

PROFESSIONALS' VIEWS OF THE  
"DANGERS" OF SELF-HELP GROUPS

by  
Mark Chesler

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## Professionals' Views of the "Dangers" of Self-Help Groups

My interest in this issue developed first as a result of personal involvement as a member of a self-help group for families of children with cancer, and later in the course of a national study of the relations between such groups and the medical systems that treat families and children. A constant issue raised by group members (parents of ill children) was a perception that professionals were reluctant to trust groups to operate independently from staff guidance and supervision; as a result, parents felt, professionals often created subtle restrictions and barriers to autonomous group operation. Informal conversations with professionals, even those advocating and supporting self-help groups, elicited their discomfort about an autonomous group process, discomfort often couched in language about the potential "dangers" posed by these groups. Convinced that exploration of the "dangers of self-help groups" was an opportunity to investigate key issues in group-hospital interaction, and more broadly in professional-client relationships, we began a systematic inquiry into professionals' views. Our inquiry proceeded according to grounded theory methods as described throughout this paper. Since there are many ways of doing grounded theory, we describe our approach in detail, in order to enrich methodological as well as substantive discussion. Thus, our purpose here is twofold: (1) to explore and generate substantive theory about professionals' views of self-help groups; and (2) to document some of the processes involved in qualitative data analysis.

Prior discussions of self-help groups instruct us in aspects of professional rhetoric and ideology, but do not provide very concrete images of this ideology, nor of how professionals and self-help groups actually interact with one another. After reviewing the literature regarding professionals' views of self-help groups and their analysis of the dangers of such groups, we examine data from a study of health care professionals working directly with self-help groups of families of children with cancer.

### Prior Literature

Although this paper begins with a review of some pertinent literature, we did not read much of this material until after data was collected and partially analyzed; as Glaser suggests, "reading the theoretical literature should be avoided when possible until after the discovered framework is stabilized (1978, p. 51)." The reason for this choice was to avoid the tendency to "test" prior conceptualizations or

theory, and to place priority on discovering meaning and generating theory from the data being collected. We did search the relevant literature later, in the midst of the process of data analysis and theory generation, after thorough grounding in the data. The literature review is presented first here, however, in order to ground the reader who is new to the phenomena under inquiry and to their scholarly history.

The literature on self-help groups is complex and often confusing. Efforts to define these phenomena emphasize relatively informal organizations, composed of and led by people suffering in common from a given condition or situation. In self-help groups, people do "for" and "with" one another, generating an alternative to sole reliance on professional expertise and guidance. Although this definition is relatively standard, the literature often fails to recognize important distinctions; thus, "support groups", "mutual support", "groups", "group discussions", "group programs", "group therapy", "group work", "group support", "social support", "peer support", "group meetings" and "helping" often are used interchangeably and carelessly (Killilea, 1976). One has to read carefully to discover which variety of self-help or mutual support is being discussed in any given article. The core structural distinction, made by Rosenberg (1984) among others, distinguishes between self-help groups, where the leader's "experience with the problem usually constitutes the authority necessary to lead the group (p. 183)", and support groups, where "authority for leadership emanates from expertise and training in groups or human development (p. 183)." In like fashion, Powell (1985) contrasts "hybrid" self-help groups with "autonomous" ones: the hybrid self-help group is sponsored or supervised by professionals while the autonomous group is led by people with the condition that calls them together. Mellor et al. (1984) create a continuum for categorizing groups on this dimension, extending from the "traditional structured professionally led group" to the "pure self-help group with no professional leader (p. 98)." Searching discussions of the differences between the "experiential" and "expert" knowledge that constitute the bases for indigenous or professional group leadership, respectively, are contained in Borkman (1976), Klass & Shinnars (1982-3), and Rheinharz (1981).

A second important distinction stems from groups' different ideologies and underlying goals or activities. Thus, Cordoba et al. (1984) discuss the differences among self-help, education/discussion and counselling/therapy groups. These functions may cut across group structures or leadership patterns, but professional leadership is most likely to occur in groups oriented to counselling/therapy and least likely

in self-help groups. In fact, Killilea (1976) argues that self-help groups utilize a "therapeutic process" that is quite different from traditional psychotherapy, and that these different processes require and utilize quite different leadership expertise/experience and roles. As Yoak & Chesler (1985) demonstrate in their studies of groups for families of children with cancer, formal emotional support is more likely to occur in professionally led groups, while informal sharing and mutual education are more likely to occur in parent-led groups. The resolution of concerns about professional versus lay leadership or control thus is related to conceptions of what does and should occur in different types of self-help groups.

Discussions of different types of support groups, and of the pros and cons of self-help groups in particular, often articulate a series of potential dangers or problems. These dangers or problems are based upon assumptions or experiences professionals have regarding the relatively autonomous form of self-help groups. Professionals seldom see many dangers in self-help or mutual support groups that they themselves run or guide, or that have clear goals with which they agree. If some groups are and will continue to be member-led, and also to relate to the professional system of care, it is useful to understand the nature and basis of professionals' concerns.

#### The "dangers" of self-help groups.

Discussions of the dangers of relatively autonomous self-help groups roughly sort these dangers into two dominant categories: a) dangers to members, and b) dangers to professionals. For the professionals creating this literature, it appears that the dangers self-help groups pose to members (patient and their families) far outweigh the dangers they pose to professionals themselves. These dangers usually are identified in the apparent interest of protecting patients/clients and improving support and service. Such altruism is, of course, a dominant feature of the professional ideology.

One oft-mentioned danger focuses on how self-help group discussions of deeply held feelings may upset some people in the group, escalating anger, anxiety and disrupting individuals' psychological defenses (Belle-Isle & Conratt, 1979; Binger et al., 1969; Heffron, 1975; Johnson & Stark, 1980; Kartha & Ertel, 1976; Ringler et al., 1981). The possibility that patients would "become terribly depressed, overwhelmingly anxious, even suicidal or psychotic as a result of talking together about having cancer (Ringler et al., 1981, p. 331)," is seen as an inappropriate increase of others' already considerable burdens.

The literature also cautions that as fellow-patients or their relatives share information and feelings they may spread medical misinformation and give rise to false fears or unrealistic hopes (Belle-Isle & Conradt, 1979; Deneke, 1983; Mantell et al., 1976). Peers and lay-people may also give psychosocial advice and, as Claflin notes, one root of professional resistance to self-help groups is the "prevalent assumption that peer support groups practice group therapy (1984, p. 125)".

Some professionals have argued that over an extended period of time groups may be "habit forming", act as a "crutch", and foster member dependency in ways that are inadvisable and inappropriate (Mantell et al., 1976; Toseland & Hacker, 1982). As groups seek to counter dependency upon professionals and professional orthodoxy, they may create an orthodoxy of their own. In so doing, they may place undue pressure on people to join and may urge deviants to conform to the group's ideology or practices regarding ways of thinking about or coping with their situation (Henry, 1978; King, 1980; Rosenberg, 1984).

Some of the typical dynamics of all groups, when they occur in this self-help context, also are seen by professionals as dangerous. For instance, several writers warn of group factionalism or cliquishness, and some note that groups' attempts to solve instrumental problems of management and maintenance may draw attention away from individuals' problems and concerns regarding themselves and their families (King, 1980). Rather than seeing involvement with others in group tasks as a positive development, as a way of gaining distance from intra-psychic stress, it is sometimes seen as an escape or diversion from "real" issues.

Many of these conceptions of "danger" are based upon assumptions about what is different when a professional is "running" or "guiding" a group, and the ways in which professionals' help groups avoid these problems. For instance, it is argued that professional training and experience leads to a form of expertise that is somewhat "objective" in character: it is based upon scientific knowledge and a certain degree of distance from immediate and heated feelings. (Rheinharz, 1981; Borkman, 1976). The lack of objectivity of non-professional leaders is sometimes seen to lead to inadequate individual support or counselling, as poorly trained leaders become over-involved with peers' dilemmas or lack perspective on individuals' problems. Indeed, Rosenberg (1984) argues that it also may lead an entire group to misconceptions of its role, to "heightened sensitivity about marginality" and to "self-fulfilling prophecies and/or delusions (p. 183)".

Commentary about the differences between professionally-led and member-led groups are not only often invidious in character, they usually are undertaken without sound comparative data. For instance, Lindamood, et al., (1979) conclude discussion of their roles in leading a group for bereaved parents with a gratuitous note that: "Subsequent discussions with members of a local self-help bereavement group which had no professionals involved supported the conclusion that objective leadership was preferable...(p. 1032)." While the authors may or may not be right, they fail to articulate the meaning of "objective" in this context, nor the advantages and disadvantages such a stance might engender among bereaved parents. Moreover, they do not analyze the potential costs, to themselves or their clients, of the acknowledgement that their own objectivity does not allow them "to fully experience the group process (p. 1033)." Finally, they fail to provide any evidence for their comparison and conclusion, other than some form of "subsequent discussion."

A second major form of danger reported in the literature, much less common, involves those dangers that self-help groups may pose to professionals. Chief within this category is concern about the development on the part of members of an anti-professional or anti-intellectual stance (Henry, 1978; Mantell et al., 1976; Rodolfa & Hungerford, 1982; Rosenberg, 1984; Toseland & Hacker, 1982). This stance is seen as working to clients' disadvantage, as they do not avail themselves of necessary services or appropriate services (Deneke, 1983); but it also works to the disadvantage of professionals, as they encounter resistance to use of their services. Anti-professionalism also may surface in the form of patient pain and anger directed at the staff (Ringler et al., 1981) or in direct challenges to the relevance of professionals' expertise and authority (Mantell, 1983; Wollert et al., 1984).

Another danger (to professionals) may arise as professionals seek to maintain their own roles or the stability of the institutions with which they are involved. For instance, Mantell (1983, p.47) suggests that some professionals fear that "lay people who adopt professional activities will squeeze professionals out of their jobs." In a somewhat different example, Silverman & Smith (1984) note that in a mutual help group for the physically disabled a dissatisfied patient was informed that "she could choose her physician, and was not obligated to stay in the clinic. Members gave her the names of several physicians who had worked out well for people with similar problems (1984, p. 85)." The fear that patient interaction will lead to a lessened need for professional services, or even to a loss of patients, is cited often as a basis of professionals' reluctance to refer people to cancer support groups (Cordoba, et

al., 1984, p. 28-29). As an antidote to these fears, The Leukemia Society of America's guidelines for professional facilitators of cancer support groups takes pains to point out that it is "a neutral organization and does not support one institution in the community over another (Family Support Group Guidelines, n.d., p. 10)".

Some authors, considering these dangers, worry about even the positive things that appear to occur as a function of autonomous self-help group activity. For instance, Knapp & Hansen (1973) report some of the positive actions members performed in a preventive therapy group they ran for parents of ill children (collecting blood for accident victims, sending cookies to American soldiers in Vietnam, participating in church functions). They note: "Underlying all these efforts was a need to help others, and do good, perhaps in the hope that it might save their child" (p. 73). Unfortunately, the authors provide no evidence for the attribution of this self-interest basis ("save their child") of parental motivation; was the hope of saving their child really the basis of involvement and good works? Concerns about danger may thus lead some professional observers to unwittingly convert positive outcomes and processes into dangers. More positive and altruistic interpretations of the motivations of people in crisis have been offered by Riessman and his colleagues (Riessman, 1965; Dory & Riessman, 1982), as they discuss the "helper-therapy" principle often operative in self-help groups. They argue that one receives benefits in giving to others. In sharing resources one may learn, grow, develop positive self-esteem, develop self-insight, find one is not totally bereft, and discover spare resources to offer others.

The professional role, as well as clients' activities that may encroach on this role, often are constrained by rules and norms about appropriate behavior in a peer or mutual support group setting. Chief among these, for professionals, is the need to avoid providing medical advice and therapy. For instance, The Leukemia Society of America's Family Support Group Guidelines state explicitly that "a family support group does not provide medical care, medical treatment, medical advice or psychotherapy (n.d., p. 8)". What is interesting about these warnings is that they are often violated in practice: they simply do not make sense in the reality of an informal group setting. People discussing their common problems do give and get medical advice; it is one of the most important things people share with one another. Although psychotherapy may be performed only by a formally credentialed psychologist or psychotherapist, peers who care for one another, who listen, talk, hug, and cry together undoubtedly are involved in "a therapeutic process" if not in "therapy". Unfortunately, no definition of therapy is offered

in most of these discussions, simply that it should not be provided. Such unclarity regarding the reality of interpersonal and group experience suggests that the primary reasons such prohibitions are made have less to do with meaningful statements about client/patient welfare, or with real-life experience, than with concerns about protection from malpractice suits, from physician resistance to unwarranted intervention with "their" patients, and from desires to pacify professional interest groups' notions of appropriate "turf". Perhaps these are the primary dangers for professionals.

Given the paucity of systematic empirical research, the extent to which any or all of these dangers actually exist is still unclear. We do know, however, that many scholars and professionals "see" these potential dangers in self-help group operations. In the following portions of this paper we report our inquiries into the nature and meaning of this professional phenomenon. We felt that fruitful inquiry had to explore the meaning systems professionals construct with regard to self-help groups and their associated dangers, and the ideologies (explicit or implicit) that underly these interpretations. Such meaning systems shape professionals' attitudes and behaviors and provide the frameworks within which they help patients and their families make sense out of their experiences and interactions with the medical care system. The focus on the discovery of meaning systems, rather than the test of a priori conceptions or theories regarding their meaning, led us to elect a grounded theory approach to the study of these issues (Glazer & Strauss, 1967). The derivation of inductive theory explaining these meaning systems occur subsequent to their discovery and elaboration, according to the following methods.

#### Methods

The data reported here were gathered and analyzed within the framework of qualitative research procedures, and qualitative procedures conducted in an inductive (non-positivist or non-hypothetico-deductive) framework. Careful reading of substantial literature in qualitative methods indicates that there are far too few details provided in most works as to why and how scholars code and analyze their data. While the methods of contextual coding and constant comparison are often invoked, they are seldom described in detail. In the interest of providing good case material for students and practitioners of qualitative and inductive methods, we elaborate our methods in detail in the following pages.

This inquiry into professionals' views of the dangers of self-help groups was undertaken as part of a larger study of the organization and operation of self-help groups for families of children with cancer (Yoak & Chesler, 1985). In this study, personal and group interviews were conducted on-site with members of over 50 local self-help groups. In addition to group interviews with parent members of these groups, interviews (some personal and some group) were conducted with some of those professionals (physicians, nurses, social workers) who worked closely with the local group.

Professionals were asked three relatively standard questions: (1) Some professionals say that self-help groups can be dangerous: have you ever heard that stated? (2) Have you seen evidence in the local group of such dangers actually occurring? (3) What do professionals mean when they talk about the dangers of self-help groups? The first and third questions do not necessarily focus on individual professionals' personal views; rather, they elicit descriptions and analyses of a professional ideology, of beliefs associated with a certain role. Interviews asking these questions were conducted with 63 professionals working with 35 of the 50 groups; some groups had no professionals working with them while others had several. While all 63 professional informants answered questions 1 and 2, only 48 responded to question number 3.

Once the interviews are transcribed verbatim or reconstructed (written from memory when a tape record is unavailable or undecipherable), the raw text is read carefully, and portions of the response that identify a "danger" are underlined. Here we depart from some approaches to developing grounded theory, because we are already approaching the data with a specific question in mind - the question of "dangers of self-help groups." Thus, the entire interview is not coded or analyzed for all its emergent categories or themes; the analysis is limited to this specific problem.

"In vivo," coding, coding that uses informants' own language and imagery, done directly on the text, line by line, is usually the first step in preparing a coding/analysis scheme, although it is done differently by different analysts (Charmaz, 1983; Corbin, 1986). Corbin also underlines the text, but both she and Charmaz appear to move immediately from textual inspection to code categories that interpret rather than reproduce the text. For instance, in analyzing field notes of her study of children's response to hospitalization, Corbin codes the underlined words of the text of "Today a 4-year old male child was hospitalized with possible pneumonia as "preschooler," "separation," and "confined" (1986, p. 103). We prefer to move more slowly, and the second step in our process involves restating the

underlined portion of the response, in words as close as possible to the original text. Since all later steps in the development and application of a coding scheme flow from this first reduction, it is done in a way that permits doubling-back to the larger context and detailed rechecking against the text, perhaps by several observers. In order to facilitate repeated checking of the utility, accuracy and reliability of this initial reduction, we conduct steps 1 and 2 in a side-by-side fashion. Below are several examples of in-vivo underlining of text and subsequent restatements.

**Step 1: Underline key terms in the text**

**Step 2: Restate Key Phrases**

Social worker, Gp. 3: The professionals are afraid people will be repeating misinformation, that people will compare one diagnosis to another and come back and say, "Why aren't we getting XXXX?" There is a fear that they will get people who are obsessed with the disease, and not coping well, and totally fixated in getting the secondary gains from the disease. Frankly, I've seen that happen in a few individual cases.

repeat misinformation  
compare diagnosis  
obsession with disease  
cope poorly  
fixation on secondary gains

Nurse, Gp. 6: Groups perhaps generate unwarranted criticism of professionals.

criticism of professionals

Social worker, Gp. 7: Professionals are afraid that a group could get out of hand, take power or just be harmful in some way.

get out of hand  
take power  
be harmful

Social worker, Gp. 10: Doctors feel threatened because groups may undermine their authority. Groups also may generate parental anger or dissatisfaction with the doctor and then go elsewhere. Groups make doctors struggle to maintain their practice: patients are money.

undermine authority  
generate anger at staff  
generate dissatisfaction  
change doctors  
threaten doctor's practice

Physician, Gp. 18: Professionals are concerned with retaining control. Groups also can sometimes generate misinformation. They also can stir up unnecessary emotion and promote too many questions which do not help people resolve problems.

concerned with retaining  
control  
generate misinformation  
stir up emotions  
promote too many questions

Patient educator, Gp. 19: Professionals feel that parents in groups are practicing medicine. Doctors are generally very protective and a little pompous. Doctors also are territorial; they may be worried that parents will get too educated and become less compliant.

practice medicine  
doctors protective  
doctors territorial  
get too educated  
parents less compliant

Physician, Gp. 21: Doctors sometimes feel threatened by groups because in them parents gain momentum and power and question the "whys" of treatment. Through the groups parents' power increases. Treatment is talked about amongst themselves and doctors feel threatened because they do not always have the answers.

gain power  
question treatment  
increase parents' power  
talk about treatment  
doctors not have answers

Psychologist, Gp. 21: Professionals fear groups because they may lead parents to resort to exotic treatments which could result in complications. Doctors fear loss of control. Doctors fear something new.

lead to exotic treatments  
complications  
doctors fear loss of control  
doctors fear new things  
reopen painful issues

Social worker, Gp. 26: Groups may reopen painful issues for parents.

Social worker, Gp. 43: Professionals have fears from the sharing and comparing of information. Parents also may hurt each other.

sharing information  
comparing information  
hurt each other

Physician, Gp. 50: Parents need a professional to guide them. Otherwise they won't understand what's happening to their children and will not know how to interpret diagnoses or cope appropriately. The staff fears parents will use non-conventional medicine; especially as parents compare treatments. Parents need knowledgeable direction from professionals to get benefits from a group. Parents' coping mechanisms may not be very healthy.

won't understand what's  
happening  
not know how to interpret  
information  
not know how to cope  
use non-conventional medicine  
compare treatments  
coping mechanisms may not be  
healthy

**Step 2: Restate key phrases in the margin of the text (see above).**

**Step 3: Reduce the phrases and create clusters.**

The third step in this coding process involves reducing the wording of the key phrases and organizing them into clusters. This step generally must be done several times, as different clustering patterns are tried, altered as phrases are moved to another cluster, and tried again. This process is a core element in the "method of constant comparison" (Glaser & Strauss, 1967). Since the articulation of one cluster as distinct from another cluster involves making comparisons, only a constant series of comparisons enables the coder to feel secure about the creation of a conceptually distinct category. In

our case, when one coder completes the clustering process another coder, starting from step 1, redoes the clustering. It is important to start from step 1, and not step 2, to ensure the maintenance of the context for key phrases contained in the original text.

As described eloquently by Glaser (1978, p.55), these analytic processes involve "fracturing the data, then conceptually grouping it into codes." The potential price of such fracturing, of course, is a loss of meaning contained in the textual context. Indeed, even with "in vivo" underlining and restatement in the margins it sometimes is impossible to be sure of the meaning of a given phrase, and hence its appropriate cluster, without re-reading the entire text. As two coders compare their results they continue the process of constant comparison, ending with some changed clusters and some new clusters. Some examples of the end result of this step, with phrases that are grouped together in clusters, follows (these examples are necessarily not limited to the text presented above).

Control will be taken away

proprietary control  
concerned with retaining control  
fear loss of control

Parent power will increase

take power  
gain power

Challenge

challenge their professional role  
being challenged

Create misunderstanding/misinformation

generate misinformation  
repeat misinformation  
misinformation circulating  
giving out misinformation  
generating misinformation  
misinformation can be exchanged  
won't understand what's happening

The completion of this step resulted in 40 apparently distinct clusters, four of which are represented above. With a total of 76 individual dangers noted, several of the 40 clusters had only 1 entry, and one had as many as 11 entries. Although each of the clusters illustrated above may appear internally coherent and consistent, we felt that 40 clusters were unnecessarily differentiated from one another and probably too great a number for feasible analysis.

**Step 4: Reduction of clusters...and attaching labels.**

The process of constant comparison method once again describes the operation of this step, often referred to as pattern coding or meta-coding (Charmaz, 1983; Miles & Huberman, 1984). These expanded code categories entail a greater level of abstraction, moving away from the concrete level of detail involved in Step 3. As clusters are reduced in number and combined, comparisons constantly are made at the boundaries of each cluster. Decisions about which entries go (and stay or be moved) into which cluster involve more implicit and explicit comparisons, and thus increasing levels of interpretation. The final result of this step was the creation of 10 meta-clusters of professionals' meanings of the dangers of self-help groups. These meta-clusters are outlined and discussed in the section on results.

**Step 5: Generalizations about the phrases in each cluster.****Step 6: Generating theory: memo writing that poses explanations.****Step 7: Integrating mini-theories in an explanatory framework.**

These next three steps involve analysis and interpretation of the coded entries. They are processes typical of all social scientific analysis, except that we undertake them here in an inductive rather than deductive manner. We are not testing or applying a priori generalizations or theory presented in prior literature, but trying to discover or generate themes that underlie and explain intra- and inter- cluster findings. In the results and discussion section we discuss the general meanings involved in each meta-cluster and generate theories that may explain why professionals see these kinds of dangers in self-help groups.

**Results and Discussion.**

Ninety percent (57/63) of the professionals interviewed reported that they had heard that there were dangers associated with self-help groups. However, only 24% (15/63) reported that they had seen evidence of such dangers in groups that they worked with or knew about. This dramatic difference is verified in other accounts of professionals' experiences. For instance, Black & Drackman report that fully 37% of social workers in large hospitals rarely or never referred medical and psychiatric patients to self-help groups; however, the 63% who did make referrals report no harmful outcomes (1985, p.100). This contrast between ideology or assumption and experience is important for several reasons. First,

the high prevalence of "knowledge" about the dangers of self-help groups suggests that perceived dangers are not haphazard or trivial. They are part of the belief system associated with a professional role and status. Whether they are learned on the job (from peer discussions) or as part of pre-professional socialization is impossible to tell from these data, but both possibilities make sense and are mutually consistent. Second, the low prevalence of dangers actually encountered or experienced suggests that self-help groups, at least as far as these professionals are concerned, really are not very dangerous, or at least not very often. The difference between dangers "heard about" and dangers "experienced" (90% v 24%) emphasizes the importance of considering professional ideology about self-help groups as ideology, and not as things that self-help groups really do that are dangerous. However, this does not mean that such ideology is irrelevant; it impacts on professionals' behavior (and perhaps on patients' and parents' as well) regardless of its congruence with first-hand experiences.

What is the content of this ideology? Table 1 presents the ten meta-clusters of dangers mentioned by professionals, with the incidence of each reported danger (Step 4).

(Insert Table 1 Here)

Meta-clusters numbers 2,3,4,8 and 10 focus on dangers that may accrue to parents, and numbers 1,5,6,7 and 9 focus on dangers accruing to professionals working with these groups. Although this division is undoubtedly arbitrary with regard to some individual comments, we will consider the meaning of these two major divisions as the analysis proceeds.

**Step 5: Generalizations about each (meta-)cluster.**

In order to lay the groundwork for a theoretical understanding of the potential dangers of self-help groups, at least as far as professionals are concerned, we examine each of the clusters in detail. By identifying and illustrating specific comments we can establish a basis for generalizing about the meaning of each cluster, and then for generalizing across clusters - if possible. In Step 5, we discuss each cluster briefly, providing several statements professionals made that were considered part of that cluster.

Among those dangers that professionals see as potentially harmful for members, the possibility that self-help groups might create emotional problems for parents is often anticipated in the literature.

Professionals' comments focus upon parents' release of their emotions in the group setting, and the lack of professional control or direction over this process. As some parents are overwhelmed by their own feelings, or their identification with others, they may experience pain and distress. In general, professionals argue that parents of children with cancer experience enough distress, and that is not advisable (indeed, even dangerous) for them to be involved deeply with additional distress from others. Some comments in this cluster include:

Doctors discouraged parents from talking with one another because they would intensify problems.

Groups also cause unnecessary depression and pain.

Parents with pathology may have that pathology supported by others who don't know how to handle it.

Groups may be dangerous if overreactive parents work up other parents.

Professionals' concern that parents' discussions may manufacture misinformation and spread false ideas also is quite consistent with prior literature. Sharing ignorance multiplies it, and may lead to rumors that encourage false hopes or undermine trust in the medical system. Misunderstandings also may promote confusion. Elsewhere we have argued that one of the primary stresses of being a parent of a child with cancer involves dealing with large amounts of new information about the diagnosis, treatment, prognosis and the medical system itself (Chesler & Yoak, 1984). If meetings with other parents provide misinformation, as opposed to information, they are likely to magnify these intellectual stresses. Some comments in this cluster include:

There is suspicion they are going to be priming the pump with pathological information.

Groups can sometimes generate misinformation.

Doctors don't want a parent giving out misinformation.

Quite a different cluster involves the danger that parents might learn too much: not become mis-informed but become too well-informed. Professionals noting this danger suggest that when parents compare notes and information they may reach a level of expertise that rivals that of professionals. As parents become well-educated they may resist professional direction without extensive and time-consuming explanations. This concern is not anticipated in prior literature, but is reflected in the following comments.

Table 1: Health professionals' views of the  
 "dangers" of self-help groups.

Danger (meta-)cluster	Incidence
1. Challenge the power of professionals.....	17
2. Create emotional problems for parents.....	15
3. Parents learn/know too much.....	11
4. Spread misinformation.....	8
5. Take over professionals' job (social work).....	6
6. Transfer doctors or increase physician competition.....	6
7. Question medical authority/judgment.....	6
8. Parents act as professionals.....	4
9. Emotional attacks on professionals.....	2
10. Group goals and objectives.....	1

Professionals have fears from the sharing/comparing of information.

Doctors are worried that parents will get too educated.

Professionals are afraid that parents will compare notes, compare protocols and learn of experiments.

The concern about parents acting as professionals involves a focus on parents helping each other in ways that appear to be therapeutic in orientation and intent. As parents attempt things that professionals assume are beyond their skill and training, activities that are normally reserved for professionals, they may be seen as endangering themselves and others.

Groups may be dangerous if members do things beyond their skill and training.

Professionals feel that parents in a group are practicing medicine.

Among those dangers that appear to threaten professionals' status and role, challenges to the power of professionals is the single most common danger mentioned. It focuses upon the ways in which peer support may reduce parental dependence upon professionals. As professionals are unable to control or guide parent group activity the power of their role may be compromised. In addition, some parent groups might go outside normal staff channels to achieve their objectives, perhaps mobilizing community pressure on the hospital to alter its patterns of service delivery. Examples from this cluster include:

Professionals fear being challenged.

Professionals are concerned with retaining control.

Doctors sometimes feel threatened by a group because parents gain momentum and power...through the group parent power increases.

As parents provide important resources to one another they may be seen as taking over the professionals' role, reducing the necessity for staff involvement. One aspect of danger in this kind of competition is replacement itself; if parents can do what a social worker can do perhaps physicians will conclude that there is no need for a paid social worker on staff.

Possible posing competition to social workers.

Social workers are afraid someone is going to step on their space.

A somewhat different danger is involved when parent groups are seen as encouraging the kind of information sharing that escalates competition among physicians, especially competition for patients. It is not a trivial matter for physicians to maintain a patient load adequate to guarantee a stable income for the hospital unit, to warrant outlays for new and expensive equipment or to justify added staff

positions. Moreover, many physicians feel that patients who transfer to other doctors or other forms of treatment will compromise their reputation in the community; they also are concerned that children may then get a less adequate form of care. For example, consider the following comments:

Staff fears parents will encourage each other to use non-conventional medicine.

Groups make doctors struggle to maintain their practice. Patients are money...they may go elsewhere for care.

Local doctors are afraid that the group will give information about other medical centers, and that parents may go comparison shopping for doctors.

Another threat arises when professionals fear that parent groups encourage questioning of medical authority and judgment. The concern here again is with information that may challenge professionals' authority and omniscience, especially in an area where uncertainty is the rule. Some argue that in order for physicians and other staff members to take and prescribe action in an area of great uncertainty, they must have the unquestioned compliance of patients and patient families. The practice of medicine in a situation where the stakes are so high (life and death of children) is difficult enough without parents being encouraged by groups to ask lots of inappropriate and unnecessary questions.

Groups can promote too many questions.

Doctors may have to take more time to answer questions..they become threatened by questioning.

Groups generate questioning of doctor's judgment.

Finally, some professionals mention parents' emotionally inappropriate attacks on them as a potential danger. The primary concern here is that under great distress, parental pain or anger may be inflamed by group discussion and displaced onto professionals. Some comments reflecting this danger include:

Professionals are worried about the displacement of anger onto them.

Groups generate unwarranted criticism of professionals.

Interestingly, this last category is much more prominent in the literature than it is in this sample. One explanation is that our coding process generated a clear distinction between concern about emotional attacks on professionals and concern about challenges to professionals' power and authority, a distinction not clearly made in the literature; indeed, there were far more mentions of the latter cluster.

### Step 6: Generating mini-theories: memo writing that poses explanations

As these (meta-)clusters are created and refined, compared internally and contrasted with one another, we are well into the process of generating theory that explains their meaning. Glaser suggests that these implicit comparisons should be articulated in a series of memos; in fact, he suggests, "one should always interrupt coding to write memos (1978, p.55)." Memos are a written record of the process of analysis, and of one's own intellectual search, and they represent tentative bridges from data to theory. They help overcome total immersion in the data and slowly construct pieces of a conceptual or theoretical framework. Memos can include the scholar's reactions to the data, reflections upon similar experiences, dreams and flights of fantasy, attempts to play devil's advocate with oneself, reactions to other readings, efforts to provoke feedback from others, and the like.

Two examples of analytical memos written during this process of analysis, memos which themselves are an important step toward building theory, follow. They are formalized/edited here solely to omit spelling and grammatical errors.

Why is too much information a danger? I was prepared to hear professionals state that parent misinformation of lack of information was a danger, but why too much information? What is involved here? I remember an article I read many years ago, in which Rieff wrote about knowledge being the basis of professional practice.\* Therefore, he argued, if one wants to diminish the power of professionals, one has to democratize the knowledge base upon which professionalism rests. So perhaps the danger to professionals is that as parents get informed, the professionals no longer have that edge in expertise and thus status and control. In fact, I invited the article for a special Journal issue I was editing after hearing him give a talk.

I also remember our interviews with parents of children with cancer, where the most highly educated parents more often report "problems" with the medical staff serving their children.\*\* In analyzing these data, I thought that educated parents might represent a threat to professionals because they might know as much as they do, or that they might understand the uncertain knowledge base upon which much social work practice and even some medicine rests. In addition, I thought that highly educated parents also were more active copers, thus being more assertive/aggressive and making more demands and even criticisms of professionals. Maybe this is a piece of what is at stake here: as groups educate parents, parents get more active; as parents become more active, they violate the passive patient role and become an irritant. This certainly links the category of information/education to the category of challenging professionals.

The "too informed" concern also may connect to the issue of comparing treatments and experiences with physicians, and the worry that comparing may lead people to switch.

What is the issue with concern about parents' emotional problems and inappropriate coping?

Sure some parents cope inappropriately, but who's to say? Why is this such a powerful issue or concern for professionals? Maybe professionals, especially social workers, feel they are the "experts" in coping, so they "know" how parents should react. I think the group arena generally helps people cope more appropriately, rather than less so, so what's up?

When I talk with parents about this issue,\*\*\* they say that nothing that can happen in a group is any worse than what has already happened - the information that their child has cancer is worse than anything else, so why worry about the group process? But that's what parents say. What are professionals worried about? Maybe they are a little worried about themselves, and about getting in over their own heads in an intense conversation with a lot of fear and anger and crying and hugging and stuff. Maybe, since they haven't had the experience of being a parent of a sick or dying child, they are afraid they don't know how to help, or even behave, in the face of such strong emotions.

When I have sat on professional committees, I have heard physicians, social workers, and agency executives talk about this issue as a major reason trained people ought to be leading groups - untrained leaders may do damage. But untrained people help each other all the time. Is the issue under whose auspices - is the hospital accountable - untrained people help? Basically, why are they so worried about parents who are not their responsibility? They are adults, and ready to take risks. I don't think it is likely that we are going to hurt each other; I have a lot of faith in the natural good sense of people working together like this.

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\* Later unearthed as Rieff, 1974.

\*\* Chesler & Barbarin, 1984.

\*\*\* Referred to by Douglas (1976) as a process of seeking explanations, or verification of theorizing, by seeing if informants recognize or accept them.

These think pieces are done rapidly and informally, to record ideas as they come, and before they fly away in the midst of other, more urgent data collection or analysis tasks. They not only create analyses within (meta-)clusters, but also begin the process of comparing and contrasting cluster with cross-cutting ideas.

#### **Step 7: Integrating theories in an explanatory framework.**

The elaboration of each of these clusters of dangers and the creation of analytic memos begin to address the question of why such dangers are perceived by professionals. Moreover, the patterns that exist among these explanations may embrace a wide range of dangers in a single series of explanations or in an integrated set of theoretical statements. This search for thematic patterns in the data set is complemented by reflection upon parallel themes that may exist in the scientific literature on professionals' ideologies and roles.

A critical phase of theory building rises above the internal analysis of each cluster of dangers, looks back over all the individual statements and all 10 clusters and tries to understand what common themes underly the entire data set. One theme constantly emerging from these statements and clusters is the image of control exercised by professionals and their perception that autonomous parent self-help activity (and groups) threatens professional control. Control of what? Professionals' control of various aspects of health and medical care is rooted in the right and power to exercise a monopoly over health

care: a monopoly of the knowledge base upon which care is based; a monopoly of practice or service in delivering medical and psychosocial care; and a monopoly of moral values regarding how people should behave when in contact with the health care system. Threats to this triple monopoly may be the fundamental underlying danger!

Several scholars indicate the extent to which special training and experience are required for access to a professional role and status. Certification in a specialized base of knowledge is an essential ingredient of a profession and a necessary basis for according professionals special rights and privileges in a democratic society. Behavior that challenges the monopoly of knowledge that undergirds the profession of medicine challenges the very basis of the profession (Reiff, 1974). Not only is the effective care of patients or clients at stake here, so is the privileged social position of the professional. As Friedson (1970) notes, the professional monopoly on the applied uses of medical knowledge and technical expertise often leaks into social and interpersonal status and power as well. Several perceived dangers reflect professionals' fears regarding ways in which self-help group activity may challenge their monopoly of knowledge: #s 3, 4, and 7. Parents who learn a lot (too much) and who question medical authority and judgment are asserting their knowledge base to professionals, and some professionals clearly feel that an independent patient/parent knowledge base threatens them. Concern about parental misinformation further expresses the view that a professional monopoly is necessary in order to contain the spread of misinformation. However vital professional knowledge is to the structure of a profession, and indeed to the effective care of ill children, the preservation of a monopoly, per se, may be at stake here.

In addition to a monopoly of knowledge, a monopoly of service or practice is an essential ingredient of a profession. If anyone can practice medicine, or psychotherapy, why should any practitioner be accorded special rights, pay and privileges? Moreover, if anyone can practice such arts, how can an unwary or uninformed public be protected against ignorant practitioners, charlatans, quacks and fakers? In operation, the requirement that professionals be credentialed and certified by the state is the means by which a monopoly of practice is guaranteed - both to the needy public and to the practitioner who has undergone lengthy and expensive training and preparation. Several perceived dangers reflect professional concern about a challenge to their monopoly of practice/service: #s 1,5,6,8. Concern about challenges to the power of professionals clearly reflects concern about patient

establishment of limits or directions for a role that professionals feel they themselves ought to define. Bliwise & Lieberman (1984) note that "service delivery is rarely controlled by the client", and that "Self-help organizations are unique among help systems in that the client rather than the professional or an external agency has primary responsibility for care (p. 227)".

The concern about the power to control and maintain accountability over the delivery of services is escalated when professionals perceive that parents in self-help groups are beginning not only to challenge professionals' power, but to take over their job and to act as professionals as well. As Claflin points out, it is difficult for professionals to "share treatment responsibilities with patients or patient families (1984, p. 126)". If parents begin to do professionals' jobs, they also reduce parental dependence upon the professional, thereby reducing professional power as well. As Hasenfeld has argued in a slightly different context (1987), professionals and professional organizations seek to maintain their power over clients, as a root basis of their general social power, at all costs. Patients who "comparison shop" present a slightly different challenge to this service monopoly; although they do not challenge the monopoly, per se, they do challenge any single professional's ability to maintain monopolistic control over her/his service sector (thus "my patients" or "her patients"). This is no idle concern, in a time when federal cutbacks of funds for health care, budget restrictions on human service institutions, and automation and computerization lead to cutbacks in personnel (LaVoie, 1983; Mantell, 1983). The fear that self-help groups will encourage members to try different doctors, and encourage competition among physicians, threatens some professionals' economic security. Pressing this concern is tantamount to arguing for monopolistic control over the medical marketplace and against free trade.

A third monopoly often defended by professionals is the monopoly of moral values that define patient behavior and the patient-professional relationship. This monopoly is neither as clear nor as firmly entrenched as the other two, but as Featherstone has pointed out, assumptions about medical competence and superior knowledge often leak into assumptions about superior values, life styles and coping strategies (Featherstone, 1980). The power to define and label appropriate and inappropriate coping behavior permits professionals to make (and often enforce) judgments about the moral inadequacy of clients who cope in ways that differ from those that professionals prefer. As Katz notes, "If consumers do not conform to professional expectations, or follow the requirements laid down by the service agency they are thought to be resistant or refractory (1984, p. 233)." The key here is resistant

or refractory, rather than different: the conversion of "different" coping styles or service preferences into "inadequate" or "wrong" styles or preferences is the signal that moral judgments are being made. Professional assumptions of a monopoly in this regard may not only be intolerant, it may create a "danger" for parents, especially if moral superiority is used (knowingly or unwittingly) as a screen for psychological self-defense. For instance, in a startlingly forthright article, Ringler et al. (1984) discuss their own fears and perceptions of the dangers of self-help groups for cancer patients. They admit that many of their fears are based more on their personal anxieties and defenses than on rational judgments about what goes on in groups or what is good for parents. They articulate one of the intra-psychic bases of their own fears as follows: "Under the guise of 'protecting the patients', we were actually projecting our own terror at disfigurement, pain, loss of functioning, and death onto the group members....many of the group members were more than ready to look at those terrors (Ringler et al., 1984, p. 339)". These professionals' moral judgments regarding what patients were or should be ready for differed from those of the patients themselves. Instead of honest exploration of these differences, or support for different styles, these professionals sought to impose their judgments on patients by controlling the group's agenda and process. Fortunately, Ringler, et al., were attentive to their attempt at imposition, learned from its erroneous judgment, and are honest enough to admit it - in print! Judgments that represent monopolies of moral choice are even more dangerous when they are rooted in demographic features common to professionals: white racial groupings, male-dominated medical systems, and middle and upper middle class backgrounds. Then the choices made by members of racial minority groups, women and less affluent patients and their families are especially unlikely to be tolerated or supported.

#### Conclusion

It is clear from these data that professionals' views of the dangers of relatively autonomous parent self-help and support groups are more often discussed in theory than actually experienced in practice. Moreover, many of the dangers that professionals do encounter represent threats to their own established ways of thinking and acting as health care professionals. Some dangers, however, appear to professionals to exist in reality, and to threaten parents' own health and welfare. Finally, these dangers are not haphazard or accidental; they are rooted in structural aspects of the health care profession, in the monopolistic organization of professional knowledge, practice and moral judgement that so clearly characterize contemporary health care. They are especially likely to occur in the organized operations of

highly complex and technical health care systems, such as those involving children with cancer and people with other serious and chronic illnesses. As Katz (1984) notes, self-help groups have the "corollary (social) benefit of reducing monopolistic social controls by professionals (p. 234)". This "benefit" is often seen by professionals as a danger, or as underlying other specific dangers.

To the extent that specific dangers can be demythologized and disaggregated, and discussed in concrete detail between professionals and parents, there are grounds for collaboration in the provision of multiple forms of organized social support. However, to the extent that these dangers, discussed or not, are rooted in permanent and highly defended aspects of current medical monopolies, they will be very resistant to reasoned discussion, problem-solving, and change. Moreover, when change in professional attitudes and behavior regarding self-help groups occurs, they will generate other pressure for changes in the organization of staff roles and medical care itself. These changes will press for non-monopolistic forms of interaction between professionals and patients/parents, forms that adopt more symmetrical partnerships around the sharing of knowledge and expertise, around joint control of practice and practice options, and around adoption of plural norms about moral behavior.

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Table 1: Health professionals' views of the  
"dangers" of self-help groups.

Danger (meta-)cluster	Incidence
1. Challenge the power of professionals.....	17
2. Create emotional problems for parents.....	15
3. Parents learn/know too much.....	11
4. Spread misinformation.....	8
5. Take over professionals' job (social work).....	6
6. Transfer doctors or increase physician competition.....	6
7. Question medical authority/judgment.....	6
8. Parents act as professionals.....	4
9. Emotional attacks on professionals.....	2
10. Group goals and objectives.....	1