

SELF-HELP GROUPS AS INTERVENORS
IN PATIENT-PROVIDER CONFLICT
IN HEALTH CARE

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This paper explores the roles of self-help groups in mediating and intervening in conflicts occurring between parents of children with cancer and local health care systems. It is intended as an informal exploration of issues and concepts, preliminary to the report of empirical research and action efforts.

Conflict is intrinsic to the organized relations between providers of health care and the recipients of such services. When service recipients are suffering from chronic and serious illnesses, and have an especially dependent and long-term relationship with the medical care system, this structural conflict is likely to be particularly potent and pervasive. The case of children with cancer is an exemplar of chronic and serious illness, and a useful setting for examining sustained and escalated conflict. The consequences of such conflict may include patient dissatisfaction, staff distress and in some cases inadequate medical care. Self-help groups represent a social innovation that responds to such conflict: they help organize and channel patient concerns, provide support and legitimation for new forms of patient-patient and patient-staff relationships, establish an arena for mutual communication and problem-solving, help lessen patient dependency upon the medical staff, and often advocate for change in those organizational conditions that create conflict. Groups formed by/for parents of children with cancer are representative of a wide range of self-help groups in the health care field, and the dynamics of conflict relationships in health care can be seen as examples of broader issues affecting recipient (client, student) - provider (professional, teacher) relations in a wide range of human services. Thus, we are concerned here with sketching a conceptual and practical framework for studying and acting upon conflicts in the medical arena in particular, and in the human services broadly.

The background of conflict in health care.

It is not novel to characterize the relationship between providers of health care services and their patients as fraught with interpersonal and organizational conflict. The roots of these conflicts have been discussed by several prominent authors, and have been located in such structural variables as: the professional role and status, power asymmetry between provider and recipient, the bureaucratic organization of care, and differential bases of expertise and experience (Friedson, 1970; Mechanic, 1978; Antonovsky, 1980). All these examples are social-psychological or micro-sociological in character; one also could identify the roots of such conflict in the broader political-economy and culture of health care in the United States (the entrepreneurial form and profit motive of medicine, state sanctioning of professional roles and competencies, gross disparities in access to medical care as a function of economic class and the cultural bias toward mind-body dualism in western medicine).

The phenomenology of being a patient usually involves anxiety, physical discomfort and often pain. In addition, a medical crisis usually makes one feel vulnerable, both physically and emotionally, and confused about how to express a new set of basic needs and concerns. Such confusion may lead to repression and withdrawal, to acting out and anger at the medical staff, to searching for new information, and to caring for oneself and others in new ways. Whatever form of the "sick person role" is adopted (Parsons, 1951), it involves delicate entry into attitudes and behavior consistent with being ill, and gradual loss of the role of a healthy and "normal" person. These role transitions are fraught with intrapersonal confusion and conflict, necessarily affecting interpersonal relationships - with intimate others, with strangers and with members of the medical staff.

The reality of being a patient also requires reassessment of one's own body and bodily situation, and the recognition and semi-public expression of highly personal needs. Every person is somewhat of an expert on her or his own body, bodily reactions and medical history. Professionals, experts in generalized medical knowledge (including bodies), are not expert in each patient's bodily history and affliction. Thus, patients and professionals come to the treatment relationship with

differential sets of expertise and knowledge: one specific and the other general, one experiential and the other intellectual, one personal and the other vicarious, one based on a need to be cured and the other on a need to cure (Borkman, 1976; Haug, 1975). These different vantage points, with their different interests and roles, may be complementary, but are often conflictual. The ways in which such differential expertise and interests are combined - sought or not, respected or not, fit into a hierarchy of validity or value or not - foretell a great deal about the consensual, complementary or conflictual basis upon which patients and providers plan and carry out their interactions.

The special training, knowledge and expertise of the professional staff, codified in their status and roles, provides them with a set of privileges and obligations that carry enormous power over patients. The professional role embodies knowledge of patients' illness, the power to label and treat (perhaps to cure), and state-sanctioned responsibilities for medication and hospitalization (Abbott, 1983; Friedson, 1970; Parsons, 1951). This professional status and role usually leads to an asymmetrical power relationship between providers and their patients (Szasz & Hollender, 1956). Patients who seek and need help usually must play a dependent and passive role vis-a-vis their helpers. Some scholars have argued that this is not only an unnecessary role construction, but that it often is detrimental to a high quality of care, disempowering patients from responding effectively to treatment (Taylor, 1979). A patient who accedes to dominant medical norms, and who takes on the compliant and passive role of a "good patient", may at the same time give up substantial amounts of self-control and self-responsibility for treatment and its outcomes (Antonovsky, 1980; Featherstone, 1980; Lorber, 1975).

When staff members' commitments to the emotional distance and affective neutrality embodied in the professional role encounter patients' needs for emotional support and engagement, threat and conflict may be experienced by both parties (Cassileth & Hamilton, 1979; Meadow, 1968; Parsons, 1951). Staff members involved in such conflict with patients often express their feelings of tension, anger or hurt by labelling and derogating the behavior and/or character of individual patients, or of patients as a general category. When they express such feelings directly

to patients, or "leak" them in subtle form, they may create open conflict on the ward or in the clinic.

The organization of patient-provider relationships in the context of large, complex and highly bureaucratized medical systems, adds more layers of mystery and difficulty to professional-patient relationships (Friedson, 1970; Lipsky, 1980). It is not just in the health care system that low power consumers or clients feel awed by massive bureaucracies, but here even their relationships with their bodies and intimate physical needs are set within a depersonalized context (Goffman, 1961). Such depersonalization, and the simultaneous rigidification of power and status distinctions, generates additional feelings of powerlessness and alienation for many patients (DiMatteo, 1979; Haug, 1975). As the anxiety and discomfort of illness is exacerbated by the conditions of organized care, patients may resent, resist or rebel against the care-giving system.

Some patient-provider conflict is generated because of clear inadequacies or gaps in the provision of medical care. The economics of health care in the United States result in some people not receiving treatment, let alone adequate treatment, because they lack insurance or the ability to pay for private or under-funded public medical services. Even when competent technical medical care is provided, the cost structures and incentives underlying health care systems place a low priority on effective psychosocial care. While a lack of adequate resources may partly account for this psychosocial gap, it also reflects an historic insensitivity to interpersonal relations in health care (Ehrenreich, 1978; Friedman & DiMatteo, 1979).

These issues now occur within the context of rising public concern about the "rights" of patients and patient families. The concern with more than services or treatment, per se, but with the rights of clients of human services, is part of a broad movement toward consumerism and consumer power in the United States. Haug and Sussman (1969) identified this trend almost two decades ago, in discussing the "revolt of the client" in human service systems. Current cutbacks in federal funds for human services escalate the level of need and of "felt need", creating a ready and fertile ground for the expression of unmet consumer needs. Increasingly, recipients of human

services feel it appropriate to express their individual and collective needs, and to demand to participate in shaping and ensuring the delivery of satisfactory care.

All these factors lead to a medical care system that is caught in the conflict between primary service to patients' needs and values and to the interests and values of professionals themselves. Clearly, direction and control of the medical relationship remains in professionals' hands. Patients who automatically accept these values and services, who behave as "good patients", often avoid overt conflict by internalizing their own diminution and denying their felt needs. When patients do value their own knowledge, do want their needs or values met as a priority, or do wish to (co-)direct the medical relationship, overt conflict may be unavoidable.

The symptoms and consequences of patient-provider conflict.

What does patient-provider conflict look like? What are the symptoms of conflict in organized relations between patients and medical caregivers or health care systems? What are the consequences of these dynamics? Although an adequate causal analysis of conflict relations would distinguish symptoms from consequences, we are not pressed for such distinctions at this point. Since the causes of these conflicts are hard to determine in specific instances, the consequences may only appear in the form of symptoms. Moreover, by the time symptoms of conflict appear, they already have had consequences for key actors. As we cross levels of analysis, from individual behavior to organizational operations, we often encounter such tautologies between symptoms and consequences.

The consequences of conflict in patient-provider relations may be multiple, and they may be quite subtle, not commanding the attention given to personal suicide, sustained organizational tension or an open revolt. Moreover, since not all conflict takes the form of obvious oppression or systemic error, not all consequences show up in the form of boycotts, noisy confrontations or medical malpractice suits.

One typical consequence of conflict in medical care is sustained patient dissatisfaction. Such dissatisfaction is not necessarily focussed on technical aspects of care, but often is reported as failed

communication, a lack of patient compliance with medical regimens, and inadequate interpersonal relationships between patients and providers (DiMatteo & Hays, 1980).

A second typical consequence involves patient (or patient family) behavior that expresses a sense of disempowerment, a passivity, lack of self-confidence or even fear in relations with the staff. Illness itself may be disempowering for individuals, and it may make previously energetic and active persons seek relief and assistance in ways that are overly passive and dependent. The medical staff that presses for compliant patient behavior may exacerbate these feelings. In response, some patients who would prefer to become active may suppress their needs and accustomed styles, and simply comply (perhaps overcomply) with medical expectations; other patients may subtly rebel against norms of passivity, resenting the staff and covertly deviating from or sabotaging these norms. Under such conditions, patients may lose sense of "who they are", as their loss of health is combined with an assault on their identity.

Some patients become so confused and distressed with their relations with the medical staff that they engage in what may appear (or be labelled) as "crazy" or "irrational" behavior. Discussions of serious illnesses (and some not so serious) are replete with stories of patients exiting from traditional medical institutions and seeking alternative treatments of dubious character and effect. Typically, patients electing such options report that they were desperate, and that their desperation stemmed as much from a lack of trust and confidence in their relations with staff members as from the nature of their illness and treatment, per se (Cobb, 1954). Indeed, several reports from cancer patients treated at Mexican laetrile clinics indicate that they felt they were treated especially nicely and courteously (including straightforward communication and a lack of bureaucratic procedures) by the staffs of these alternative treatment systems. Alternative medicine's concern for wholistic approaches to illness generally include a concern with the patient's mind as well as body, family as well as person, and community as well as family.

Finally, some patients join with others to engage in vigorous and well-organized protest against the interpersonal treatment they receive. Overt protests may take the form of letters or phone calls complaining about the behavior of individual staff members, and public behavior

designed to embarrass the staff or the medical institution in the eyes of the community. More covert forms of protest may occur behind the scenes, in polite discussions between patients (or patient representatives) and members of the medical staff.

Patients are not the only actors in the patient-provider relationship, and they are not the only party to experience or express the conflicts that surround this relationship. For instance, physicians and nurses may become quite distressed when they are unable to affect a cure (Rothenberg, 1967; Vaux, 1977). Indeed, Levine (1975) discusses the "hero" element present in many staff members' self-concepts, and the conflict created when such conceptions of oneself cannot be realized in practice. When these strains are accompanied by tense interpersonal relations with patients, staff members may experience frustration and "burn-out". Interestingly, several researchers suggest that it often is the most talented and compassionate professionals who experience burn-out, partially because their expectations and commitments, and consequent disappointments, may be the highest (Cherniss, 1980; Freudenberger, 1974; Maslach, 1976; Stone, 1983; Vachon, Lyall & Freeman, 1978).

Finally, staff members also may experience conflict in their relations with other staff members and with the institutional setting of care, and not just with patients (Stone, 1983). Staff-staff or staff-institution conflict may be particularly poignant when staff members attempt to advocate patients' interests, and find themselves also confronted with unyielding medical bureaucracies and resistant officials. As the least potent actor in the medical setting, patients may become a target of scapegoating by powerless and frustrated staff members.

Conflict in "institutionalized" relations between providers and recipients: the case of childhood cancer.

These conflicts (or potential conflicts) and their consequences are exacerbated when the patient-provider relationship is institutionalized; that is, when it takes on a regular and stable character in an organized setting. For a variety of reasons, explained below, childhood cancer

represents an exemplar illness for the investigation of institutionalized conflict between patients and providers of medical services.

When the patient has a more serious illness he or she is especially vulnerable, perhaps in pain, and more dependent upon the staff's good will and technical expertise. Childhood cancer fits the model of a serious illness, since approximately 50% of those young people diagnosed with cancer will not live five years beyond their diagnosis. Moreover, many of those who do survive will suffer substantial side effects of the disease and its treatment (from radiologic, chemotherapeutic and/or surgical procedures). Since children are at once the most vulnerable and emotionally compelling of human beings, their serious illnesses always feel even more "serious" than adults'.

Similarly, when an illness is chronic in nature, the interpersonal relationship between providers and recipients is likely to be more crucial. As patients and staff members are linked for a longer period of time, and relate to one another on a regular basis, minor irritations may grow into nettlesome problems. On the other hand, participants in a long-term relationship may be able to create the "space" for a unique set of interactions, ones that substitute individual familiarity and trust for universalistic rules and norms. The potential for commitment and intimacy embodied in a long-term relationship may encourage some staff members to step beyond their technical expertise and to make judgements in areas of moral concern (e.g., values about life-style, coping and child-rearing, as well as about good patient behavior). Although some patients may appreciate unsolicited advice, Featherstone notes that moral judgement or instruction does stretch the limits of most professionals' expertise and is resented by many patients/parents (Featherstone, 1980). Most childhood cancers require a multi-year period of treatment; even under the best of circumstances two to three years of treatment, including repeated hospitalization, is quite common. In the event of a relapse, this treatment period is extended in time and probably in vigor, complexity and risk as well. During this period parents often develop their own expertise in monitoring treatment, and a knowledge basis that may rival that of some professionals. Then the potential conflict between parental and professional values and knowledge, and the need to adopt

egalitarian, or at least exchange, norms of information-sharing and decision-making, is even more potent.

Patients with serious and chronic illnesses are likely to require specialized care, and their treatment is usually provided by medical specialists, members of highly professionalized cadres. These cadres are most likely to practice in large specialty centers. For instance, the most effective medical treatment for childhood cancer occurs at specialized centers or research hospitals, especially sophisticated institutions that can justify the costs of the latest technology (Miller & Miller, 1984). Even when this technology is available, its cost to families may be enormous. Medical insurance often fails to cover "experimental" procedures for children who relapse, and the high costs of travel and other non-reimbursable expenses (meals, lodging, childcare, time away from work) strain many families' budgets (Lensky, et al., 1979). Some families experience bankruptcy or major changes in their economic status as a result of treatment requirements, and some children fail to obtain adequate care because of financial pressures. Hospitals, too, labor under the high cost of treatment and inadequate provisions for catastrophic illnesses, and are hard-pressed themselves to aid all families who need assistance.

When the stakes are high, and when care is provided in highly bureaucratized specialty institutions, norms about proper staff and patient behavior are likely to be more rigid and more rigorously enforced. Divisions of labor are more precise in these settings, and staff-patient relationships generally more distant, rule-bound and rushed. While the chronic patient's relationship with these institutions may be long-term and stable, relationships with individual physicians may be of very short duration. Teaching hospitals and research centers are noted for their constant rotation of staff members, and thus a constantly changing individual patient-physician relationship. In these circumstances, the establishment of familiarity and trust, and the negotiation of norms of interaction, may have to be repeated numerous times.

Specialized treatment centers also amass large numbers of continuing patients with similar disease characteristics into a relatively few service settings. In so doing, they create a facile arena for patient exchange, comparison and the development of a collective consciousness. In these

settings, individual concerns or difficulties are more easily organized and transformed into collective grievances.

Thus, the realities of serious and chronic illness lead to "institutionalized" medical relationships, relationships that because they bring together actors with substantially different needs and experiences, in a situation of high stakes and sustained interdependence, are more likely to encounter conflict. Moreover, the conflicts that are experienced (by all parties) in these situations are likely to have more serious consequences. A person with a mild and short-lived illness may be able to avoid staff or modify treatment and still survive; a person with a serious and chronic illness cannot take these risks. A poor relationship between patient and provider may be overlooked or overcome in a one-visit procedure; when treatment extends over a long period, these poor relations are likely to escalate and to interfere with satisfaction and even with effective treatment. Having a serious and chronic illness is not like having a mild cold or even a "simple" broken wrist, and the rules governing seeking/receiving and providing medical care are not the same either.

In addition to these aspects of the illness and the treatment setting, children are unlikely to enter the medical system and to create a patient-provider relationship on their own; they typically are represented or accompanied by their parents. Parents carry a primary role as the protectors and defenders of their young, and they are not likely to relinquish this role simply because their youngster is seriously ill. Even while they are terribly concerned and worried, and thus dependent upon the staff and responsive to its associated norms for proper patient (and parent) behavior, parents adopt (more or less consciously) an advocacy/protector role. Where patients themselves may be unwilling to risk confrontation with the medical staff norms, repressing or avoiding potential conflict, parents (or other patient representatives or advocates) are more likely to recognize and surface these background conflicts.

Our research with parents of children with cancer indicates that a considerable proportion (60% or 44 out of a sample of 74 parents) report some problems in their relations with staff

members, and that 39% report 3 or more problems. Table 1 shows the different kinds of problems these 44 parents report (Chesler & Barbarin, 1984).

Table 1. Problems Encountered with the Staff, Specified by Category and by Number and Percentage of Parents Reporting

Kinds of Problems Reported	Number of Parents Reporting Problems (N = 44)	Percentage of Parents*
Conflict resolution	23	52
Interpersonal contact	21	48
Empathy with the child	18	41
Acceptance of parental efficacy	19	43
Transmission of information	12	27
Communication	16	36
Staff's competence	19	43

*Percentage of 44 parents reporting any problems who reported this problem.

Although any of the problems reported in Table 1 can and do generate conflict in relations between parents and staff members, the most prominent category is conflict resolution itself; that is, the process by which various other problems or conflicts are resolved. Consider the following parents' comments on the process of conflict resolution they encountered (Chesler & Barbarin, 1984, p. 56).

Another doctor became quite incensed over my comments. He came down to our room and called me a "rabble-rouser" and said that if I did not allow whomever was there to work on our child, she should not be treated at the hospital. He said if we didn't like it we could take her someplace else.

If I confronted the nurses with how I feel about some of them, my child would suffer.

A number of parents repeat these themes, suggesting that the status and power differentials between themselves and the staff often make it difficult to communicate about problems, cause them to fear staff retaliation if they are too assertive, and make it difficult to resolve differences or problems in any way other than that preferred or dictated by the staff.

Our studies also indicate that parents with a higher level of education report more problems and conflict with the medical staff than do parents with less education (87% of parents who had graduated from college, compared with 42% of parents who had a high school education or less, report problems with the staff). As we suggest: (Chesler & Barbarin, 1984, p. 62):

Perhaps this finding is part of the general trend in this country for people with higher educational status to be more critical of human service institutions (such as schools and municipal governments). Perhaps more highly educated parents do not hold the medical staff in as much awe as less highly educated parents do. Perhaps parents with higher educational status are more critical or assertive as they deal with the treatment process, and thus irritate professionals, who then respond in ways that exacerbate the issues underlying these interactions.

These aspects of serious and chronic childhood illness, requiring complex and highly specialized care, suggest that childhood cancer is a good context in which to examine the existence and resolution of patient-provider conflict. Since many parents of children with cancer engage in self-help and mutual support, their situation also provides an opportunity to examine the particular role of organized self-help groups in the "mediation" of such conflicts. We now turn to that inquiry.

The role of self-help groups in patient-provider conflict.

Self-help groups are voluntary organizations composed of people who are affected by a common condition or crisis, and who wish to give and receive mutual aid and support. In the context of issues of health and illness, self-help groups are typically formed by and for patients and their families. Several recent reports suggest that self-help groups have become a significant presence in and around medical systems (Katz, 1981; Lieberman & Borman, 1979; Pancoast et al., 1983). They are part of a rapidly growing phenomenon, composed of informal helping systems, voluntary organizations and non-professional options for psychosocial care and support (Fischer et al., 1983; Gottlieb, 1981; Killilea, 1976).

According to the Candlelighters Childhood Cancer Foundation, self-help groups of families of children with cancer exist in over 300 communities or medical treatment centers across the nation¹. These groups play a variety of roles in providing support to families, and in helping them to reduce the stresses typically accompanying the diagnosis and treatment of childhood cancer

(Chesler & Yoak, 1984). Among their typical programs and activities are: information and education sessions; instrumental assistance to families (money, transportation, coping hints); emotional sharing and support; new interpersonal and social networks; and opportunities to raise funds or otherwise support hospital services.

In addition to these efforts to reduce individual stress and to provide support to individuals, self-help groups sometimes engage in the "mediation" of conflict between parents and the medical care system². This mediative role may take several different forms: (1) identifying, collectivizing and articulating parental perceptions and concerns, permitting them to express and act upon their concerns together; (2) enhancing individuals' skills in conflict management - in themselves, in their families, in the group, and in the medical system; (3) creating opportunities for service providers and service recipients to meet together, encouraging them to share and exchange views with one another and to engage in joint problem-solving; and (4) creating changes in the organization and delivery of medical care to patients and families, either via positive incentives and persuasion or via negative sanctions and threats.³

In intimate groupings of people suffering from the same stressful social situation, parents of children with cancer can meet and connect with other people "like ourselves". "Going public" is an important part of adapting to a new life situation, and open discussion and sharing of individual pain and experience leads to the creation of new social networks. Through a process of mutual disclosure and networking, people also may begin to see how some of their concerns are not simply troublesome individual issues, but common reactions to a legitimately stressful situation. As feelings are legitimized and shared, parents may feel less alone, bizarre or disempowered.

In these group settings, distressed feelings that are common to many people often are translated and organized into grievances, especially when aspects of the medical care system are identified as playing a role in creating or escalating distress. Thus, self-help groups often provide a channel for the organized expression of these grievances. Instead of many individual actions, perhaps chaotic and unconnected, a self-help group may collect and express concerns in an orderly

manner to appropriate members of the medical staff. Such organized expression may take several forms: feedback to the staff with regard to particular practices, education of the staff with regard to patient and parent needs, appeals to higher medical authorities, and protests that involve the larger public community.

Self-help groups also provide an arena within which parents of ill children learn more about the illness and treatment, and how other people cope with common issues and experiences (Borkman, 1976). Thus, people teach and learn new coping skills with each other, constituting what Riessman (1965) has called the "helper-therapy" principle of personal growth and social support. Among the most important skills parents learn are: how to care for their ill child, how to deal with siblings' reactions, how to express their needs to the medical staff, how to monitor their child's treatment, and how to deal with their child's school system. Many of these skills are directly related to the effective management of conflict in a wide variety of settings- within the family, the community and the medical system. For instance, in a recent edition of the Quarterly Newsletter of the Candlelighters Childhood Cancer Foundation, a periodical designed for self-help group members, Stanford makes the following suggestions for parents desiring to resolve their conflicts with the staff (Stanford, 1984, p. 4-5):

1. use careful listening to determine how the other person sees the conflict
2. describe how you see the conflict
3. ask the other person to explain what he/she wants
4. tell the other person what you want
5. seek a win-win solution
6. agree on a solution
7. make an agenda

Although these suggestions focus on one-to-one interactions, they may also guide group activities.

As parents receive important information, interpersonal counselling, new coping skills and social support from self-help groups, some of their needs may be met directly. As a result, their reliance and dependence upon the medical and psychosocial staff may be reduced. With reduced parent dependency, the staff's workload is reduced, easing the potential for burnout. In addition, the staff's power over parents may be reduced, and then power distinctions are less likely to fuel and escalate conflicts that arise from other factors.

Many self-help groups also have established meetings where parents and medical staff members communicate and engage in collaborative problem solving. The dynamics of power asymmetry between providers and patients may make it difficult for individual parents to fully express themselves in the clinic or hospital wards - on doctors' "turf". In a neutral or parent-oriented setting, with many parents together, it may be easier for low power actors to express themselves. If high power actors can avoid defensiveness, such communication may help transcend the status and role barriers to effective interpersonal relations and collaboration in care. For instance, both medical staffs and parents may feel that there is a need to increase the level of communication between the hospital, the family and the local school system, so as to ease the re-entry of ill children to their classrooms, studies and peer groups. But on their own, neither families nor the medical staff may be able to solve this problem. By bringing these groups together, and perhaps also by inviting representatives from the local school system to such a meeting, the self help group may establish the opportunity for all parties to address their common concern, and to set new policies and procedures that solve problems they have identified.

Some self-help groups play an active and direct role in creating change within the medical system. A first round of tactics for making changes often includes the communication and problem-solving efforts discussed above. In addition, some self-help groups urge hospitals to revise their emergency room procedures, their staffing systems, or their clinic schedules. In a number of communities, groups raise substantial funds to support new programs, new personnel or temporary housing facilities (e.g., Ronald McDonald Houses) that they feel are essential for the care of their children. Organized parent groups also may be instrumental in helping to institutionalize new procedures or organizational mechanisms that help all parties respond to conflict. For instance, the use of parent ombudspersons, patient/parent advocates, and parent representatives on the professional staff (Pitel, et al., 1985) all constitute organizational innovations that are designed to intervene between patients and providers. These regularized roles or mechanisms may help anticipate or resolve conflicts much earlier or at a lower level of distress or escalation. Should such persuasion and positive incentives fail, however, some groups also

utilize negative sanctions or pressure to encourage change in the medical system. Among the more coercive strategies that may be used to alter the conditions underlying parental stress or creating conflict are: representation of parental interests to medical authorities, coalitions with others who want to alter the medical system, media campaigns, lobbying efforts with local and state authorities, and public demonstrations or boycotts.

In all these efforts, of course, self-help groups run the danger of "cooling out" parental concerns or substituting non-change or tokenism for actual reorganization of patient-provider relationships (Klienman, et al., 1976). Such premature reduction or resolution of conflict may create a "raisin in the sun", an undealt-with set of grievances storing enough heat to eventually explode. To the extent that self-help groups themselves are accepted within the medical staff's operational portfolio, or actually run by staff members, this danger is most severe. When co-optation or tokenism continues for a substantial period of time, members whose needs are not being met will struggle to change the group, perhaps engaging in the kinds of internal conflict that render the self-help group ineffective and dysfunctional. Others will leave the group. Still others may vent their frustration on the staff.

Our own studies indicate that self-help groups may be categorized according to their relationship with the medical care system (Yoak & Chesler, 1985). Some groups are "run" by the professional staff, like psychological counselling or support groups.⁴ Other groups are very independent of the medical staff, excluding staff from all positions of leadership and control, and relating only rarely to the hospital system. And some groups are characterized by a shared leadership style, wherein professionals and parents both play important roles in the management and direction of the group. Groups that are totally managed by the professional staff are unlikely to deviate from that staff's agenda, and are unlikely to be involved in organizing grievances, problem-solving, or encouraging change in the medical care system. They are too dependent upon the staff to challenge the staff and the organization of care. Groups that are completely independent from the medical staff are safe from the danger of cooptation and control. However, because they have more limited access to staff resources they may have difficulty recruiting new

members, and may otherwise be rendered less effective. Yoak & Chesler (1985) indicate that the shared leadership or coalition-type groups may combine the advantages of both prior types; they are free from professional control and still maintain access to the personal and institutional resources professionals can provide. Indeed, results show that the shared leadership groups typically are larger, last longer and engage in a greater variety of activities than either of the other two types. Thus, self-help groups that are most effective in the midst of change may play both aspects of the mediator role: (1) helping to organize and represent the needs of their parent constituency, perhaps even in challenging ways; and (2) communicating and collaborating with the medical staff and organization.

Inter-organizational conflict between self-help groups and the medical system

As self-help groups play these roles in the mediation of patient-provider conflict, they often become directly involved in inter-organizational conflict. Any agency acting as an advocate or representative for one party in a bilateral or multilateral conflict, or any agency intervening in a conflict between several parties, is likely to be drawn into the maelstrom. As organized representatives of patients'/parents' interests, even self-help groups that adopt a collaborative posture vis-a-vis the medical system may become direct parties to conflict (Katz, 1981; Klienman, et al., 1976). This certainly is the case if one of their roles is to help organize relatively powerless parents into a knowledgeable, organizationally competent and potentially powerful force. While some observers expect a high level of group-system conflict, arguing that self-help groups pose an inherently anti-professional ideology and style, others suggest that group system conflict is not inherently high (Lieberman & Borman, 1979). As Wollert et al. (1984) note: "while conflicts often characterize the interaction of professionals and self-help groups, there are other modes of relating which can avoid these pitfalls (p. 137)". The reality of what happens depends more on local dynamics than on vague generalizations.

Self-help groups are vulnerable in their relations with the medical organization because, like patients or parents of patients, they are to some extent dependent upon the staff for their existence and success. For instance, gaining access to new members is a constant problem for any

voluntary organization, and local self-help groups must meet and recruit parents of newly diagnosed children. Since the professional staff generally controls access to new patients, they may exercise considerable power over this key element in group life. When referrals have not been forthcoming from the staff, some groups have bypassed the staff and recruited new patients and their families from hospital wards or clinics. While this may be officially permissible, it does represent a conflict over access mechanisms, and in response, some medical staff members have cautioned parents "not to talk to other parents".

Control of the group's direction and activities represents another arena of potential system-group conflict (Kleinman, et al., 1976). For instance, many professionals are quite concerned that groups may practice psychotherapy or do psychological counselling⁵. Very few groups do venture into this turf without professional assistance, but the emphasis on peer support and co-counselling creates dynamics similar to formal counselling. In a different vein, some professionals feel that parents should discuss their deep feelings in a group (although still not conduct formal counselling), and that groups that do not do so, that focus on having parties and raising money, may be "avoiding" or "denying" real issues. What is at stake in both examples is conflicting moral judgements or values regarding what groups should do and how parents should cope, rooted in different bases of expertise and experience.

Groups that discuss parents' feelings about the medical staff may be especially threatening to staff members. Professionals often express concern that in the midst of great parental stress and crisis, parents who talk together may inappropriately escalate one another's fears and anger, resulting in unjustifiable and uncomfortable attacks on the staff. Although this threat to professionals is real and understandable, the sharing that occurs in most groups is far more likely to translate, cathart, dissipate or channel parental anger productively than to escalate or target it inappropriately.

Groups that actually try to make changes in the staff or in hospital procedures also may encounter conflict with professionals who feel they are already doing all that they can - and more - for their patients and families. To the extent that the practices that are the focus of change are

rooted in deeply held staff values or interests, conflict over these change efforts are likely to be intense.

We examined some of these potential conflicts in interviews with professionals (doctors, nurses, social workers) working with self-help groups of parents of children with cancer. When asked whether they "had heard the viewpoint that self-help groups could be dangerous", 90% of 63 professionals answered in the affirmative. The most common "dangers" mentioned include (Chesler, 1987):

1. challenge to the power of the professional
2. create emotional problems for parents
3. parents will know too much
4. spread misinformation
5. take over the job and turf of social workers
6. promote competition for patients with other hospitals
7. promote questioning of medical judgement

These perceived "dangers" are understandable to anyone sympathetic to professionals' difficult roles working with parents of chronically and seriously ill children, and with self-help groups formed by/for parents of these children. However, these "dangers" also illuminate structural conflicts between professionals' accustomed roles and stances and patient/parent needs.

Underlying these conflicts, at least for professionals, are concerns about the threats self-help groups may pose to their own power, power that rests on professionals' triple monopolies of knowledge, service and values.

Contemporary health care, at least for chronically and seriously ill people, especially children, proceeds according to a monopoly of knowledge organized and expressed by professionals. Professionals have privileged access to and control of that knowledge by virtue of years of special training and experience. Concerns about the spread of information, of misinformation, and about questioning medical authority, all relate to professionals' maintenance of their (relative) monopoly. Informed parents and self-help groups that provide information to parents threaten the professional monopoly of knowledge.

The licensing and certification of health care professionals by state agencies establishes a monopoly of service or practice that is just as crucial to the organization of medical care as is the

monopoly of knowledge. Only people who have special training are permitted to formally practice or provide medical, nursing or social work services. Concerns about challenges to the power of professionals, taking over their jobs, and promoting competition with other staffs relate to this professional monopoly. As a result, staffs may be concerned both about parent participation in care and about parent selection of a competing practitioner. As parents become educated and skillful in coping, and as groups provide parents with supportive services, parents may become less dependent upon the medical (especially psychosocial) staff. The disruption of this service monopoly may be a welcome relief to some staffs struggling with overwhelming patient loads and minimal resources, but it nevertheless challenges some professionals' "turf" and deviates from a traditional approach to health care practice.

The professional monopoly of values regarding health behavior also is an outgrowth of the technical training, education and experience embodied in the professional role. Although this monopoly is not as coherent as the prior two, the concern that groups will create emotional problems for parents is related to professionals' values regarding the way people ought to cope and the level of stress they ought to seek/avoid. Earlier we discussed Featherstone's argument that assumptions of medical competence often stretch into assumptions about competence and superior knowledge regarding patients' moral values and life-style choices. Parents may prefer not to cope in ways professionals prefer; and these choices may be experienced by professionals as inappropriate. This is especially problematic when parents or parent groups express coping styles, moral values or behavior patterns that depart from race, gender and class orientations that are dominant in professional groupings.

In the context of these conflicts between self-help groups and the medical system, are there meaningful avenues for collaboration among professionals and parents in these groups? Is the situation so fraught with conflict that separatism should be the order of the day? Despite somewhat normal and inevitable interpersonal and intergroup conflict, self-help groups and medical institutions can and do experiment with new roles and new structural arrangements that may help mediate these conflicts. For instance, as staff members interface with self-help groups

they may provide them with some of the core resources they need to operate: access to new patients and families, hospital meeting rooms, contact with medical staff members, a good reputation, funds for coffee and a newsletter and links to community agencies, etc. (Remine, et al., n.d.; Toseland & Hacker, 1982). They may also help groups become established and consult on organizational matters, teaching members how to run a meeting, educating them about the dynamics of the medical staff, and helping them to plan programs (Chutis, 1983; Dory & Riessman, 1982; Wollert & Barron, 1983). They also may help the rest of the staff understand and be more receptive to the self-help group (Bakker & Karel, 1983; Masiak, et al., 1981; Toseland & Hacker, 1982). When conflict escalates, some staff members may even be able to play a mediator role themselves, intervening between parents and other staff members to help create understanding and reduce conflict (Chesler & Barbarin, 1984; Foster & Mandel, 1979; Klass & Skinner, 1982-3). Such innovative roles may lead to the establishment of a coalition-type relationship between members of the staff and leaders of the self-help group, a model for a relationship that emphasizes both ongoing independence/difference and continuing collaboration (Yoak & Chesler, 1985).

Although some examples of innovative and successful relationships between self-help groups and provider institutions do exist, these innovations seldom have been institutionalized; that is, they seldom have become part of the normal operations of the medical care system or of the regular relationship between the self-help group and the medical system. Opponents of regularization and institutionalization argue that self-help groups, as more or less informal and temporary organizations, may be fundamentally altered and their special utility compromised if they were formalized and integrated into the medical organization. Moreover, once institutionalized, they might be more easily co-opted or rendered impotent by powerful professional figures and bureaucratic norms and procedures. Some professionals object to institutionalization on the grounds that it would cede too much legitimacy and power to non-professional agencies and actors. Supporters of institutionalization argue that such mechanisms may open the door to greater access to professional resources, creating new patterns of exchange

and collaboration. Professionals, too, emphasize the new resources that may become available to the medical system when parental support and energy are widely available. The "trick" appears to be to accomplish institutionalization of new mechanisms of patient - provider conflict resolution without necessarily institutionalizing the self-help group itself.

New and more powerful patterns of patient/family - provider collaboration, exchange of information and expertise, problem-solving around patient concerns/grievances, representation of patients in institutional decision-making, monitoring of institutional procedures, and expansion of patient-to-patient support programs are all examples of institutional mechanisms which self-help groups have helped local medical systems adopt. They stand as part of a new generation of mechanisms that recognize and seek to resolve patient-provider conflict in medical care. We need to know more about them, and about more of them.

A research note.

The issues raised here, especially those relating to new mechanisms of parent/group/staff/institutional collaboration, are currently being explored in a series of action-research projects. One project, in which data have already been collected, is investigating patient-provider and group-medical institution relations in a sample of 50 self-help groups formed by/for parents of children with cancer. Individual level (patient-provider conflict and its resolution) and group level (group-institution conflict and its resolution) data from this study are currently being analyzed⁶.

A second study, recently funded by the United States Department of Health and Human Services, will investigate these and other issues in self-help groups in the United States and Israel⁷. In the United States, self-help groups of parents of children with cancer (PCHCA) and self-help groups of parents of murdered children (POMC) will be studied. In Israel, self-help groups of families of immigrants (FI) and self-help groups of families of mentally ill children (FMIC) will be studied. This comparative study will permit exploration of these conflicts, and of the roles of self-help groups in mediating them, in groups serving parents with different life crises

and in societies with different perspectives and arrangements regarding the role and structure of human services.

Reports from these projects should advance our understanding of the theory and practice of conflict resolution in the health care system. Considered together with related work of colleagues at Michigan and elsewhere (see footnote #7), they should generate ideas and mechanisms applicable to a wide variety of human service and public sector settings.

FOOTNOTES

1. The Candlelighters Childhood Cancer Foundation is a national clearinghouse and education organization that provides information and networking services to children with cancer, to their families, to professionals serving these families, to self-help groups serving these families, and to the general public.

2. As the following discussion indicates, we employ a multi-faceted definition of mediation, one that goes far beyond a narrow focus on external and neutral intervention or "Guidance by a third party to an acceptable accommodation (Kerr, 19??, p. 236)." Self-help groups are both actors and intervenors; they may act directly as organizers and representatives of one of the parties to a conflict and they may act as intervenors between patients and providers. In this former role they help empower low power parties to a dispute, a tactic Laue & Cormick (1978) discuss as necessary for ethical mediation. In both roles they may mediate conflict.

3. Other scholars have emphasized the ways in which these kinds of group actions may be strategically useful or functional in conflictual settings (Coser, 1966; Dodson, 1960; Himes, 1966): surfacing and clarifying differences, heightening consciousness and group identity, correcting justice and service inadequacies, tuning programs to the real needs of service recipients, and providing a safety valve against more escalated explosions.

4. Some scholars suggest that these professionally-run variants not be called "self-help" groups; they may more appropriately be labeled as "support", "mutual support", or "counselling" groups.

5. As noted earlier, reports and discussions within most professional organizations (e.g., American Cancer Society, Leukemia Society of America, Association of Pediatric Oncology Social Workers) and most voluntary or lay groups as well (Candlelighters Childhood Cancer Foundation, local self-help groups) explicitly caution against such activity.

6. This project was funded partly by a Rackham Foundation grant from the University of Michigan and partly by the Candlelighters Childhood Cancer Foundation.

7. Funded under the auspices of the Office of Human Development Services, and a special Program in the International Transfer of Innovations, this project represents one of the new theory and research development efforts of the Program in Conflict Management Alternatives (PCMA). The PCMA is an interdisciplinary program that conducts research and action projects aimed at developing new ways of managing social conflict. It is particularly concerned with the relation between social conflict and social injustice or disempowerment of certain groups, and with the necessity for long-term change in social structures and processes as a condition for lasting peace.

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