

This article explores some of the dynamics of a special and fast-growing form of small group phenomenon—the self-help group. Specifically, the article analyzes the role of self-help group membership as a major facilitator of activism for parents of children with cancer. Few studies of self-help groups have compared members with nonmembers, let alone related membership to reported life change. Using data from 93 parents of children with cancer, this article assesses the relationships between parents' demographics, coping styles, self-help group membership status, and reports of positive changes in parents' activism—their active involvement in improving the medical system caring for their children. Findings indicate that although individual parents' active coping styles are linked to increased activism, self-help group membership clearly plays the most important role in explaining the variance in this aspect of parents' life change. In contrast to much of the existing literature, discussion and implications focus not only on the individual activism that may be related to self-help group membership but also on the potential for social activism or collective effort that groups can enhance.

ACTIVISM THROUGH SELF-HELP GROUP MEMBERSHIP Reported Life Changes of Parents of Children With Cancer

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Self-help and mutual support groups can provide a unique resource and set of benefits for parents of children with cancer in terms of psychosocial adaptation and growth. Existing research on self-help groups in the medical setting has emphasized their structural and procedural characteristics but has largely ignored their individual-level impact. This article explores reported changes in

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parents' activism related to their demographics, individual coping styles, and self-help group membership status. It argues that parents' reported activism is increased through participation in self-help groups.

THE CRISIS AND CHALLENGE OF CHILDHOOD CANCER

Childhood cancer represents an especially serious and far-reaching challenge, because it creates potentially disempowering stress and anxiety for both parents and their children. This life-threatening diagnosis affects the entire family in ways that severely threaten both their past and future emotional, practical, and intellectual resources (Chesler & Barbarin, 1986; Chesney, 1989). The prevalent medical model, which encourages professionals to be assertive and patients to be compliant, can lessen parents' desires and ability to play an active role in the treatment process (Chesler & Barbarin, 1984; Chesler & Chesney, 1988).

Parents elect to cope with these stresses and threats in various ways, recognizing that different coping strategies are differentially effective for different people in different situations (Mattlin, Wethington, & Kessler, 1990; Pearlin & Schooler, 1978). Some withdraw from ordinary social interaction and deal privately with their anxieties. Others remain passive, waiting for instruction from the medical staff or for time itself to ease their struggle and heal their pain. Such passive coping is characterized as rare by much of the general literature (Wethington & Kessler, 1991) but is frequently employed by parents of children with cancer, who are witnessing a life-and-death struggle in the context of a complex and high-technology medical care bureaucracy. Some parents cope in public ways, seeking connection with and assistance from others and organizing family and friendship networks. Others adopt active forms of coping, attempting to learn about the illness, deal vigorously with the medical staff, and play an active role in restructuring their crisis environment (Billings & Moos, 1981; Pearlin & Schooler, 1978). Although the literature on coping styles lacks consensus, much of it does support the positive value of an active,

and at least somewhat public, approach to dealing with illness (Lazarus, 1981; Menaghan, 1983).

The coping scales utilized in this study and described below mirror the existing literature through their major foci—private versus public coping and help seeking, and active versus passive coping. However, because the relatively standard ways of measuring these coping options generally do not attend to the special, chronic demands faced by parents of children with cancer (Cohen, 1987), unique items have been generated for this analysis with wording that *does* reflect those particular psychosocial challenges and dynamics. In addition, a scale was designed to measure parents' use of emotion-management strategies, especially the possibility that they would elect to share their feelings and reactions to this trauma with others.

SELF-HELP GROUPS AS FACILITATORS OF ACTIVISM

Through interactions with others in similar situations, parents can develop new role definitions and new views of their own and their children's options. Many find in these groups a unique forum for individually helpful mutual aid and sharing (Chesler & Chesney, 1988; Chesney, 1989; Stewart, 1990; Vugia, 1991). In fact, in the context of self-help group activity, some parents develop new roles and styles that lead to the assumption of leadership skills and positions (Chesler & Barbarin, 1984; Yoak & Chesler, 1985). In self-help groups, parents also often find support for their collective and externally oriented initiatives in establishing a network of peer and lay helpers, discovering and acting upon a new identity and role as active partner in the medical care process and team; requesting or demanding expanded visitation privileges; generating lobbying efforts on behalf of improved medical care, legal rights, or insurance options (Gilder, 1976); raising funds for staff positions, research, and new school and community outreach programs (Chesler, Chesney, & Gidron, 1990). They can also benefit from a setting that emphasizes the lay resources that all parents have and

that avoids escalating parental dependency on the medical care system and its social services.

The underlying assumption here is that parental activism is both created and facilitated by self-help group membership (Stewart, 1990)—an echo of the concept that collective efforts are stronger than individual ones and also are strengthening for individuals (Zimmerman & Rappaport, 1988). Although the focus here is on increased activism as a positive life change for individual parents' mental health and well-being, this analysis also challenges the existing notion (Riessman, 1965) that self-help groups are necessarily more internally than externally oriented, that they are more focused on aiding individual adjustment or coping than on stimulating collective action. This analysis represents a step toward exploring the collective, activist potential of self-help groups—a potential that does not deny, but in fact enhances, positive outcomes for individual group members.

STUDY DESIGN

The Candlelighters Childhood Cancer Foundation (CCCCF) network of self-help groups for parents of children with cancer in Washington, DC, provided a list of groups across the United States. Initial screening calls were made to a number of group leaders and liaison persons, in an effort to update information on groups studied previously (Chesler & Barbarin, 1984; Yoak, Chesney, & Schwartz, 1985), and to gather information about new groups.

Eight groups were chosen for site visits from the complete list of CCCC self-help groups. Groups were chosen to maximize heterogeneity on the following purposeful sampling factors: location (urban and rural, small and large catchment areas), parent involvement patterns (members and nonmembers), group composition and structure (class, leadership patterns), and agenda (support, fund-raising, advocacy).

Approximately 15 individual self-help group members and 15 nonmembers were systematically selected from a clinical list at each group site, according to a two-stage sample design. Only

parents of children with cancer were included. Although interviews were conducted with individual parents as well as professionals and also with entire groups at self-help group meetings, only questionnaires distributed by either study investigators or clinical liaison staff are analyzed here. These self-administered questionnaires were mailed back to the study office directly. Telephone follow-up procedures contacted parents through the liaison person at each group site.

The data in this report on parents of children with cancer are questionnaire responses from 93 parents representing the eight groups and sites studied. The overall study response rate was 49.2% (116/236). From the original set of 116 parents of children with cancer who responded to the self-report questionnaire, a subset of 93 parents responding to all items of interest has been developed for these analyses to alleviate problems of missing data on crucial model components. Additionally, the 23 cases not included in these analyses were investigated with respect to comparability, based on the same set of site factors discussed above and key parent demographics and background factors. This level of nonresponse analysis revealed no significant differences between the 23 cases deleted for reasons of missing data and the 93 cases retained for analysis. At another level of nonresponse analysis, the group of parents who did not respond to the questionnaire were not significantly different from the 116 study respondents, according to hospital-record demographics.

Of the 93 parents' responses analyzed here, 64.5% ($n = 60$) defined themselves as members of self-help groups. Individuals whose children were known to have been affected by cancer (primarily leukemias and lymphomas) but who did not choose to become involved in a support group also were queried at each site. As will be discussed below in relation to potential self-selection bias, *all* parents received uniform referrals to self-help groups from professionals at each site. The parent member demographics are comparable to other populations of self-help groups for parents of children with cancer (Chesler & Barbarin, 1986; Chesler & Chesney, 1988; Chesney, 1989), suggesting that this sample may

represent those populations fairly well. However, no such representative quality is assumed on the part of the nonmember population, and inferences throughout this analysis are framed within these limits.

MEASUREMENT

Scaled measures of reported changes in activism (dependent variable) and parents' coping styles (independent variable) will be described below. In addition, self-help group membership (independent variable of focus) will be discussed in terms of a dichotomous measure.

Life changes: activism. A scale was designed to measure reported change in one's life in terms of activism. This *activism* scale, with a reliability coefficient (Cronbach & Meehl, 1955) of .80 (alpha), was developed from two items documenting parents' reports of life changes over the course of their children's illness: parents' sense of what they as individuals can do and their willingness to join up with others to change things. Both items were scaled as -1 (change for the worse), 0 (no change), or +1 (change for the better). This retrospective, dependent-variable measure of perceived life changes should be interpreted cautiously (Cronbach & Furby, 1989), given the cross-sectional design of the study (Groves, 1989).

Self-help group membership. A dichotomous variable was created to indicate parents' relationship to the self-help group, denoting members as opposed to nonmembers. Parents were coded as *nonmembers* (0) if they reported neither themselves nor any of their family as currently active in the local parent support group. If parents reported being currently involved, with or without a history of having an office or a position on the board or in the planning of the self-help group, they were coded as *members* (1). As discussed above, *only* parents of children with cancer were included as study respondents.

Coping. Five scales of coping styles were constructed from a series of individual items (coded 1-4, from *never used* to *used a lot*) documenting separate coping strategies. With one exception, the coping scales all produced reliability coefficients near or beyond .50. Help seeking ($\alpha = .57$) includes getting help in solving problems; seeking help from professionals, relatives, friends, and the medical staff; sharing feelings with others; and talking about things with someone. Coping alone ($\alpha = .46$), a private strategy, is measured by reports of trying to be alone, keeping feelings to oneself, and going off by oneself. Passive coping ($\alpha = .49$) is defined by reports of acceptance of things as they come, avoidance of thoughts about one's problems, and doing nothing at all. In contrast, active coping ($\alpha = .38$) is operationalized in terms of keeping family life normal, changing family plans, reassigning household tasks, taking charge of things, and focusing on problems and solving them. Finally, sharing feelings and emotions ($\alpha = .56$) is measured by a scale which includes sharing feelings with one's spouse and others, talking about things to someone, and talking things out as a family.

FINDINGS

MAIN EFFECTS OF MEMBERSHIP

Mean statistics and distributions (not shown) for parent demographics and personal characteristics for the total member/nonmember study population indicate that most informants are female—88.7%—with an average age of 39.3 years. The median annual family income is approximately \$30,000, and 53.2% of parents completed either high school or some college, making this a relatively high-status population. Most parents are married (84.3%), most are likely (86.1%) to have a living diagnosed child, and most have children who were diagnosed more than 2 years ago.

A number of significant differences in the demographics of group members and nonmembers are revealed in Table 1. Chi-square statistics are presented for categorical variable comparisons

TABLE 1: Parent Demographics by Membership (N = 93)

<i>Parent Demographics</i>	<i>% Member</i>	<i>% Nonmember</i>	<i>Chi-Square</i>
Marital status			2.052
Single (N = 2)	50.0	50.0	
Married (N = 78)	65.4	34.6	
Separated/divorced (N = 12)	66.7	33.3	
Other (N = 1)	0.0	100.0	
Time since diagnosis			4.651*
Less than 2 years (N = 28)	46.4	53.6	
More than 2 years (N = 65)	72.3	27.7	
Gender			1.541
Female (N = 84)	61.9	38.1	
Male (N = 9)	88.9	11.1	
Child's status			4.417*
Living (N = 79)	59.5	40.5	
Deceased (N = 14)	92.9	7.1	
Age			2.033
Less than 36 (N = 32)	56.2	43.8	
36-41 (N = 34)	64.7	35.3	
42-63 (N = 27)	74.1	25.9	
Education			7.587*
High school graduation or less (N = 18)	44.4	55.6	
Some college (N = 36)	58.3	41.7	
College graduation or more (N = 39)	79.5	20.5	
Family income			7.874
Less than \$10,000 (N = 9)	33.3	66.7	
\$10,000-\$20,000 (N = 19)	78.9	21.1	
\$20,000-\$40,000 (N = 23)	56.5	43.5	
\$40,000-\$60,000 (N = 17)	58.8	41.2	
More than \$60,000 (N = 25)	76.0	24.0	

*Difference is statistically significant at the .05 level or better, using a chi-square test of independence.

of parent subgroups. Three significant demographic differences are of particular interest. It is more likely that the parents of a deceased child are members. Members also report that their children have been diagnosed less recently. Finally, members are also significantly more likely to have a college or postcollege education.

TABLE 2: Changes in Activism by Membership (*N* = 93)

Reported Change ^a	Mean Perceived Activism			F Statistic
	Total (<i>N</i> = 93)	Members (<i>N</i> = 60)	Nonmembers (<i>N</i> = 33)	
Activism (What I can do as an individual; my willingness to join up with others to change things)	.50	.68	.17	20.429*

a. Coded on a 3-point scale: -1 = *changed for the worse*, 0 = *stayed the same*, and 1 = *changed for the better*.

*Difference is statistically significant at the .05 level or better, using the *F* test of means in a one-way, single-factor analysis of variance.

Members and nonmembers of self-help groups in this study do *not*, however, differ significantly by marital status, gender, parent age, or family income. Although the differences between members and nonmembers in variables related to their children's medical status or educational level cannot be ignored, the absence of differences in other parent demographics confirms the universality of the childhood cancer experience for parents.

However, reported changes in activism *do* differ significantly by self-help group membership status, as shown in Table 2. Members report significantly more positive changes in activism ($M = .68$)—changes in their sense of their own capabilities and their willingness to work with others for change (presumably in the medical system)—than do nonmembers ($M = .17$). The membership and activism measures correlate at the .43 level.

Table 3 reveals that none of the five scales measuring individual coping styles—help seeking, coping alone, passive coping, active coping, or sharing feelings and emotions—differ significantly by parents' membership status. Observed correlations (not shown) between coping style scales and membership range from $-.102$ for coping alone to $.166$ for help seeking.

In contrast, each of the five scales measuring coping styles is significantly correlated with reported changes in activism. As shown in Table 4, individual strategies of passive coping ($r = -.275$) and

TABLE 3: Coping Styles by Membership (N = 93)

Coping Styles ^a	Mean Perceived Activism			F Statistic
	Total (N = 93)	Members (N = 60)	Nonmembers (N = 33)	
Help seeking	2.95	3.01	2.85	2.592 (<i>n.s.</i>) ^b
Sharing feelings and emotions	3.35	3.39	3.28	.907 (<i>n.s.</i>)
Active	3.23	3.24	3.19	.393 (<i>n.s.</i>)
Passive	2.46	2.53	2.43	.556 (<i>n.s.</i>)
Coping alone	2.51	2.59	2.59	.958 (<i>n.s.</i>)

a. Coded on a 4-point scale, ranging from 1 = *never used*, to 4 = *used a lot*.

b. The abbreviation *n.s.* indicates that the difference is *not* statistically significant at the .05 level or better, using the *F* test of means in a one-way, single-factor analysis of variance.

TABLE 4: Coping Styles by Changes in Activism (N = 93)

Coping Styles	Changes in Activism
Passive	-.275 ($p = .004$)
Active	.297 ($p = .002$)
Sharing feelings and emotions	.288 ($p = .004$)
Coping alone	-.195 ($p = .031$)
Help seeking	.381 ($p = .000$)

coping alone ($r = -.195$) are negatively and significantly correlated with activism. There are positive correlations between reported changes in activism and active coping ($r = .297$), sharing feelings ($r = .288$), and help seeking ($r = .381$) styles of individual coping.

REGRESSION ANALYSIS

A hierarchical regression model was employed to isolate the effect of parent demographics, coping styles, and self-help group membership on reported changes in activism. Table 5 indicates that parent demographics alone explain only 1.4% of the variance in reported activism, whereas the five measures of coping style help explain an additional 17% of the variance. Most notably, another

TABLE 5: Impact of Demographics, Coping Styles, and Membership on Changes in Activism ($N = 93$)^a

	<i>Steps</i>		
	<i>1</i>	<i>2</i>	<i>3</i>
Demographics			
Time since diagnosis	-.181	-.195	-.117
Education	.085	.076	-.064
Marital status	-.126	-.148	-.184
Gender	-.135	-.029	-.019
Child's status	-.021	.045	.122
Parent age	-.066	-.013	-.000
Family income	.149	.087	.149
Coping styles			
Passive		-.122	-.121
Active		.206*	.217*
Sharing feelings and emotions		.052	.034
Coping alone		-.199	-.151
Help seeking		.209	.186
Membership			.359*
Adjusted R^2	.014	.184*	.290*
R^2 change	.089	.201*	.100*
F -statistic R^2 change	1.184	4.538*	12.970*

a. Entries include standardized regression coefficients, the adjusted R^2 (adjusted amount of variance explained by all variables in each step), the R^2 change (net contribution of the variable or block of variables added on each step), and the F -statistic R^2 change (significance test for the effect of the variable of block of variables added on each step, using adjusted R^2 change).

* $p < .05$.

10.6% is explained by the addition of self-help group membership status, so that a total of 29% of the variance in reported changes in activism is explained by the full model.

DISCUSSION

Self-help group membership explains a significant amount of the variance in parents' reports of changes in activism—changes in their potential for making a functional impact on the medical system

of which their child is a part. The regression analysis results are consistent with the notion that self-help groups can facilitate parents' activism in ways that complement their own coping styles and that uniquely respond to the specific demands of childhood cancer.

Different parents will draw different types and levels of sustenance from their group involvement (Chesler & Barbarin, 1984; Suler, 1984) and may join for various reasons (Powell, 1985). However, involvement is, overall, positive in terms of changes in activism for those who choose to join, as indicated by these findings. Although an active coping style was significantly linked to both self-help group membership and reported activism in the regression model, none of the five coping style scales was significantly correlated with membership individually; and, in fact, an active coping style was *not* significantly related to activism when members alone were analyzed (not shown).

Thus, although these study findings do not allow a perfect discrimination between the effects of coping style and membership, they *do* permit a modest affirmation of the activating potential of self-help groups above and beyond individual characteristics and resources. The self-help group can be both a forum and a catalyst for increased activism by parents of children with cancer.

Demographic differences suggest equally simple but useful inferences about why parents of children with cancer at different stages of the illness and with different background characteristics might report varying levels of activism and self-help group involvement. Perhaps parents of deceased children have more time for activism, including participating in self-help group collective efforts. For parents of living children, when more time has elapsed since the diagnosis, children's sustained remission may leave them freer for group involvement. Even if their children are not in remission, parents who have had more time to adjust to the diagnosis may be more open to the kind of shared experience and activism possible through a self-help group. At an earlier point in their children's diagnosis and treatment, parents simply may not have had enough time to consider or act upon perceived change in their own activism.

STUDY LIMITATIONS

Retrospective reports—problematic in their own way (Folkman & Lazarus, 1985)—from parents must be examined in light of a self-selection bias, especially for self-help group members. Unless comparability exists between members and nonmembers and between demographic and coping-style subsets of parents, serious threats could be posed to the validity of these measures and analyses (Berk & Ray, 1982). Referrals to self-help groups from professionals were uniform both for parents who eventually availed themselves of group resources through membership and for those who did not. Thus the relative comparability of design conditions for the two parent subpopulations can be argued.

More important, this study provided only posttest measures of parents' self-reports by self-help group members and nonmembers. An argument can be made for the differential impact of membership, but there are real limits to the investigation of competing hypotheses, given the "pre-experimental" (Campbell & Stanley, 1966) nature of this design. The difficulty of gaining access to such a parent population, especially to a nonmember population, presents real methodological dilemmas (Levy, 1976), but the opportunity for exploring the activism potential of self-help group membership warrants analysis and interpretation of findings, albeit cautiously.

The potential for bias in the regression coefficients introduced by varying levels of reliability in the scales used (Duncan, 1975) must be recognized. However, even after adjusting for demographics and coping-style variables, self-help group membership is significant.

The value of the above limitation lies in their ability to identify the parameters of a stronger study design. A longitudinal study with systematic, random selection of both members and nonmembers of self-help groups would permit less cautious inference about the activism potential of group membership. In the absence of a longitudinal study design, it is difficult to differentiate the directional effects that may be occurring. It may not be the case that self-help group membership *leads* to activism: Activism may lead to self-

help group membership, or a third variable not measured here may lead to both.

It is important, moreover, to understand *why* self-help group membership promotes activism. What group processes and structures matter most? Is it merely the opportunity to interact in concert with fellow sufferers? Is the lay dynamic of a mutual support group the critical variable in such empowerment? Does sustained contact with the medical culture of childhood cancer suffice? What particular dynamics of small group leadership and membership are relevant? Given this brief survey of the positive impact of self-help groups on the views of parents of children with cancer concerning their options, these questions about group structures and processes gain importance. Future articles will explore these issues.

These analyses have identified a small set of parent demographics and coping styles that are *not* as clearly linked to reported changes in perceived activism. Although that is a useful contribution to the literature and, more important, to the understanding of how self-help groups can be a resource for parents, these preliminary findings leave questions unanswered. The challenge lies in the execution of a more ideal study design within the boundaries of privacy and realistic access to the special population of parents of children with cancer.

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