

Are national coalitions possible between support groups for parents of children with cancer and cancer associations?

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One meaningful and compassionate response to the stress faced by parents of children with cancer is mutual support groups. Such groups provide social and emotional support for families and advocate for improved medical and psychosocial services for children with cancer throughout the world. Sometimes parents form and conduct these groups in the context of harmonious and supportive relationships with national Cancer Associations, and sometimes these relationships are characterized by conflict and tension. Various factors may hinder or facilitate the formation and operation of cooperative relations and coalitions between these organizations.

What do national childhood cancer parent organizations (CCPOs) do?

National organizations of parents of children with cancer (CCPOs) generally seek to coordinate and share information and resources (sometimes including money but usually information, advice and support for leaders) among local families and local support groups. They accomplish this via face-to-face meetings and conferences, as well as through newsletters and electronic media. In addition, national groups often have access to influential policy-makers and national Cancer Associations (CAs) concerned with cancer policy, health benefits, funding of childhood cancer research and treatment, environmental regulations that impact cancer, psychosocially sensitive treatment protocols, etc. CCPOs often are advocates of change in the delivery of medical and psychosocial care, and thereby represent parent concerns as they establish liaison with national organizations of oncology physicians, nurses, social workers and psychologists. Some national level organizations also 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.

There is substantial variety in how national parent groups are organized and operate. The United States national parent organization (Candlelighters Childhood Cancer Foundation) counts some 400 local groups in its family, Canada (The Candlelighters Childhood Cancer Foundation - Canada) 49 and Germany (Deutsche Leukämie-Forschungshilfe) 50. However, the Japanese CCPO (Childrens Cancer Association of Japan) has only 11 local chapters, Sweden (BarnCancerFonden) 7, and Iceland (The Icelandic Childhood Cancer Parent Organization) and The Netherlands (Vereniging Ouders Kinderen en Kanker) 1. South Africa and the United Kingdom currently are trying to create a national organization as an umbrella for multiple local or regional groups (or for groups focused on individual types of childhood cancer). Geography, as well as population size and communication systems, are involved in these differences, as are the skills and resources of indigenous leaders and members or potential members.

Similarly, they vary greatly in the amount of funds they raise: parent organizations in Japan, Sweden, Italy (Comitato M. Verga) and Austria (Kinder-Krebs-Hilfe Dachverband) each raise more than \$1,000,000USD annually, while CCPOs in Portugal (Acreditar-Movement of Portuguese League Against Cancer), Greece (FLOGA and IASO) and other national organizations exist with annual budgets well under \$50,000USD; some CCPOs, particularly those in the less affluent nations, have no funds at all.

There are strong lines of accountability between local groups and the national organization 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 structure has not yet emerged.

Working (or non-working) relations between CCPOs and CAs

Parent self-help and support groups and cancer associations both are concerned with the physical and emotional/social health of children with cancer and their families. 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 includes substantial conflict and negotiation as well as 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 thoughtful and compassionate 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% reported helpful contact with local offices of the American Cancer Society (ACS); 36% reported no contact or no helpful contact, and 16% reported negative contact (Chesler & Chesney, 1995). The US National Candlelighters Childhood Cancer Foundation (CCCCF) was linked with the ACS from its beginnings in 1970, and for over 25 years the ACS provided CCCC with between 60%-75% of its yearly budget. But this relationship always was fraught with conflict and struggles.

Several other national level Childhood Cancer Parent Organizations (CCPOs) report similar tensions in their relations with national Cancer Associations (CAs). The conflicts often involve issues such as: CAs efforts to control the content and style of parent group newsletters and programs, disagreements about either party's relevant expertise, exclusion of CA sponsors and funders from CCPO plans and programs, exclusion of parent representatives from CAs 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 organizations priorities, operations and staff (I emphasize that disagreement, disrespect, attacks and gossip flow in both directions). In addition, parent organizations' programs and parents/families needs often outgrow the level of financial support CAs feel able and willing to provide.

The results often take the form of competition and separation or dissolution. For instance, in the United States, in 1997, rather than lose its identity and control over its own staff and programs, CCCC decided to become financially independent of the ACS. 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 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, especially their fund-raising. The Swedish CCPO reports no sustained relationship with the national CA. A similarly separate and independent relationship is reported by the Italian CCPO - The Federation of Associations of Parents of Children with Onco-Hematologic Diseases (Federazione Italiana Delle Associazioni di Genitori di Onco-Ematologia Pediatrica) and the Italian Cancer Association.

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 and Children do cooperate. In other nations the CAs provide parents organizations with a portion of their yearly budget, meet to share information and program ideas, and generally share resources.

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, psychological orientations or national idiosyncracies.

Sources of conflict

The different roles and stakes of CCPOs and CAs in their common pursuit of the medical, psychosocial, and politico-economic welfare of families of children with cancer lead to (or maybe flow from) different organizational missions, goals, and operating procedures.

CAs are governed and managed by professionals - by medical clinicians and researchers and professional bureaucratic managers, through typical bureaucratic theories of organizational leadership. They usually operate themselves and their local affiliates according to a corporate model. CCPOs, on the other hand, are led by parent volunteers, or in some cases professional parent managers, managed or governed through grass-roots democratic organizational principles.

Not only are they typically less formally organized than are the cancer associations local/regional/national offices; they (the parents) are themselves the targets as well as the providers of services/programs. This difference often is reflected in the Cancer Associations discomfort with, and occasionally strong objection to, the non-professional style and quality of CCPO management practices, and their creation and delivery to parents of lay-oriented medical and educational materials. Parental or 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, CCPOs often object to the 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. The contrast is 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.

Perhaps more importantly, 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. 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 the CCPOs run their 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!

Moreover, in the effort to raise 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 childhood cancer parent organizations, who often see this as a form of exploitation without adequate recompense (or as intrusion into their turf without permission or payoff). 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 material and symbolic resources (e.g., money - grants and public donations, people - workers, volunteers and audiences, influence - setting and delivering health care agendas and policies).

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, to be organized on a national level, and to generate a large base of support. Then the CCPOs may 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. Then the Cancer Associations are more likely to vigorously defend their prerogatives, sometimes by attacking CCPOs and sometimes by sitting on their superior resources and playing a waiting game for the parent organizations to disappear.

Coalitional prospects?

The coalition form of interorganizational relationships represents our best bet in common. But the principal burden for initiating these cooperative or coalitional efforts lies with the CCPOs. 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 often is delay and mutual resentment. An interesting example of such an international coalition currently is being explored informally by the International Confederation of Childhood Cancer Parent Organizations (ICCCPO) and the International Society of Pediatric Oncologists (SIOP). SIOP and ICCCP are collaborating in planning joint meetings and presentations, accommodating parents and physicians (and nurses) at one another's annual conferences, and considering joint efforts to improve the total (medical and psychosocial) care of children with cancer in the developing nations. The development of effective interorganizational coalitions requires 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. They will require interdependent relationships between independent organizations: if CCPOs elect or need to be largely 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 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, parents of children with cancer need them both, and everyone needs them both to work together better.