and clarity.

Some of the dilemmas staff members face in working with parent self-help groups are rooted in basic differences in their role definitions and experiences (Reinharz, 1982). Staff members, of course, are not defined as parents of children with cancer. They often are locked into the role of "givers of help" while parents are fixed in the reciprocal role of "receivers of help." Moreover, staff members' knowledge is based in technical training and experience that is quite different from that of parents. Whereas parents' knowledge is likely to be experiential and individually unique, staff members' knowledge is more likely to be academic-abstract and universal - made to fit a wider range of individual cases. The staff member is primarily accountable to other staff members, perhaps to an institutional hierarchy; parents are accountable to themselves and their children. The role of family relations differs as well: the staff member's family generally provides a respite from issues of childhood cancer; for the parent of an ill child the family is one more setting in which children's cancer is a preeminent factor. In reverse fashion, a parent's job role usually is removed from the hospital and direct contact with childhood cancer; the staff member's job role focuses directly on these issues.

The nature of these differences establishes some operating dilemmas for staff members. First, their role often is unclear - to themselves, their employers and self-help groups. Are they supposed to consider themselves part of the group or not? Are they insiders or outsiders? Are they regular members or people with a special role? In actual practice, when self-help group members share their feelings, should social workers and nurses share theirs as well? If professionals work with some self-

help group members in an individual "therapy" situation, how do they relate to these same people in the group context? How can they help link particular parents with one another for mutual support without violating professional norms of confidentiality?

Second, their unclear role often is made even more confusing by ambivalent support from the medical staff. In some treatment centers the social worker's or clinical nurse's portfolio is not at all clear. Physicians may expect them primarily to control misbehaving patients and to process insurance forms. Any other activities they may engage in may be seen as their own innovation - therefore not part of their formal role obligations. They even may be sanctioned for being "deviant" and for spending after-hours time with parent groups. Even more subtly, if they do elect to work with self-help groups, these linkers may be held responsible by the rest of the staff for what the group decides to do. If the group does things the staff feels good about, all well and good. But if the self-help group starts to do things the staff would prefer they not do, this worker may be the person called upon to account for such behavior and/or to control it.

Third, the staff member who works closely with a parent group often has to act as a translator or "cross-cultural" agent of communication. This calls for fluency in the different languages of lay people and the medical staff. Beyond formal linguistic issues, the professional may feel compelled to defend and express loyalty to the medical staff in front of parents. In those circumstances where groups challenge the health care organization, close relations between professionals and group members may blunt the challenge, for better or worse. On the other hand, some professionals may find themselves defending parent activism to the medical staff. Several observers have indicated circumstances under which professionals working with parents and parent groups communicate to other staff members regarding parents' needs, just as they educate parent groups to the workings of the medical staff (McCollum and

Schwartz, 1972; Ross, 1980; Stuetzer, 1980). There is much less discussion of the ways in which professionals may mediate actual conflicts between parent groups and the medical staff (Chesler and Barbarin, 1983). Any of these roles as advocate, mutual educator or mediator may stretch the loyalty and identification of the professional as servant of client/parent needs and as employee/agent of the medical facility and staff. These issues are made more poignant by the reality that professionals working most directly with parent self-help groups generally occupy the lowest status roles within the medical staff. As such, they often are marginally tolerated or rewarded, often operate without significant power in staff meetings and constantly are buffeted by the medical staff's crises.

Fourth, we indicated previously that some health care professionals are concerned about the ways in which autonomous parent groups may present a danger, "inappropriately sharing their concerns" and "increasing each other's emotional burdens." It is impossible to assess the degree of real danger involved here, but it is clear (from our own interviews and from the literature) that some medical staff members worry about such outcomes. . .and worry about it more than do parents active in groups. Professionals' training and orientation may lead them to assume greater dangers than may actually exist, and these assumptions may be heightened when there is unclarity or disagreement regarding the goals or activities of self-help groups - therapy, emotional counselling, interpersonal support or social sharing. In fact, some staff members may become confused or threatened by group activities in which parents are providing emotional support and help to one another. Such parents may appear to be invading social workers' turf and providing "service" that professionals have been especially trained to perform. On the other hand, some professionals worry that parents will avoid the real issues and not do the "hard work" of dealing with the impacts of childhood cancer. Staff members who feel they know

what parents need may be caught in a particular bind if parents appear to need and want something else. Thus, professionals working with such groups may find their own assumptions presenting them with dilemmas of trust and concern about letting a group meet without their protective presence. Even more importantly, professional protectionism may express itself in other subtle ways: warnings against certain activities, refusal to permit some activities without professional supervision, cautious referrals of newly diagnosed parents to groups professionals cannot guide or control and general tension about advisable degrees of group autonomy and independence.

In a similar vein, professionals who feel they know which parents do/do not "need" or are/are not "ready for" a self-help group may face difficult decisions. Should they exercise this knowledge or intuition and only refer those parents who appear needy and ready to the group? Or should they refer and encourage all parents to the self-help group, trusting the parents and the group to discover who needs what and is ready for what? If everyone is referred, what do staff members do about a parent they think is not being served well by the group? Where does freedom of information, clients' rights to choose, consumers' needs to organize and professionals' responsibility for services, formal and informal, start and stop?

Fifth, staff members who care about these issues may find it difficult not to take an active leadership role in the group, despite values to the contrary. After all, staff members who have a high commitment to good psychosocial care can provide some of that care in the self-help group setting. The professional is likely to be a central person in the network, one who knows most of the parents and is known by most of them; most parents in a group that is just starting do not know many other parents. Since the staff members have access to so many of the other useful resources in the medical system (materials, mailing lists, extra funds, legitimacy, rooms) even when they do not want to exercise task leadership they may be trapped

into this role. In addition, parents' uncertainty about their own skills or their unwillingness to commit enough time may foster group dependence on available and committed professionals.

In the midst of a caring group, staff members occasionally may feel uncared for. Caring for others and reaching out to share skills with others, staff members may feel "left out" if parents do not express affection and appreciation in return (remembrance of birthdays, weddings and other events are examples). Of course, staff members are trained to be cautious and a bit distant, and to avoid such emotional dependency upon their clients. But caring is a very human feeling, and to not acknowledge and deal with these feelings ignores the human side of professional work. The natural reciprocity of caring in human relations is made most difficult by strict adherence to roles that distinguish between "givers" and "receivers" of help. Separated from parents by these role definitions, often lacking in support from peers and supervisors within the medical staff, staff members' roles may be very lonely. When and how can they ask parents for mutuality or reciprocity in caring? And if this is difficult or impossible to do, how do these staff members avoid emotional isolation and "burnout" (Freudenberger, 1974; Klagsbrun, 1970; Maslach, 1976; Rothenberg, 1967; Vachon, 1978)? Most discussions of the coping strategies health care professionals utilize to prevent or reduce burnout focus on support from family, friends and colleagues. Unfortunately, little attention has been given to the support professionals may receive from their clients or patients, especially when they have been active together in a long-term support group. In some groups, parents recognize these dilemmas facing the professionals with whom they work closely, perhaps because staff members share or deliberately educate parents about them. Under these circumstances parents and professionals may develop a collaborative pattern in which they support and "take care of" each other - and thus improve the quality of work

and life for everyone involved in providing health care to children.

Conclusion

Self-help groups formed by and for families of children with cancer combine aspects of small voluntary organizations and of support systems for people undergoing chronic and severe stress. As such their organizational principles are embedded in the nature of parents' stressful situations and the coping strategies they utilize to gain social support relevant to dealing with those stresses. In addition, these organizations are grounded in the group dynamics typically generated by people utilizing social support networks as a way of accomplishing personal and group tasks (Smith and Pillemer, 1983; Toch, 1965).

The experience of childhood cancer visits long-term stress on parents and family members. For some of those family members, those who elect to seek social support, self-help groups can be a useful and growth-producing aid. In these groups parents may find others who help them deal with the intellectual, instrumental, interpersonal, emotional and existential stresses associated with their situation. Not all people desire to be part of, nor benefit from, parent self-help groups. Those that elect to be active appear to have a coping strategy that seeks and uses help from others, especially others in like situation. Moreover, they often express a commitment to contribute to others' welfare, perhaps even to alter the environments in which they find themselves.

Professionals working with such groups often must wrestle with problems of leadership and control. Some observers argue that support groups always should be run or guided by professional staff members, thus preventing inappropriate sharing or burdens on parents who already are vulnerable. Other observers suggest that parent

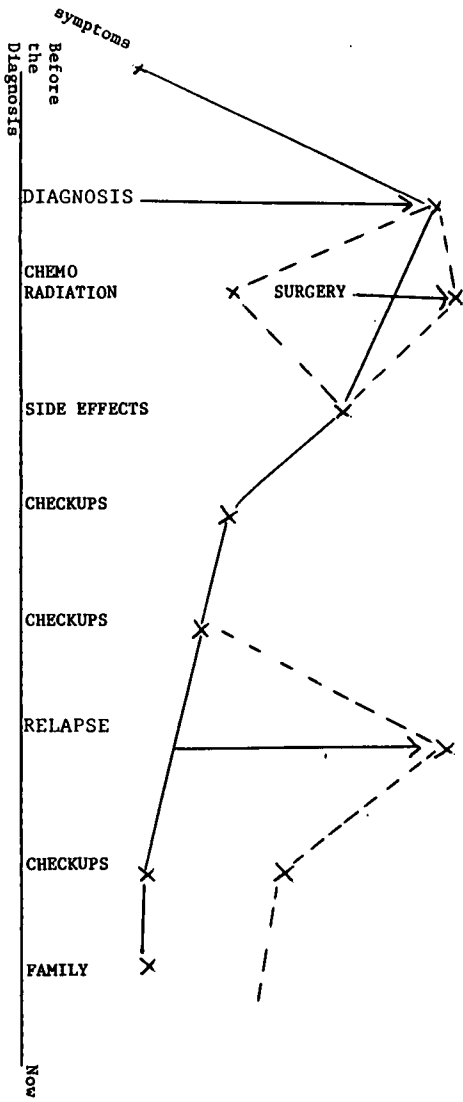
groups should be relatively autonomous from professional direction, the better to provide parents with a feeling they can "do" on their own, even in the midst of crisis. A series of professional role dilemmas center on questions of proper role, degree of openness, institutional loyalty and ideological assumptions about the helping process. If parents and professionals can share and work through these dilemmas together they may be able to create exciting new partnerships in the psychosocial care of ill children and their families.

Footnotes

1. Chesler, Barbarin, Chesler, Hughes and Lebo (1981) conducted interviews with 94 parents of children with cancer treated at a major midwestern hospital, expressly focusing on their reports of stressful experiences, coping strategies and social support systems (including participation in a local self-help group). Chesler & Yoak (1983) conducted interviews with parents and professionals active in a nationwide sample of 30 self-help or support groups of families of children with cancer. We appreciate the contributions of our colleague, Oscar Barbarin, in these studies and especially in developing the ideas underlying Figure 2. We also are grateful to the Rackham Graduate School for a Faculty Research Grant that has financially supported part of this work.

HERE IS A CHART, A TIMELINE, THAT CAN BE USED TO DESCRIBE THE TIME THAT HAS ELAPSED FROM BEFORE YOU LEARNED THE DIAGNOSIS UNTIL NOW.

1. MARK ON THIS LINE THE CRITICAL EVENTS OR STAGES IN YOUR EXPERIENCE WITH YOUR CHILD'S CANCER. INDICATE THE APPROXIMATE DATE OF EACH.



COMPOSITE STRESS CHART OF PARENTS OF LIVING CHILDREN

Figure 1

2. WHICH OF THESE EVENTS OR STAGES WERE MOST STRESSFUL? DRAW AN ARROW FOR EACH EVENT, INDICATING WITH A HIGH LINE THE HIGHEST STRESS TIMES OR EVENTS, AND WITH A LOW LINE THE LOWER STRESS TIMES OR EVENTS.

Figure 2

Stresses, Coping Tasks, Social Support And Self-Help Group Activities
For Parents Of Children With Cancer

<u>Categories of Stress</u>	<u>Relevant Coping Tasks/Strategies</u>	<u>Forms of Social Support</u>	<u>Agents of Social Support</u>	<u>Self-help Group Activities</u>
Intellectual	Getting information about cancer and treatment procedures Interpreting medical jargon Protecting against information overload Getting information about the hospital	Information Ideas Books, newsletters	Medical staff Social service staff Scientists	Lectures by staff Handbooks Library of articles Newsletters Information sharing by parents
Instrumental	Getting help at home (childcare, chores) Getting help at work Negotiating with hospital Making financial plans Solving other problems Caring for the sick child	Problem-solving activities Practical assistance at home or work Financial aid Transportation Negotiations with the hospital	Social service staff Family members Friends Neighbors and co-workers Institutional representatives	Funds for wigs, prostheses, parking Transportation Parent lodging (R. McDonald house or other) Efforts to improve local medical care Fund-raising for research or added services
Interpersonal	Maintaining relationships with family members and friends Creating new social roles Talking, sharing with others Relating to the medical staff Informing others (and avoiding stigma)	Affection Listening Caring Being there	Family members Close friends Medical and social service staff	Reference group processes Meeting new people Having someone to talk with
Emotional	Getting counselling Finding love and affirmation Dealing with hope/anger/fear/despair Stabilizing self Monitoring somatic reactions Feeling efficacious in providing care	Affirmation Counselling Clarifying feelings	Close friends Spouse Social service staff	Professional counselling Peer counselling Sharing intimate feelings
Existential	Seeking meaning and explanations for the illness Creating new social identity Relating to God and Fate Re-ordering life plan/dreams	Reflection on God and Fate Creating a community	Clergypeople Philosophers	Talking about religious beliefs Sharing the struggle

References

- Adams, D. Childhood Malignancy: The Psychosocial Care of the Child and His Family. Springfield: C.C. Thomas, 1979.
- Adams, M. "Helping the parents of children with malignancy." The Journal of Pediatrics, 1978, 93 (5), 734-738.
- American Cancer Society. Cancer Facts and Figures, New York, American Cancer Society, 1982.
- Back, K. and R. Taylor. Self-help groups: tool or symbol. Journal of Applied Behavioral Sciences, 1976, 12 (3), 295-309.
- Banhoff, E. "Widow groups as an alternative to informal social support." In Lieberman & Borman (Eds.) Self-help Groups for Coping With Crises. San Francisco, Jossey-Bass, 1979.
- Barbarin, O. and M. Chesler. "The school experience of children with cancer: news of parents, educators, adolescents and physicians." Ann Arbor, Michigan. Center for Research on Social Organization. Working Paper #283. 1982
- Belle-Isle, J. and B. Conradt. "Report of a discussion group for parents of children with leukemia." Maternal-child Nursing Journal, 1979, 8, (1), 49-58.
- Binger, C., A. Ablin, R. Feuerstein, J. Kushner, S. Zoger and C. Mikelsen. "Childhood Leukemia: Emotional Impact on Patient and Family." New England Journal of Medicine. 1969, 280, 414-418.

- Bloom, J., R. Ross and G. Burnell. "The effect of social support on patient adjustment after breast surgery." Patient Counselling and Health Education 1978, 1, (2), 50-59.
- Cassileth, B. and J. Hamilton. "The Family with Cancer." In B. Cassileth (Ed.), The Cancer Patient: Social and Medical Aspects of Care. Philadelphia: Lea and Febiger, 1979.
- Chesler, M. and O. Barbarin. "Problems between the medical staff and parents of children with cancer." Health and Social Work, 1983. (In press).
- Chesler, M., O. Barbarin, J. Chesler, D. Hughes, & J. Lebo-Stein. "Role of informal networks and medical care organizations in helping families cope with childhood cancer." Ann Arbor, Michigan. Center for Research on Social Organization Working Paper #243. August, 1981.
- Chesler, M. and M. Yoak. "The organization of self-help groups for families of children with cancer." Ann Arbor, Michigan. Center for Research on Social Organization. Working Paper #285, 1983.
- Collins, A., and D. Pancoast. Natural Helping Networks. Washington, D.C. National Association of Social Workers, 1976.
- Coping with Cancer. Bethesda, Md., U.S. Department of Health and Human Services (National Cancer Institute), 1980.
- Coyne, J. and K. Holroyd. "Stress, coping and illness: A transactional perspective." In T. Millon, C. Green and R. Meagher (Eds.) Handbook of Health Care and Clinical Psychology. New York, Plenum, 1983.

- D'Angio, G. "Late sequelae after cure of childhood cancer." Hospital Practice 1980, 109-121.
- DiMatteo, R., and R. Hays. "Social support and serious illness." In B. Gottlieb (Ed.), Social Networks and Social Support. Beverly Hills, Sage, 1981.
- Dohrenwend, B. "Social class and stressful events." In E. Hare and J. Wing (Eds.), Psychiatric Epidemiology, New York, Oxford University Press, 1970.
- Dory, F., and F. Riessman. "Training professionals in organizing self-help groups." Citizen Participation, 1982, 3 (3), 27-28.
- Freudenberger, H. "Staff burn-out." Journal of Social Issues, 1974 30, 159-165.
- Friedman, S., P. Chodoff, J. Mason and D. Hamburg. "Behavioral observations on parents anticipating the death of a child." Pediatrics, 1963, 32 (4), 610-625.
- Futterman, E. and I. Hoffman. "Crisis and adaptation in the families of fatally ill children." In J. Anthony and C. Koupernick (Eds.) The Child in his Family: The Impact of Death and Disease. Vol. 2. New York: Wiley, 1973.
- Gartner, A. and F. Riessman. Self-help in the Human Services. 1977, San Francisco: Jossey-Bass.
- Gilder, R., P. Buschman, A. Sitarz and J. Wolff. "Group therapy for parents of children with leukemia." American Journal of Psychotherapy,

- 1976, 30, 276-287.
- Goffman, E. Stigma: Notes on the Management of Spoiled Identity. London, Penguin Books, 1968.
- Gogan, J., G. Koocher, D. Foster and J. O'Malley. "Impact of childhood cancer on siblings." Health & Social Work 1977, 2, 41-57.
- Gottlieb, B. (Ed.) Social Networks and Social Support. 1981. Beverly Hills: Sage.
- Hamburg, D. and J. Adams. "A perspective on coping behavior: seeking and utilizing information in major transitions." Archives of General Psychiatry 1967, 17, 277-284.
- Hamovitch, M. The Parent & The Fatally Ill Child. City of Hope Medical Center. Durante, Calif., 1964.
- Heffron, W. "Group therapy sessions as part of treatment of children with cancer." In C. Pockedly (Ed) Clinical Management of Cancer in Children Acton, Mass.: Science Gp Inc., 1975.
- Hirsch, B. "Natural support systems and coping with major life changes." American Journal of Community Psychology, 1980, 8, 159-172.
- House, J. Work, Stress and Social Support. Reading, Mass., Addison-Wesley, 1981.
- Hymovich, D. "Parents of sick children: their needs and tasks." Pediatric Clinics of North America, 1976, 23, 225-232.

- Journal of Applied Behavioral Sciences 1976, 12(3).
- Kaplan, D., A. Smith, R. Grobstein, and S. Fishman. "Family mediation of stress". Social Work, 1973, 18 (4), 60-69.
- Kartha, M. and I. Ertel. "Short-term group therapy for mothers of leukemic children". Clinical Pediatrics, 1976, 15, 803-806.
- Katz, A. "Self-help and mutual aid: an emerging social movement?" Annual Review of Sociology, 1981, 7, 129-155.
- Katz, A., and E. Bender. "Self-help groups in Western society: history and prospects." Journal of Applied Behavioral Sciences. 1976, 12 (3), 265-282.
- Katz, E. "Illness impact and social reintegration." In J. Kellerman (Ed.) Psychological Aspects of Childhood Cancer. Springfield, C. Thomas, 1980.
- Killilea, M. "Mutual help organizations: interpretations in the literature." In G. Caplan and M. Killilea (Eds.) Support Systems and Mutual Help. New York: Greene and Stratton, 1976.
- King, S. and R. Meyers. "Developing self-help groups: integrating group work and community organization strategies." Social Development Issues 1981, 5 (2-3), 33-46.
- Klagsbrun, S. "Cancer, emotions and nurses." American Journal of Psychiatry, 1970, 126, 1273-1244.
- Kleinman, H., J. Mantell and E. Alexander. "Collaboration and its discontents:

- the perils of partnership." Journal of Applied Behavioral Sciences, 1976, 12 (3), 403-409.
- Knapp, V. and H. Hanson. "Helping the parents of children with Leukemia." Social Work, 1973, 18 (4), 70-75.
- Koch, C., J. Hermann and M. Donaldson. "Supportive care of the child with cancer and his family." Seminars in Oncology, 1974, 1, 1.
- Koocher, G., J. O'Malley, J. Gogan and D. Foster. The Damocles Syndrome: Psychological Consequences of Surviving Childhood Cancer. New York: McGraw Hill, 1980.
- Kupst, M., J. Schulman, G. Honig, H. Maurer, E. Morgan and D. Fochtman. "Family coping with childhood leukemia: one year after diagnosis." Journal of Pediatric Psychology, 1982, 7 (2), 157-174.
- Kushner, H. When Bad Things Happen to Good People. New York, Schocken, 1982.
- Lascari, A. and J. Stehbens. "The reactions of families to childhood leukemia." Clinical Pediatrics, 1973, 12, 210-214.
- Lazarus, R. Psychological Stress and the Coping Process. New York: McGraw-Hill, 1966.
- Lazarus, R. and R. Launier. "Stress-related transactions between person and environment." In L. Pearlin and M. Lewis (Eds.), Perspectives in Interactional Psychology. New York: Plenum, 1978.
- Leiken, S. and P. Hassakis. "Psychological study of parents of children with Cystic Fibrosis." In J. Anthony and C. Koupernick (Eds.) The Child in His Family: Impact of Disease and Death Vol. 2. New York: Wiley, 1973.

- Lenrow, P. and R. Burch. "Mutual aid or professional services: Opposing or complementary." In B. Gottlieb (Ed.) Social Networks and Social Support. Beverly Hills: Sage, 1981.
- Lieberman, M. "Help-seeking and self-help groups." In Lieberman & Borman (Eds.) Self-help Groups for Coping with Crisis. San Francisco, Jossey-Bass, 1979.
- Lieberman, M. and L. Borman (Eds.) Self-help Groups for Coping with Crisis. San Francisco: Jossey-Bass, 1979.
- Martinson, I. "The child with leukemia: parents help each other." American Journal of Nursing, 1976, 76(7), 1120-1122.
- Martinson, I. and C. Jorgens. "Report of a parent support group." In I. Martinson (Ed.) Home Care for the Dying Child. New York: Appleton-Century-Crofts, 1976.
- Maslach, C. "Burned-out." Human Behavior, 1976, 5, 17-22.
- McCullum, A. and A. Schwartz. "Social work and the mourning patient." Social Work, 1972, 17, 25-36.
- Myers, J., J. Lindenthal and M. Pepper. "Social class, life events and psychiatric symptoms." In B. Dohrenwend and B. Dohrenwend (Eds.), Stressful Life Events: Their Nature and Effects. New York: John Wiley, 1974.
- National Cancer Institute. Decade of Discovery. Rockville, Md., National Cancer Institute, USDHHS (81-2323), 1981.

- Obetz, S., W. Swenson, C. McCarthy, G. Gilchrist and E. Burgert. "Children who survive malignant disease: emotional adaptation of the children and their families." In J. Schulman and M. Kupst (Eds.), The Child with Cancer. Springfield: C. Thomas, 1980.
- Pearlin, L. and Schooler, C. "The structure of coping." Journal of Health and Social Behavior, 1978, 19, 2-21.
- Pilisuk, M., and C. Froland. "Kinship, social networks, social support and health." Social Science and Medicine, 1978, 12B, 273-280.
- Powell, T. "The use of self-help groups as supportive reference communities." American Journal of Orthopsychiatry, 1975, 45 (5), 756-764.
- Reinharz, S. "The paradox of professional involvement in alternative settings." c/o: Journal of Alternative Human Services, 1981, 7, 21-24.
- Riessman, R. "The 'helper-therapy' principle." Social Work, 1965, 10 (2), 27-32.
- Ross, J. "Social work intervention with families of children with cancer: the changing critical phases." Social Work in Health Care, 1978, 3, 257-272.
- Ross, J. "Coping with childhood cancer: group intervention as an aid to parents in crisis." Social Work in Health Care 1979, 4 (4), 381-391.
- Ross, J. "Childhood cancer: The parents, the patients, the professional." Issues in Comprehensive Pediatric Nursing, 1980, 4, 7-16.

- Rothenberg, M. "Reactions of those who treat children with cancer." Pediatrics, 1967, 40, 507.
- Sachs, B. "Group Therapy." In J. Kellerman (Ed.) Psychological Aspects of Childhood Cancer. Springfield: C.C. Thomas, 1980.
- Siegel, S. "The current outlook of childhood cancer - the medical background." In J. Kellerman (Ed.), Psychological Aspects of Childhood Cancer. Springfield: C.C. Thomas, 1980.
- Silverman, P. "Mutual help". In R. Hirschowitz and B. Levy (Eds.) The Changing Mental Health Scene. New York, Spectrum, 1976.
- Simone, J., R. Aur, H. Hustu, JM. Verzosa, and D. Pinkel. "Three to ten years after cessation of therapy in children with leukemia." Cancer, 1978, 42, 839-844.
- Smith, D. and K. Pillemer. "Self-help groups as social movement organizations: social structure and social change". In L. Kriesberg (Ed.), Research in Social Movements: Conflict and Change, 1983, 5, 203-233.
- Sontag, S. "Illness as metaphor." Cancer News, 1979, 33(1), 6-12.
- Sourkes, B. "Siblings of the Pediatric Cancer Patient." In J. Kellerman (Ed.), Psychological Aspects of Childhood Cancer. Springfield: C.C. Thomas, 1980.
- Spinetta, J., J. Swarner, and J. Sheposh. "Effective parental coping following the death of a child from cancer." Journal of Pediatric Psychology, 1981, 6 (3), 251-263.
- Spinetta, J., P. Spinetta, F. King and D. Schwartz. Emotional Aspects of

- Childhood Cancer and Leukemia. San Diego: Leukemia Society of America, 1976.
- Stolberg, A., and J. Cunningham. "Support groups for parents of leukemic children." In J. Schulman and M. Kupst (Eds.), The Child with Cancer. Springfield: C.C. Thomas, 1980.
- Stuetzer, C. "Support systems for professionals." In J. Schulman and M. Kupst (Eds.), The Child with Cancer. Springfield: C.C. Thomas, 1980.
- Toch, H. The Social Psychology of Social Movements. Indianapolis, Bobbs-Merrill, 1965.
- Tracy, C., and Z. Gussow. "Self-help health groups: a grass roots response to a need for services." Journal of Applied Behavioral Sciences. 1976, 12 (3), 381-397.
- Vachon, M., W. Lyall and S. Freeman. "Measurement and management of stress in health professionals working with advanced cancer patients." Death Education, 1978, 1, 365-375.
- Voysey, M. "Impression management by parents with disabled children." Journal of Health and Social Behavior, 1972, 13(1), 80-89.
- Wagner, J. "Fathers of Seriously Ill Children." Gainesville, Fla., 1981, mimeo.
- Wilbur, J. "Rehabilitation of children with cancer." Cancer, 1975, 36, 809-812.
- Wortman, C., and C. Dunkel-Schetter. "Interpersonal relationships and cancer:

a theoretical analysis." Journal of Social Issues, 1979, 35 (1),
20-125.

WORKING PAPERS OF THE CENTER FOR RESEARCH ON SOCIAL ORGANIZATION

The Center for Research on Social Organization is a facility of the Department of Sociology, University of Michigan. Its primary mission is to support the research of faculty and students in the department's Social Organization graduate program. CRSO Working papers report current research and reflection by affiliates of the Center; many of them are published later elsewhere after revision. Working Papers which are still in print are available from the Center for a fee of \$.50 plus the number of pages in the paper (\$.88 for a 38-page paper, etc.). The Center will photocopy out-of-print Working Papers at cost (approximately \$.05 per page). Recent Working papers include:

- 280 "Speculations on Warmaking and Domestic Military Power," by Charles Tilly, December 1982, 23 pages.
- 281 "Statemaking, Capitalism, and Revolution in Five Provinces of Eighteenth-Century France," by Charles Tilly, January 1983, 59 pages.
- 282 "Selected Papers, 1963-1983, From the Study of Social Change and Collective Action (1/83)," by Charles Tilly, January 1983, 22 pages.
- 283 "The School Experiences of Children with Cancer: Views of Parents, Educators, Adolescents & Physicians," by Oscar Barbarin and Mark A. Chesler, December 1982, 100 pages.
- 284 "Karl Marx, Historian," by Charles Tilly, March 1983, 14 pages.
- 285 "The Organization of Self-Help Groups for Families of Children with Cancer," by Mark A. Chesler and Meg Yoak, April 1983, 39 pages.
- 286 "Demographic Origins of the European Proletariat," by Charles Tilly, March 1983, 129 pages.
- 287 "War and the Power of Warmakers in Western Europe and Elsewhere, 1600-1980," by Charles Tilly, May 1983, 29 pages.
- 288 "The Central Industrial Park Project: An Empirical Investigation into Power Relationships," by David Fasenfest, May 1983, 103 pages.
- 289 "Doing an Interview," by Robert Thomas, June 1983, 8 pages.

Request copies of these papers, the complete list of Center Working Papers and further information about the Center activities from:

Center for Research on Social Organization
University of Michigan
330 Packard Street
Ann Arbor, Michigan 48109