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SUPPORT ORGANIZATIONS FOR PARENTS OF CHILDREN WITH CANCER AND CANCER ASSOCIATIONS: LOCAL AND NATIONAL PROSPECTS AND PROBLEMS

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Throughout the world parents of children with cancer are organizing in increasing numbers to create local and national self-help and support groups and organizations. In this effort they are part of the tremendous growth of voluntary self-help efforts, sometimes called a "revolution" in health care, public service and community mobilization (Gartner and Riessman, 1984; Katz and Bender, 1990; 1976). Sometimes parents form and conduct these groups in the context of harmonious and supportive relationships with local or national Cancer Associations, and sometimes these relationships are characterized by conflict and tension. Like similar relationships between parent support groups and medical staffs, these are important issues to explore: they affect the social, emotional and even physical health of children with cancer, their families, and potentially the conduct of medical care. In this paper we explore such interorganizational relationships by: (1) setting the stage with some examples of how Childhood Cancer Parent Groups/Organizations (CCPOs) and Cancer Associations (CAs) relate with one another; (2) discussing what it is that Childhood Cancer Parent Organizations do - locally, nationally and internationally; (3) analyzing the roots of interorganizational conflict; (4) suggesting some ways of working with such conflict and the prospects of cooperation/coalitions.

Background

Parent self-help and support groups and cancer associations both are concerned with the physical and emotional/social health of children with cancer. But their roles in this common concern are quite different: their interests and resources differ greatly. As a result, the history of relationships between these parties has contained substantial conflict and negotiation as well as

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mutual support and cooperation. In many local and national situations, medical professionals and Cancer Association staffs have been instrumental in initiating or helping to initiate parent groups and organizations. But all too often these cooperative beginnings have devolved into struggles over fund-raising, mission priorities, institutional loyalties and autonomy.

In the United States, for instance, a study of 50 local self-help groups of parents of children with cancer indicated that 48% had helpful contact with local offices of the American Cancer Society; 36% had “no contact” or “no helpful contact”, and 16% had negative contact (Chesler and Chesney, 1995). The negative or non-helpful contact included unavailability or lack of interest on the part of ACS, struggles over ACS’s perceived desire to control or “guide” the content of group meetings and newsletters and ACS’s efforts to limit independent fund-raising by parent groups. At the national level, the national Candlelighters Childhood Cancer Foundation, an educational clearinghouse linked to over 400 local U.S. self-help and support groups for parents of children with cancer, recently elected to “transition to independence” from the American Cancer Society. For 20 years the American Cancer Society provided CCCF with between 60%-75% of its yearly budget. In return, national CCCF had agreed not to conduct public fund-raising efforts. But over the years this relationship had been fraught with conflict and struggles over issues such as: ACS efforts to control the content and style of CCCF newsletters and programs, disagreements about either party’s relevant expertise, exclusion of ACS sponsors and funders from CCCF plans and programs, exclusion of parent representatives from ACS sessions focused on childhood cancer, professional criticism of parental expertise and parental criticism of ACS priorities and expertise, mutual rumor-mongering and gossip about leader personalities, and occasional mutual disrespect of either organization’s priorities, operations and staff (I emphasize that disagreement, disrespect, attacks and gossip flowed in both directions). In addition, CCCF’s programs and parents/families’ needs outgrew the level of financial support ACS felt able and willing to provide. In the transformation of this 20-year relationship, in 1996-97 CCCF and ACS formed a Task Force to decide upon their joint future. ACS offered to fold CCCF entirely within the ACS structure (to operate within its Atlanta national office and mostly with its staff) or to cease providing financial support. Rather than lose its identity and control over its own staff and programs, CCCF decided to become financially independent of the ACS. At this point it remains

to be seen whether Candlelighters can generate an independent financial base quickly enough to sustain its operations on a national scale.

Several other national level Childhood Cancer Parent Organizations report similar local and national tensions in their relations with national Cancer Associations. For instance, in 1995, the Childhood Cancer Foundation of Canada severed its financially dependent relationship with the Canadian Cancer Society...for similar reasons and as a result of similar tensions. In Germany the German Leukemia Society (Deutsche Leukämie-Forschungshilfe - the German CCPO) reports an “ambiguous” relationship with the German Cancer Association (Deutsche Krebshilfe), involving a subtle power struggle with “big brother watching every step of the parent groups’ movement”. The German CA appears quite concerned about the parent organization’s effort to fund-raise. In Sweden, the BarnCancerFonden (CCPO) reports “no sustained relationship” with the national CA. When the Swedish CCPO started it requested assistance from the Swedish CA but received none. As a result, the Swedish CCPO developed independently and autonomously, and now raises millions of Swedish Krone every year for services to medical personnel as well as families, for research on childhood cancer, and for support of medical facilities. A similarly separate and independent relationship is reported by the Italian Federation of Associations of Parents of Children with Onco-Hematologic Diseases (Federazione Italiana Delle Associazioni di Genitori di Onco-Ematologia Pediatrica).

In some nations a more collaborative, but still cautious, relationship has developed. For instance, in The Netherlands the Dutch Cancer Society (Nederlandse Kankerbestrijding/Koningin Wilhelmina Fonds) and the Dutch Association of Parents, Children and Cancer (Vereniging Ouders Kinderen en Kanker) do cooperate. The parents’ organization, initiated in 1989, organized on an independent yet collaborative basis, with clear lines of differentiation between itself and the CA. As is the case in many nations, the Dutch CA focuses primarily on adult cancers, and on fund-raising for scientific cancer research, while the Dutch CCPO focuses solely on children’s cancer and deals with many local and personal socio-emotional and educational issues of concern to young families. Yet there are several indicators of their collaboration: the CA provides the national parents’ organization with a small portion of its yearly budget, leaders of the two associations meet twice a year to share information and program ideas, the Cancer Society purchases and distributes books and dolls created by the parent organization, and the parents’

association is permitted to raise public funds explicitly to meet the psychosocial needs of children and families. In order to get to this effective collaborative state, over the years, certain issues have had to be negotiated (and renegotiated): the Cancer Society's "overuse" of children in their fund-raising appeals and their preparation of materials for patients and families that do not include a focus on children or materials aimed at children and families without consulting the expert resources of the parents' association. Similar patterns of cautious collaboration, with bumps and potholes along the way, exist in other nations.

While these conflicts sometimes take the form of heated exchanges among individuals few of them involve "mean people"; there seldom are personal enmities here. The common nature of the struggles, if not the outcomes, of these inter-organizational relationships makes it clear that these are structural/cultural problems of trans-national character, not the result of individuals' predilections or national idiosyncrasies. How then can we understand these conflictual relationships, those that are in open conflict and those that continue in covert conflict while maintaining collaboration? What are their structural and cultural roots? And how have CCPOs and CAs dealt (successfully or unsuccessfully) with them? In the following discussion we focus primarily on relationships between national level CCPOs and CAs, although the conflicts, and their roots and responses, often are paralleled at the local level.

Methods

This report is part of larger research effort focusing on self-help and support groups for parents of children with cancer. Several data sets comprise the source material. In the United States a staff conducted a series of surveys, participant-observations and intensive interview studies with parents and professionals (medical professionals and CA staffs) active in over 50 local self-help groups for parents of children with cancer (reported in Chesler and Chesney, 1995). I also conducted participant-observation as a member of the Board and Executive Committee of the U.S. national parents' organization, the Candlelighters Childhood Cancer Foundation, and as a member of several committees and conferences of the national cancer association, the American Cancer Society. In the international arena we have gathered survey and interview data from leaders of more than 25 national-level Childhood Cancer Parent Organizations in different nations, have visited local and national parent organizations in several different countries, and I have

participated as a member of the Executive Committee of the international organization, the International Confederation of Childhood Cancer Parent Organizations (known affectionately as “Icky-poo”, an appropriate moniker for an organization concerned with children’s responses to chemotherapy and related treatments and hospitalizations). It should be clear that I author this report not only as a social scientist, but simultaneously as an advocate of parent self-help organizations devoted to the care and empowerment of families of children with cancer.

What are parent groups/organizations up to?

These conflicts and struggles will be understood best if we clarify what it is that groups/organizations created by and for parents of children with cancer do. Such parent groups operate at the local and national, and now international, level.

At the local level, in specific communities and often linked to specific treatment centers, effective parent groups generate programs that respond to the major stresses that parents of children with cancer face (Chesler and Chesney, 1995). As long as children get cancer parents will try to find the resources to aid their children and themselves; in so doing parents reach out to one another and find, join or create local groups. The mix of these stresses, and therefore group activities, differ according to the needs of parents in different locales, and the resources available to them, but in general they have five elements. (1) Informational stresses - groups provide parents with information about the disease and its treatments, about psychosocial issues, and about the medical center and available resources. They do this through arranging staff presentations and parent panels, and creating newsletters and libraries. (2) Practical stresses - groups ease parents’ burdens of everyday living, including child-care and financial responsibilities. They do this through the provision of financial assistance, lodging for parents who must travel long distances, respite care, and information about coping strategies. These issues are especially potent in the poorer nations and areas of the world, where basic medical treatment (trained expertise, chemotherapeutic drugs, post-treatment access to clean water and air) are either unavailable or prohibitively expensive for all but the very affluent. (3) Interpersonal stresses - groups support parents who feel isolated and awkward with their prior families and friends and provide them with alternative social networks. They do this through group meetings and discussions, connections with veteran parents who know what they are going through, social and

recreational events for the entire family, and home and hospital visits. (4) Emotional stresses - groups help people deal with the personal trauma of a child's life-threatening illness, with potentially intense familial conflict and confusion, and with the ups and downs of hope and fear attendant upon treatment. They do this through peer affirmation and co-counseling, "emotional rap" sessions, mutual empathy and arenas that encourage sharing of deeply held feelings. (5) Existential or spiritual stresses - groups help people "make sense" of their experience and to place it within a framework of belief in a spiritual or secular faith, including issues of religious belief and challenge. They do this through the creation of "narrative communities" wherein parents discuss their experiences and struggles with God and Fate, where they "make sense/meaning" of their past and future situations. Thus not only do individual parents create their own stories, the groups also create an embracing meta-narrative of stress and struggle and community. In responding to all these stresses, and through all these activities, parent groups often both work with local medical systems/personnel and attempt to create change in these systems (for examples from the US experience, see Chesler and Chesney, 1995, pp. 235cf).

Local parent groups come in many different sizes and shapes. Some are quite large (30-50 active members and several hundred on a mailing list) while others are small (4-6 members). Some groups create a very formal structure, with by-laws, elected officers and a not-for-profit tax exemption (this is especially the case for those groups that raise substantial funds) while others are quite informal and emphasize personal conversations (Smith, 1992, notes how prevalent it is for self-help groups of all types to be organized informally at the local level); many do both. Some groups are long-lasting (in existence for 20 or more years); others vanish in 2-3 years as leaders burn-out or as their children pass through this crisis (via either death or cure); still others may lie fallow for a while and rise Phoenix-like when newly energized parents emerge and decide to recreate a lay support system. Some groups are run by medical staff members (these are not really parent self-help groups although they may be a useful form of support and counseling) while others are governed by parents themselves, perhaps in coalition or collaboration with professionals. As major medical centers, especially those with large specialized children's cancer treatment programs, expand their interdisciplinary and psychosocial services, they are likely to preempt, duplicate or even Coopt the possibilities of independent parent involvement and

organization. Problems of access, transportation and networking make it more likely that medical staff members play these key roles in poorer areas (and in poorer nations, as I note below).

At the national level, parent organizations generally seek to coordinate and share information and resources (sometimes including money but usually information, advice and support for leaders) among various local groups via meetings, conferences, newsletters and electronic media. In addition, national groups often have access to influential policy-makers and to the ear of national Cancer Associations and legislatures concerned with cancer policy, health benefits, funding of childhood cancer research and treatment, environmental regulations that impact cancer, psychosocially sensitive treatment protocols, etc. They often are advocates of change in the delivery of medical and psychosocial care, and thereby represent parent concerns and establish liaison with national organizations of oncologic physicians, nurses, social workers and psychologists. In the United States, which system I know best, the Candlelighters Childhood Cancer Foundation also operates an information hotline for patient/family concerns, an ombudsperson system for second opinions on medical and legal matters, and a leadership training program and information network for current and future leaders of local parent groups. In other countries as well, national level organizations provide local groups with services that would be difficult and costly to duplicate at each local site (e.g., funds for group activities or to support individual families' needs, a national newsletter for parents or young people, camps for patients or survivors or siblings, and resources for group leaders). And most national organizations of childhood cancer parent groups sponsor yearly meetings, either of all parents or of group representatives.

At the national level there also is substantial variety in how and when groups are organized, as reflected in Figure 1 (note that since the data in this figure come from national parent organizations that are part of the ICCCPPO they are likely to be those that are most highly organized, but even here there is considerable diversity. This figure can be updated yearly, as many more previously unorganized or informal national parent organizations are developing and responding to the ICCCPPO call for mobilization and representation). Of the 24 national CCPOs currently represented in ICCCPPO, 14 were founded prior to 1990: some were initiated by parents of children with cancer, some by health care professionals, and some by professionals and activist parents working together. All these organizations have national Boards of trustees or overseers,

ranging in size from 5-17; and in every case the national Boards are dominated (60%-100% range) by parents, with some professional medical staff members and some long-term survivors of childhood cancer also sitting as Board members.

The size of these national organizations varies considerably. The United States parents' organization counts some 400 local groups in its family, Canada 49 and Germany 50; but the Japanese association (Children's Cancer Association of Japan) has only 11 local chapters, Sweden 7, Iceland (The Icelandic Childhood Cancer Parent Organization) and The Netherlands 1 and Venezuela (Asociacion Venezolana de Padres de Ninos con Cancer) 2. Similarly, they vary greatly in the amount of funds they raise: Parent associations in Japan, Sweden, Italy (Comitato M. Verga) and Austria (Kinder-Krebs-Hilfe Dachverband) each raise more than \$1,000,000USD annually, while associations in Portugal (Acreditar-Movement of Portuguese League Against Cancer), Greece (FLOGA and IASO) and other nations exist with an annual budget well under \$50,000USD; some CCPO's, particularly those in the less affluent nations, have no funds at all.

These national organizations vary much less in the ways they raise funds and the uses to which they put these funds. A few CCPOs receive a subsidy from their national CA, but almost all raise funds from public donations and corporate or governmental grants. Several solicit membership fees from parents/families and friends (Switzerland, Greece, Netherlands, Japan, Morocco) and several others require local groups to contribute to the national organization (Germany, Italy). Almost every CCPO maintains an office (and 13/24 have at least 2 paid staff members in this office). Funds are expended for educational programs (aimed at the general public, parents of children with cancer, medical and social service staffs), newsletters and meetings that link parents on a personal and/or regional/national basis, support for medical research and facilities and staff, services to families and children in terms of financial assistance or special housing and travel, and development of local groups.

In some national organizations there are strong lines of accountability between local groups and the national organization. This is true in Canada, Germany and Sweden. On the other hand, in the U.S. there are only informal linkages among local groups and between local groups and the national organization, with the latter operating primarily as an information/education clearing house and networking organization of semi-autonomous grassroots groups. The latter form is also common in nations where groups are only beginning to form and where a true

national organization has not yet emerged. Part of the difference in national-local forms may be related to the history of parent organizing efforts, and the extent to which national organizations emerged from preexisting local groups (bottom-up) or established themselves first (or early) and set out to create local groups (top-down) (Hunter, 1992). Zald (1970) emphasizes the difference between the top-down (or corporate) model where control is centralized and the bottom-up (or federation) model where the voluntary participation of local units defines the existence or power of the national organization. In addition to issues of origins and tightness-looseness, the difference between power primarily being located at the national or local level means that some national organizations' fortunes rise and fall with the economic and political progress and commitment (or lack thereof) of strong locals. Obviously, some local groups will have more influence on national programs and operations than will others.

At the international level a new organization, the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), has emerged. Formed in the mid-1990s, ICCCPPO now has member organizations of parents of children with cancer representing 24 different countries. ICCCPPO has several core goals: (1) Education - of parents, educators, physicians, nurses, etc. Parents and parent organizational leaders have areas of special experiential expertise that, when shared, can increase others' knowledge and help direct services more appropriately. (2) Public awareness - of the general public with regard to childhood cancer, children's and families' needs, the increased likelihood of survival and normality, and the continuing need for medical and psychosocial checkups and support. The ICCCPPO perspective emphasizes the need for greater awareness of the facts that while childhood cancer can be cured 70+% of the time, this is happening only in the economically wealthy nations. In poorer parts of the world, where 80% of the childhood cancer diagnoses occur, similar diseases are being cured only 20% of the time - inadequate medical financing, lack of adequate medication, lack of up-to-date training and supportive services, and poor public health and nutritional conditions account for this tragedy. (3) Mobilization and development - of parents and parent groups at the local and national levels. ICCCPPO seeks to prepare and train parents to create and lead parent groups and so strengthen this world-wide movement. In addition, parents are encouraged to act as advocates for their children with regard to medical and psychosocial services. (4) Advocacy - of adequate

medical and psychosocial treatment, of action against social stigmatization and discrimination, and for advance in “medical and psychosocial cure” rates throughout the world.

ICCCPO implements this agenda through representation and liaison to national and international Cancer Associations and physician organizations (e.g., SIOP, ESO, MISPHO), through newsletters and pamphlets distributed to national parent organizations, through visits to member organizations and meetings at which member organizations share their experiences and suggestions, and through a variety of special projects. One of these projects attempts to promote “twinning” relationships, wherein medical staffs and parent representatives in wealthier nations create personal exchange, training and resource sharing, and ongoing linkages with staff/clinics and parent organizations in poorer nations. It is precisely these international exchanges of information that led to the realization of a common experience of conflict between local/national Childhood Cancer Parent Organizations and local/national Cancer Associations.

As Hunter points out, such “suprafederations” are increasingly common on the national or international scene: they “are in effect defining an organization field or ecological niche populated by organizations of a similar kind (1993, p. 129)”. The member organizations of ICCCP share more than a common interest in the struggle with childhood cancer; they also conduct fairly similar programs, encounter generally similar organizational problems, draw on similar personal and material resource bases, and are located in roughly similar external environs - including their relations with national Cancer Associations.

The roots of conflict

Local and national self-help and/or support groups for parents of children with cancer and local or national cancer associations share a common general concern for the effective medical and psychosocial treatment of children with cancer. But their stakes in this common concern, and their approaches to the issues, are very different. Figure 2 summarizes a discussion of the differences between medical personnel and parents working together locally on the agenda of childhood cancer (Chesler and Chesney, 1995, p. 206), and these distinctions are more or less relevant to the differences between the staffs of CAs and the active members of CCPOs.

In the case of cancer associations and parent groups/organizations, these differences are raised to an organizational level. The issues are not ones of personality or of “good and evil”, but

of different organizational missions, goals, and operating procedures. CAs are governed and managed by professionals - by medical clinicians and researchers (Epstein, 1978) and professional bureaucratic managers: CCPOs are led by parent volunteers, or in some cases professional parent managers. In the U.S., Germany and The Netherlands this difference has been reflected in the Cancer Associations' discomfort with, and occasionally strong objection to, "the non-professional" or "non-accountable" style and quality of management practices and educational materials the parent organizations create and/or deliver to families. These differences also are reflected in the different salary bases, or even paid versus volunteer labor, of organizational staff members. CAs are primarily concerned with adult cancers: while they operate many excellent research, education and service programs for this large population, childhood cancer issues are a minor concern to them (indeed, Ross, 1987, in a book billed as an "official history of the American Cancer Society," contains no mention of childhood cancer issues or services - save listing one professional conference ACS held on that topic - nor of the Candlelighters Childhood Cancer Foundation, which by that time had been in a cooperative financial and programmatic relationship with ACS for over a decade). One reason, of course, is that childhood cancer is a relatively rare disease, accounting for approximately 1% of all cancer diagnoses. Parents of children with cancer, as leaders or members of self-help groups, are solely focused on childhood cancer, and their CCPOs run many programs for this specific population. They emphasize that even if childhood cancer is relatively rare disease, curing a child with cancer results in preserving 60 or more years of productive life and work - an excellent social investment! Further differences are evident as officers and operatives in CAs leave their jobs when they leave their offices; cancer is part of their professional employment but not necessarily their total life experience. Parents of children with cancer - in treatment or post-treatment, living or deceased - never leave the cancer experience; when they leave the hospital to go home they continue to carry the focus on the disease and its treatment and effects. In this sense, Cancer Association personnel are "outside" the experiential reality of childhood cancer, no matter how caring and committed they may be. For parents of children with cancer, "inside this reality", this is a major preoccupation of their lives; this is especially likely for those parents who elect to become organizational members or leaders, and to focus their energies on assisting other parents as well as themselves through this dark night. CAs are primarily governed by medical professionals, and managed through typical

bureaucratic theories of organizational leadership. CCPOs are primarily governed by parents (often with professional assistance and support), staffed by volunteers, and managed through grass-roots democratic organizational principles: especially at the local level and often at the national level they typically are less formally organized than are the cancer associations local/regional offices. In sharp contrast to the earlier discussion of the variety of organizational structures of local parent self-help groups, Ross (1987) refers to ACS's local offices as "independently chartered and incorporated divisions", and Young describes ACS as an example of "unitary national organizational entities with regional and local subdivisions and chapters...as single national organizations from the start, and their authority resides in central headquarters (1989, pp. 103-4). Thus, the more formal CAs, generally built on the "corporate model" (see the earlier discussion and Young, 1989; Zald, 1970), often object to the CCPOs' inability or unwillingness to "control" the behavior of local (often "federated model") units; the contrast here is once again between the hierarchical and bureaucratic style typical of large public charities or service organizations and the social movement characteristics of voluntary organizations or alternative human service systems. The programs of most CAs are directed primarily to fund-raising and support of research, although they also generate support programs and services for individual patients and families. CCPOs are involved in fund-raising, but conduct a much wider variety of social and emotional support, parent/patient empowerment and social advocacy programs. In this regard the goals of CAs primarily involve service and support to the medical profession seeking to control and cure cancer, with an ultimate concern for incremental improvement in the delivery of care to patients. CCPOs, while they share that overall service mission, are more likely to seek to support and serve children and families, and in this effort to work for more immediate and dramatic change in the delivery of (especially psychosocial) care.

The above discussion indicates that even when these CAs and CCPOs appear to have consonant missions and values, their different resource bases and activities mitigate against the development of structural isomorphism; and the development of different types of organizational/managerial and governing structures adds to the sources of interorganizational conflict. CAs are likely to see CCPOs as "fly by night affairs", unprofessionally managed and operated; CCPOs are likely to see CAs as authoritarian and hidebound, committed more to their

survival than to service to people in need - especially to children and families. Some of these organizational-level differences are summarized in Figure 3.

The nature of these differences are not themselves predictive of conflict, just of difference. But as so often is the case, personal and organizational dynamics turn these differences into “good” and “bad” aspects of both parties. Several factors ensure the placement of these different organizations into a competitive and conflictual struggle with one another. First, perhaps at an ideological or cultural level, Emerick and others note that there is a “natural antithesis between the philosophies of self-help and professional health care (1991)”, and the same tension exists with national self-help organizations and national bureaucratic charities. Second, as Hasenfeld and Gidron note (1993), we can expect conflict or competition whenever organizations operate in the same field of endeavor (with relatively similar missions) and compete for the same or similar resources (e.g., money, people, audience, influence). Both types of organizations seek and sometimes compete for public funds and credibility (but not always, not all parent groups at the local level seek to raise funds, although most national level organizations do). As Bennett and Di Lorenzo note, “The Big Three (referring to the large health charities - American Cancer Society, American Heart Association, American Lung Association) obviously see new charities as undesirable competition - for donations, government grants, and domination of the disease-research industry (1994, p. 205).” Moreover, in this competition for funds it is typical for Cancer Associations in most countries to use pictures of children and families in their fund-raising efforts (it is an especially effective and endearing technique), despite the fact that most of their programmatic concern and fund dispersal is focused on adult cancers. This raises the hackles of parents, and activists in parent organizations, who see this as a form of exploitation without adequate recompense (or as intrusion into their “turf” without permission or payoff). Third, even within a general arena of mission congruence, CAs and CCPOs often disagree about the focus of the programs and activities of parent groups and organizations. Dominated by medical staff members, and interlocked with government health agencies (Epstein, 1978; Bennett and Di Lorenzo, 1994), Cancer Associations privilege technical and expert medical knowledge over (and sometimes overtly disparage) the common sense experiential knowledge base of parents and children undergoing the cancer experience. Parental or parental organizational criticism of medical knowledge and practice is seen as inappropriate, generally cast as uninformed, and occasionally

experienced as a threat to the privileged knowledge and position of medical staffs guiding CAs. Likewise, parent organizations often object to the elitist assumption that these professional medical or charitable staffs and associations have a monopoly on relevant knowledge and wisdom - especially when it comes to psychosocial or organizational matters (Chesler, 1990).

These conflicts are most likely to escalate, and to become overt, in the more “developed nations”, where CCPOs are more likely to be well-organized, more likely to be organized on a national level, and more likely to have and to generate a large base of support. Then the CCPOs “feel strong enough” to seek autonomy and independence from the CAs and to pursue their goals that may be unique or different from the CAs. In turn, the CAs are more likely to feel threatened or challenged by those CCPOs that are more powerful - in financial, numerical or symbolic terms - and that conduct independent programs that attract public attention and support/funds.

The results of these differences and conflicts are that Cancer Associations typically engage in overt or covert warfare and efforts to control parent groups and organizations. They generally are the more powerful party in this relationship, by virtue of their longer history, greater resource base, established medical and governmental links, medical access and media/public credibility. Thus, they are more likely to vigorously defend their prerogatives, sometimes by attacking parent organizations and sometimes by sitting on their superior resources and “playing a waiting game” for the parent organizations to disappear. Their tactics often take the following forms:

- Prohibition of public fundraising as a condition for financial support of CCPOs.
- Attempts to edit (and sometimes censor) parent newsletter and pamphlet materials.
- Pressure on CCPOs to cease certain types of programs (e.g., parent-generated research, medical hotlines, medical suggestions).
- Pressure on CCPOs to establish bureaucratic systems of accountability with local support groups.
- Establishment of parallel (but professionally run) parent organizations.

Childhood Cancer Parent Organizations, in turn, are likely to initiate or return fire as follows:

- More or less public challenges to CAs’ efforts to “use” children to raise money for the fight against adult cancer.
- Development of independent and competitive fund-raising campaigns.

-Coalitions with other child/family focused agencies to lobby for special funds and services to be provided to children's causes.

What are the prospects?

It is clear that the relations between CCPOs and CAs involve both competition and cooperation, a dialectical situation mandated by their somewhat common (yet somewhat conflicting) goals and their common struggle for (often similar) resources (York and Zychlinski, 1996). If local and national Childhood Cancer Parent Organizations and local and national Cancer Associations are to work together it will have to be on the basis of a model of inter-agency relationships that supports mutual respect for each organization's unique mission, identity and talents. It cannot be on the basis of dominance-dependence ("big brother"- "little brother") relations, with attendant efforts of CAs to control and guide the programs of CCPOs, and CCPOs constant struggles for independence and a separate identity. Nor is it fruitful to maintain constant competition and conflict. Interestingly, the prospects faced here are not unlike those faced by CAs and other cancer-related organizations with more specialized and consumer-based interests (e.g., Ostomy Clubs, Breast Cancer Organizations, Prostate Cancer Groups), including mass patient/consumer organizations like the National Coalition of Cancer Survivors.

Hasenfeld and Gidron (1993) have suggested several options within a more cooperative model of inter-organizational relations: referral, coordination, coalition, cooptation. And Wernet and Jones (1992) discuss the possibility of consolidation, which includes both outright acquisitions (or absorptions of one organization by another) and mergers (or blendings of one organization with another). All these forms have occurred in different locales within specific nations and in different nations. In some cases CAs and CCPOs have referred patients and patient families to one another, especially in those cases where the young people involved are at the margins of childhood or adolescence (i.e., in their late teens or early twenties). Active coordination, involving the exchange of resources, is much less common, although if we consider those cases where CAs have helped to provide some funding assistance to CCPOs, have helped to initiate CCPOs, or have involved them in educational events and conferences (the initiative and invitation for such events may flow in either direction, suggesting mutual attempts at coordination), that would seem to fit the coordination model. The key here, according to Zald and

McCarthy (1987) is exchange relations based on clearly differentiated but interlinked roles and occasional joint projects. The history of these interorganizational relationships also is rife with examples of cooptation, especially wherein CAs have invited CCPO representatives to attend their meetings as special resources on childhood cancer, but not to participate otherwise. Cooptation also is common in the early stages of development of some CCPOs, when physicians or CA staff help to initiate the parent organization and then stay in control, or when the CCPO is (or remains) so dependent upon the CA that it operates only on terms acceptable to the more powerful CA. Consolidations occur when the CCPO is so weak that the CA mounts a "takeover", either on friendly or unfriendly terms. That certainly was the case in the recent negotiations between the ACS and CCCF (see earlier discussion) wherein the ACS offered CCCF the opportunity to merge within ACS on terms that CCCF Board members saw as an acquisition model, one that would strip CCCF of its ability to operate with its own agenda, staff and terms.

In my view the coalition form of interorganizational relationship represents our best bet in common. Coalitions occur among organizations and agencies that have some goals in common and some differences. They may involve competition for some resources (money and recognitions) and cooperation on some services (support for families, materials for medical professionals, lobbying efforts for new policies). The principal burden for initiating these cooperative or coalitional efforts depend on the CCPOs, however. Because the CAs have been in existence longer they are usually more powerful, more established, more traditionally organized, and have built a more secure resource base. But CCPO members, themselves a part of the clientele they feel the CAs should be serving, often feel that the CAs should be reaching out to them and recognizing/using their expertise, rather than vice versa. And CA members, being more established organizationally and professionally, often feel that the younger and weaker, and more specialized, parent organization should make petition to them. The result is more delay and increased mutual resentment..

The development of effective interorganizational coalitions require recognition of areas of mutual concern and collaboration (e.g., CCPOs and CAs together lobbying national governments or International agencies for more funds for cancer research and treatment, CCPOs and CAs and treatment centers in wealthy nations creating "twinning" relations with centers and groups in poorer nations), as well as areas of difference or even conflict (note above). They will require

interdependent relationships between independent organizations: if CCPOs elect or need to be financially dependent upon the CAs, or if CAs insist upon controlling CCPOs resources and programs, wars of independence will eventually result. Such coalitions also require mutual respect...both for acknowledged differences and commonalities...and a desire to make use of each entity's unique perspectives, talents and resources. Above all, they require acknowledgment of past conflict and careful negotiation about current and future turf in pursuit of the best (medical and psychosocial) treatment for all children with cancer and their families/communities. The CAs are generally a key source of broadly established legitimacy and resources; the CCPOs are vital links to a narrower but critical patient constituency and a source of unique expertise. They need each other, we need them both, and we need them to work together better.

References

- Bennett, J., and Di Lorenzo, T. UNHEALTHY CHARITIES. Basic Books, New York. 1994.
- Chesler, M. Professionals' views of the 'dangers' of self-help groups. In T. Powell (Ed), WORKING WITH SELF-HELP. NASW Press, Washington, DC. 1990.
- Chesler, M., and Chesney, B. CANCER AND SELF-HELP. University of Wisconsin Press, Madison, WI. 1995.
- Emerick, R. The politics of psychiatric self-help: Political factions, interaction support , and group longevity in a social movement. SOCIAL SCIENCE and MEDICINE. 1991, 32, 1121-1128.
- Epstein, S. THE POLITICS OF CANCER. Sierra Club Books, San Francisco. 1978.
- Gartner, A., and Riessman, F. (Eds), THE SELF-HELP REVOLUTION. Human Sciences Press, New York. 1984.
- Hasenfeld, Y., and Gidron, B. Self-help groups and human service organizations: An interorganizational perspective. SOCIAL SCIENCE REVIEW. 1993, June, 217-236.
- Hunter, A. National federations: The role of voluntary organizations in linking macro and micro orders in civil society. NONPROFIT AND VOLUNTARY SECTOR QUARTERLY. 1993, 22 (2), 121-136.
- Katz, A., and Bender, E. (Eds), HELPING ONE ANOTHER. Third Party Publishing, Oakland, CA. 1990.
- Katz, A., and Bender, E. (Eds), THE STRENGTH IN US: SELF-HELP GROUPS IN THE MODERN WORLD. New Viewpoints/Vision Books, New York. 1976.
- Ross, W. CRUSADE: THE OFFICIAL HISTORY OF THE AMERICAN CANCER SOCIETY. Arbor House, New York. 1987.
- Smith, D. A neglected type of voluntary nonprofit organization: Exploration of the semiformal fluid-membership organization. NONPROFIT AND VOLUNTARY SECTOR QUARTERLY. 1992, 21 (3), 251-269.
- Wernet, S., and Jones, S. Merger and acquisition activity between nonprofit social service organizations: A case study. NONPROFIT AND VOLUNTARY SECTOR QUARTERLY. 1992, 21 (4), 367-380.
- York, A., and Zychlinski, E. Competing nonprofit organizations also collaborate. NONPROFIT MANAGEMENT AND LEADERSHIP. 1996, 7 (1), 15-27.
- Young, D. Local autonomy in a franchise age: Structural change in national voluntary organizations. NONPROFIT AND VOLUNTARY SECTOR QUARTERLY. 1989, 18 (2), 101-117.
- Zald, M. ORGANIZATIONAL CHANGE. University of Chicago Press, Chicago. 1970.
- Zald, M., and McCarthy, J. Social movement industries: Competition and conflict among social movement organizations. In M. Zald and J. McCarthy (Eds), SOCIAL MOVEMENTS IN AN ORGANIZATIONAL SOCIETY. Transaction Books, New Brunswick, NJ. 1987.

Figure 1
Characteristics of National-Level Parent Associations (n=24)

Date of formation	
Before 1985	8
Between 1985-1989	6
Since 1990	10
Size of National Governing Board	
Less than 10	12
Ten or more	8
Unknown	4
Percent of Board members who are parents of children with cancer	
Under 75%	1
Between 75%-99%	5
100%	15
Unknown	3
Number of times Board meets/year	
Two times	4
Between 3-6	4
Between 7-12	12
Unknown	4
Number of local/regional "chapters"	
Only 1	8
Between 2 and 10	8
Between 11 and 50	6
Over 50	1
Unknown	1
Annual budget	
Less than \$50,000USD	12
\$50,000 to \$500,000USD	6
More than \$500,000USD	3
Unknown	3
Sources of funds raised (can be multiple)	
Individual member fees/dues	5
Local group fees/dues	2
Public donations	16
Government subsidies	4
Cancer association subsidies	2
Sales of items (cards, shirts)	5
Corporate/foundation grants	6
Unknown	4
Existence of paid staff members	
No	5
Yes, 1-2	10
Yes, more than 2	6
Unknown	3

Figure 2
Major Differences Between Parents of Children with Cancer
and Professionals Working with These Parents and Children

Difference	Parent	Professional
Function and status	Service recipient Relatively powerless Medical visitor	Service provider Relatively powerful Medical home team/host
Knowledge base	Experiential wisdom Personal Particular Uncredentialed	Academic expertise Technical General Legitimate/credentialed
Interests and accountability	Children Particular child Child and family	Career or profession Children in general Medical community
Mindset/emotional state	Emotional closeness/ expression	Emotional distance/ caution
Job and family concerns	Family internal to illness Job external to illness	Family external to illness Job internal to illness

Adapted from Chesler and Chesney, Cancer and Self-Help, University of Wisconsin Press, 1995, p. 206.

Figure 3
The Potentials for Interorganizational Conflict and Coalition

Dimension	Cancer Associations	Childhood Cancer Parent Organizations
Mission focus	Adults Support for incremental improvement in medical care	Children/families Advocacy for change in psychosocial care
Management/leadership	Professional control Physicians Organizational managers Formal bureaucracy Large staff Paid staff plus volunteers	Citizen control Parents Informal, grassroots movement Small staff Mostly volunteer
Structure	Distinctive roles for "staff-client" Hierarchy Unit accountability Permanent and established	Joint roles for "staff-client" Loose democracy Unit autonomy Relatively new and evolving
Program	Fund-raising Support for research Support medical staffs Some service to individuals - financial, informational Lobbying Liaison with other agencies	Fund-raising Little research support Serve local groups Service to individuals - financial, comradeship, emotional, informational Advocacy Liaison with other agencies
Images of client/ constituents/members	Medical professionals Patients to be served Dependent people Member roles partial, peripheral	Parents, youth, and families Comrades to be empowered Active and involved people Member roles central