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STUDY OF SOCIAL SUPPORT
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**SELF-HELP GROUPS: A COMPARATIVE AND INTERNATIONAL STUDY
OF SOCIAL SUPPORT AND SOCIAL ACTION***

**Mark A. Chesler & Barbara K. Chesney
University of Michigan**

**Benjamin Gidron
Ben Gurion University
of the Negev, Israel**

**Harriet Hartman
University of California
at Los Angeles**

**Steven Sunderland
University of Cincinnati**

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Services, Department of Health and Human Services (Project #90-
PD-0119)**

In response to the need for a supportive social technology to aid persons and families coping with personal and medical crises, the resource capabilities of mutual support or self-help groups were studied in two nations--the United States and Israel. This working paper summarizes the design and preliminary results of the study, and is a revised version of the opening chapter of a final report submitted to the Office of Human Development Services, Department of Health and Human Services (Project #90-PD-0119). Funded from July, 1986, to September, 1988, the research was conducted jointly by faculty at the Center for Research on Social Organization, University of Michigan (U.S.) and Ben Gurion University of the Negev (Israel). Pilot funds from the University of Michigan's Program in Conflict Management Alternatives (through a program development grant from the William and Flora Hewlett Foundation) greatly facilitated early development of the study design.

The self-help group dynamic was examined as it occurred for parents facing four different types of family crises, with data gathered from 13 self-help groups in the United States and 7 in Israel. Eight groups for parents of children with cancer (PCHCA) and 5 groups for parents of murdered children (POMC) were explored in the U.S., while 5 groups for parents of mentally ill children (PMIC) and 2 groups for parents in families of new immigrants (PFNI) were studied in Israel.

These self-help groups were examined with regard to both

their organizational characteristics (resources, activities, external relationships, internal processes, interactions between parents and human service professionals) and the characteristics of individual participants (or in some cases the "impact" of groups on individual parents). In some groups, individuals who were known to have been impacted by the disease or event under examination (childhood cancer, children's mental illness), but who did not avail themselves of potential group resources and support, also were queried.

The results indicate that parents facing different family crises and living in different national cultures often experience and cope with these crises in different ways. The social networks and professional resources available to them, and utilized by them, often differ markedly. The results also suggest that the dynamics of self-help group operations and the benefits individuals derive from participation in such groups are remarkably similar across life experiences and national cultures. Different self-help groups, however, do have some different priorities regarding programs and activities, and the Israeli and American groups utilize professional resources in different ways.

Problem Background and Study Framework

Families experiencing a prolonged crisis, especially one involving children, encounter a number of potent stresses. We have tried to identify some of the major stresses facing such

families, and their accompanying coping strategies, in Figure 1. For instance, most families in crisis experience a serious need for information relative to the new diagnosis, tragedy, or life style change to which they have just been exposed. They also may be traumatized emotionally by the shock and stress of the crisis. Additionally, practical solutions to daily instrumental or logistic problems are a crucial need, one which may be exacerbated, rather than alleviated, when families' social networks are tested, disrupted, and reorganized. Parents also usually experience a range of interpersonal stresses, as old relationships are strained and new relationships created in response to their child's illness or death. In addition, there is a variety of personal emotional stresses, psychological and psychosomatic pressures that many parents encounter when faced with grief, worry and the ongoing threat to their normal living patterns. Finally, parents often experience existential stresses, challenges to their understanding or evaluation of the meaning of their careers and lives as the normal order of life and death is cast into doubt, and the very meaning of roles as parents come into question.

Parents, and the families of which they are members, will respond to these stressors in different ways and differently at different points in the crisis process. However they cope, and however they find help, most individuals will utilize some form of social support. The scientific literature suggests that social support resources may provide a buffering effect against

Figure 1: STRESS & SOCIAL SUPPORT & SELF-HELP IN FAMILIES IN CRISIS

<u>Categories of Stress</u>	<u>Forms of Support</u>	<u>Sources of Social Support</u>	<u>Self-Help Group Activities</u>
Informational Confusion Ignorance of technical jargon Ignorance of how the institutions (hospital, court) work Ignorance about the staff Unclearly about how to explain the situation to others	Information Ideas Books, articles	Technical, staff Social Workers Scientists Professionals & treatment institutions	Lectures by staff Handbooks & articles Library of articles & videotapes Information sharing among parents Information sharing
Instrumental Disorder & chaos at home Financial pressures Lack of time & transportation to facilities Monitoring treatments Reallocation of family tasks	Practical assistance at home or work Financial aid Transportation Problem-solving activities	Social work staff Family members Friends Neighbors & co-workers Institutional representatives Lawyers Social service agencies	Funds for wigs, prostheses, parking, special help, etc. Transportation & parent lodging Efforts to improve local services Fund-raising for research or added services & staff
Interpersonal Needs of other family members Friends' needs & reactions Relations with the staff Behaving in public as the parent of an ill/murdered child - and stigma	Affection Listening Comforting Caring Being There	Family members Close friends Professional & Social work staffs Other parents of families in crisis	Reference group identification Meeting new people like oneself Having someone to talk with
Emotional Shock Lack of sleep & nutrition Feelings of fear, defeat, anger, sadness, powerlessness Physical or psychosomatic reactions Alienation from loved ones	Affirmation Counseling Clarifying feelings Grieving	Close friends Spouse & other children Close relatives Social workers/psychologists	Referral for professional counseling Peer counseling Sharing intimate feelings
Existential Confusion about "why this happened to us" Uncertainty about the future Changes in future goals, careers Uncertainty about God, fate and a "just world"	Reflection on God & Fate Creating a community	Clergypeople & fellow congregants Philosophers	Talking about religious beliefs Sharing the struggle Creating a community

many of these stresses. (Bloom, Ross and Burnell, 1978; DiMatteo and Hays, 1981; Gottlieb, 1981; Hirsch, 1980; Pilisuk and Froland, 1978). The process of giving and receiving support is quite complex, however, and many persons indicate that they do not find what they need at the time they need it (Chesler and Barbarin, 1984; Sontag, 1979; Wagner, 1981). Moreover, several observers discuss how the stigma of illness and death may make it even more difficult for friends and family members, or for professionals and social service agencies, to offer and deliver effective support (Sontag, 1979; Sunderland, 1984; Wortman and Dunkel-Schetter, 1979).

While one's family, one's social network and various human service professionals can provide some of this help, recent literature and practice suggests that mutual support and self-help groups hold tremendous potential, both as supplements and as complements to more traditional sources of support. Self-help groups have been defined in different ways, but most literature defines them as composed of an identifiable group of people, in a similar situation or with common needs, coming together voluntarily to help each other cope with a common problem. The focus on "doing for themselves" distinguishes self-help groups from other support groups run or guided by professionals. As Smith and Pillemer (1983) note, many support and service groups "involve people not suffering from an alterable, pressing personal problem attempting to help those who do suffer from such a problem" (p. 206). In the case of

pure self-help groups, the people with the problem are the ones helping people who suffer from the same problem.

Self-help and mutual support groups may engage in a variety of activities or programs. (Yoak and Chesler, 1985). In the fourth column of Figure 1 we have identified several different types of self-help group activities, in terms of the major stresses to which they are most relevant. Given the acute need for social technology that is both innovative and effective in helping people navigate these family crises, the self-help dynamic is a worthy focus for study. Group activities, goals, agendas, and structures appear to vary considerably among self-help and mutual support groups, as does the impact of a group on any of its members. As a complementary form of psycho-social care, as one part of a "continuum of care" (Froland, 1980), the potential of self-help is vast--not only across different crisis phenomena, but also across national and cultural boundaries.

As public resources are stretched by myriad demands, volunteer and self-help efforts that preserve familial integrity in the face of major crises are essential. Both Israel and the United States have moved dramatically in the past decade to decentralize human service systems, and to encourage a new mix of public and private, statutory and voluntary, services. One key result of this trend has been to escalate the growth of self-help groups and to increase public and private support for them.

The course of self-help group development appears to be quite different in Israel and the U.S., however. In the United States, decentralization of public sector services is more advanced, and many national and local self-help organizations exist (although often with professional support - see Borman, 1982). Israel is characterized by a much more centralized human service system, and the self-help phenomenon is more recent (Bargal & Gidron, 1983). Moreover, the Israeli Ministry of Health, as well as Labor and Social Welfare, sometimes has been involved in initiating, providing services, or helping to finance some of the activities of federations of self-help groups, as well as their local branches. While differences in Israeli and American civic cultures highlight different problems Israeli and U.S. groups face in dealing with these environments, a comparative analysis of self-help groups that are relevant for both nations should broaden our understanding of these phenomena and will permit maximum international transfer of this innovative social technology.

Research Methods

The basic study design utilizes four levels of analysis to understand these phenomena. At the individual level, characteristics of the samples of parents facing each of the four family crises are described and compared. At the organizational level, the four types of self-help groups (and 20 individual groups) are compared and contrasted. At the individual-organizational level, parents facing the four types

of crises are compared in terms of the ways in which individual participation in groups and group characteristics affect coping processes, informational resources, perceptions of benefits, etc. Finally, at the national-cultural level, parental responses and group operations are compared in Israel and the U.S.

Both individual and organizational level data were gathered via a number of different procedures. Group interviews with a subset of active members and a review of group publications (newsletters, brochures, etc.) yielded data on group structures, goals, activities, and processes. In addition, individual interviews were conducted with key parents who were group members, as well as with professionals connected with the groups.

Information was obtained at the individual level using personal interviews with a small sample of group members, as well as with some non-members. In addition, self-administered questionnaires distributed to a larger number of these parents provided individual data via a more private method. These individual data included reports of coping strategies, sources and types of help received, changes in one's life, involvement in voluntary or civic activities, self-help group programs or activities and group benefits to members.

Detailed descriptions of each of the groups studied and the process of access to each are contained in chapter III of the final report. The following table summarizes the data

gathered in each nation, from each type of group, in terms of number of groups visited, number of individual parent-informants, and the number of professional-informants.

	<u>Israel</u>		<u>United States</u>	
	<u>PMIC</u>	<u>PFNI</u>	<u>PCHCA</u>	<u>POMC</u>
Number of Groups Visited	5	2	8	5
Number of Individual Informants-parents	50	69	111	104
Number of Individual Informants-professionals	65	--	32	--

Research with grass roots voluntary organizations, in this case self-help and mutual support groups, encounters considerable problems. Because these organizations are less formally structured than large bureaucracies, effective access requires linkage to many people in each locale, and not simply to one national organizational leader or local spokesperson. When the groups in question are formed in order to deal with intimate stresses and difficulties in peoples' lives, these access problems are even more substantial. Concerns about privacy, and a desire not to cause added pain and suffering, often make investigators and informants more cautious and tentative. In the case of populations who are dependent on (and vulnerable to) professional service providers, there often is distrust of the motives and loyalty of professional social

scientists.

One of the principal conditions for such research is the establishment of trust between scholars and informants, so that access to these special populations and their often private feelings is assured with safety. This takes time and energy. Chesler's position as a parent of a child with cancer, and an officer of the Candlelighters Childhood Cancer Foundation, facilitated his staff's access to these groups across the United States. In addition, Chesney's role as a guest and visitor to many local groups in a prior study helped legitimate her presence in this effort. Sunderland's role as a grief counselor, and a national board member and advisor to Parents of Murdered Children, provided him with the same ease of entry. In Israel, Gidron has been an organizer of one local ENOSH group and an advisor to the national organization. Hartman, herself a western immigrant to Israel, was able to draw upon her prior work with immigrants as well as her own social role to gain entry and trust in these groups.

With this background of normal difficulties in social research with self-help groups dealing with family crises, we can identify other problems that arose, and that we would normally expect to arise, in the operation and coordination of comparative research conducted in two nations. With the two principal investigators (Chesler and Gidron) housed, respectively, in the United States and in Israel, it was at times difficult to maintain rapid and effective communication

about emergent issues. Sporadic meetings, telephone calls and electronic-mail did not fully overcome minor differences in a generally excellent common understanding and approach.

In the United States the primary modes of data collection were self-administered questionnaires for individuals, and small group interviews with groups. In Israel, problems of literacy required the use of face to face interviews in all individual data collection efforts. These differences create some level of incomparability (exact level unknown) across the two national samples. In addition, problems arose in the wording of questions themselves. While a great deal of planning time and attention was paid to insuring that we asked the same (or very similar) questions in both nations, in all sets of groups, this did not always occur. While we are quite pleased with the degree of replicability and overlap attained in this study, these minor "glitches" cannot be overlooked. Finally, cultural and language differences sometimes made it impossible to utilize exactly the same wording in Hebrew and in English in all cases and on all questions.

We present here preliminary tabular descriptions and a variety of one-factor bi-variate analyses of parents' responses. Part of our purpose is to illustrate the different areas of inquiry we undertook and the range of data contained in the Final Report and available for continuing analysis. More complete data analysis will be conducted utilizing indices created from clusters of discrete items, multi-factor analyses

of the interactions among various personal, group and national cultural variables, and analyses of qualitative data that further informs the quantitative findings.

Profiles of Four Parent/Group Samples

Parents facing different family crises may be expected to experience stress, cope with these stresses or crises, and seek/receive social support in quite different ways. Moreover, not all parents experiencing even the same family crisis, in the same nation, cope in the same fashion, choose the same social support system, or utilize the option of a self-help group in the same way. Despite this range of individual differences, however, there also are some similarities within the various samples of parents. We first report data from within each of the four sets of parents facing different family crises and later proceed to comparative analyses. (see Chapter IV of the final report)

Parents of Children With Cancer. The data on coping styles utilized by parents of children with cancer indicate a preference for active rather than passive coping styles and a substantial amount of public coping with feelings. Most parents also indicate seeking help from professionals and working actively on family issues. It is a picture of an actively coping population.

Within this set of parents of children with cancer, differences were expected between those with living children

and those who are parents of deceased children. As Table 1 indicates, the two sets of parents do not differ markedly in terms of reported coping patterns, but do differ with regard to the amount and sources of help they received. Parents of living children (PLC) report substantially more help from social workers, while parents of deceased children report substantially more help from their other children, the parent self-help group and funeral directors. Overall, spouse, nurses and doctors, and close friends are the most common and potent sources of help reported in this table. These data are generally consistent with other research on the help-seeking/receiving experience of parents of children with cancer (Chesler & Barbarin, 1987, p. 191).

When all parents (PLC and PDC) were asked whether there were ways in which their lives had changed (for better or worse) since their child's diagnosis, the only socio-demographic variable related to the report of such change is income (using a one-way analysis of variance); more positive life changes are reported by parents with higher family incomes. More positive life changes also are reported by parents whose child had been diagnosed more than three years before the study period. These findings suggest that greater resources, or perhaps more time to adjust to the crisis, may provide the opportunity for greater personal growth as an outcome of one's experience with a child with cancer. Future analyses will explore whether and how both factors interact to

facilitate such growth.

Parents of children with cancer who are members of self-help groups and parents who are not members of such groups do not differ to any great extent in terms of the degree to which they utilize various coping styles, the kinds of help they reported receiving, or the sources of that help and support. One interesting exception is that self-help group non-members report more help from social workers than do members. It is impossible, without further analysis, to know the causal explanation of this relationship: e.g., whether parents are more active in the group because they receive less help from the social worker, or whether parents receive less help from the social worker because they are more active (either because they do not need or wish this help or because the social worker maintains a distance from the group and group members). Table 2 does indicate that reported life changes are significantly related to parents' involvement in the self-help groups. While the type of analysis used here also constrains assumptions about causality, parents involved in the groups--either actively as leaders, or merely as regular members--report more positive changes over time in terms of their personal sense of identity and their sense of empowerment or ability to take action to alter their environment than do parents who are not at all involved in a self-help group. These findings support the view that self-help and mutual support groups can

TABLE 1: COMPARISONS BETWEEN PARENTS OF LIVING CHILDREN (PLC) AND PARENTS OF DECEASED CHILDREN (PDC) WITH CANCER

<u>Selected Experiences of Parents</u>	Mean Score	
	PLC	PDC
<u>Selected Coping Styles</u>		
Do nothing	1.74	1.86
Focus on problems & solve them	3.59	3.87
Keep feelings to myself	2.50	2.53
Share feelings with others	3.42	3.53
Get help in solving problems	2.88	2.87
Seek professional help	2.71	2.74
Keep family life normal	3.66	3.69
Talk as a family	3.29	3.30
<u>Selected Sources of Support</u>		
Spouse	4.28	4.27
My other children	3.86	4.64
Close friends	4.30	4.40
Neighbors	3.45	3.33
Nurses	4.42	4.69
Social workers	3.45	2.93
Funeral directors	1.01	3.47
Other parents of ill children	4.08	4.53
Parent support group	3.42	4.43

TABLE 2: COMPARISONS BETWEEN PARENTS OF CHILDREN WITH CANCER BY LEVEL OF INVOLVEMENT IN SELF-HELP GROUPS.

Life changes reported by parents (higher scores indicate more positive change)	Mean reports of life changes		
	Active leaders	Members	Not Involved
Physical health	4.00	3.84	3.63
Life satisfaction	3.89	4.07	3.65
Personal identity	2.22	2.07	1.79@
Action potential	2.78	2.53	2.24*

Statistically significant differences at the .05(@) and .01(*) level of confidence, using an F test of means in a one-way analysis of variance (ANOVA).

complement traditional medical and psycho-social care, especially in terms of parents' active involvement in dealing with their child's cancer.

Since not all self-help groups for parents of children with cancer operate the same way or perform the same functions, we were not surprised to find significant differences among parents' experiences in the eight PCHCA groups. One group with a particularly high rating of helpfulness to parents is very large and stable, no doubt utilizing its great diversity and resources to fulfill a wide range of parental needs. Two groups with low helpfulness ratings have had numerous, laborious leadership transitions. There is little variation among groups in terms of how much informational and emotionally supportive activities takes place, since these programs are a high priority universally. There are group differences in how much fundraising, change work activity, social programs, maintenance activities (leadership patterns, recruitment, meeting formats) take place. Few differences occur in reported benefits linked to specific activities, suggesting that involvement in general, not particular activities, may be the root of perceived benefit from group membership.

Parents of Murdered Children. Within the set of groups for parents of murdered children, other important differences and similarities emerged. Table 3 indicates that these parents cope with the aftermath of their child's death most often by talking and sharing their feelings within a take-charge,

TABLE 3: COPING STYLES OF PARENTS OF MURDERED CHILDREN

Coping styles	Percent reporting using			Not at All
	A lot	Some	Seldom	
Passive v. active styles				
Do nothing	11	36	30	23
Avoid thinking about problems	11	36	33	20
Focus on problems and solve them	41	51	8	0
Take charge of things	36	52	9	4
Private v. public styles				
Try to be alone	19	54	22	6
Go off by myself	13	54	26	7
Keep feelings to myself	28	42	24	6
Talk about things to someone	43	44	11	1
Share feelings with others	45	41	13	1
Get help in solving problems	14	44	31	12
Use of professionals				
Seek professional help	13	30	28	28
Family focus				
Keep family normal	57	32	13	4
Talk as a family	19	35	32	15
Change family plans	13	37	38	12
Reassign homework	6	18	42	34

problem-solving approach. They also report a relatively low incidence of practical help with family chores. As might be expected, given the context of their crisis, these parents receive most help from the self-help group, funeral directors, and lawyers, in addition to their families. Evidently, friends and neighbors gradually wander away or are relied on less often by these parents than by parents of children with cancer. Reported benefits of group participation center on both emotional sharing with a commonly-afflicted group and assistance in the form of advocacy, problem consultation, and referrals for help from professionals. A dichotomy of sorts is revealed in the form of life changes reported by these parents of murdered children. In tandem with a worsening sense of loss and general satisfaction, these parents also express changes in the positive (growth) direction in terms of their own perceived ability and willingness to take action and change their environment.

Several variables were significantly related to life changes reported by parents of murdered children. For instance, more positive life satisfaction is reported by parents with higher family incomes and parents who were (still) married and a more positive change in sense of personal identity is reported by parents with higher incomes and by parents whose child had been murdered more than three years prior to the study interval. A better potential for taking action for changes in their environment is reported by parents

who were (still) married and by parents who lost their child more than three years prior to the study. Females report more negative changes over time in their physical health than do males. Religious differences emerge, but cell size prevents any real statistical confidence in these trends.

Table 4 indicates that significant differences were discovered between the five self-help groups for parents of murdered children in terms of helpfulness of members, with the highest rated group being one with considerable outreach capacity. Very few significant differences were found between groups in terms of frequency of group activities and members' reports of the benefits of those activities, with the groups really only differing on social agendas and recruitment methods. As noted earlier, these findings on self-help group variation (or lack thereof) are quite similar for groups of parents of children with cancer.

Parents of Mentally Ill Children (ENOSH). Data were gathered from Israeli parents of children with mental illness in a fashion parallel to the data gathered in the United States from parents of children with cancer and parents of murdered children. While some items asked of the American samples were not asked of the Israeli parents, a good number of comparisons are possible. The Israeli parents' choices of coping strategies reflect both a strong reliance on professionals and a reserve or avoidance of sharing feelings that contrasts

TABLE 4: PARENTS OF MURDERED CHILDREN'S EXPERIENCES WITH SELF-HELP GROUP PROCESSES, BY GROUP

Experiences	Mean of all groups	Range of means	# of highest group	# of lowest group	F-Stat
1. <u>Amount of help received</u>					
From other parents of murdered children	4.42	3.3-5.0	10	11	2.6@
From parent support group	4.30	3.3-4.7	10	11	1.8
2. <u>Activity frequency</u>					
Informational/educational					
Discuss recent advances in treatment	3.38	3.2-3.6	11	10	.4
Sharing/dealing with feelings					
Talk about family stresses	3.41	3.3-3.7	11	9	.9
Talk about personal feelings	3.46	3.3-3.7	12	11	.4
Deal with emotional issues	3.17	2.9-3.5	12	9	1.8
Fund raising					
Raise money for the system	2.49	2.0-2.8	12	10	.8
Raise funds for needy families	1.61	1.4-1.7	11	12	.3
Social events					
Plan to get together socially	2.23	1.8-2.9	11	13	3.5@
Making change					
Give feedback to staff	2.61	1.8-2.9	9	10	2.3
Plan to change the system	2.86	2.5-3.0	11	10	.3
Change social policies	2.69	2.3-2.9	13	11	.6
Maintenance					
Plan group activities	2.22	1.9-2.6	11	13	1.3
Discuss recruitment of new members	1.83	1.1-2.8	10	13	7.2*
3. <u>Benefits</u>					
Informational					
Getting information	3.34	2.7-3.6	13	10	1.4
Learning the staff	3.46	2.8-3.7	9	10	1.7
Learning my "rights"	3.16	2.2-3.5	12	10	3.1@
Practical coping					
Coping with child's problems	3.46	2.7-3.7	9	10	1.7
Coping with family's problems	2.95	2.9-3.1	11	12	.2
Learning to cope differently	3.17	3.0-3.3	10	11	.1
Coping with death of child	3.63	3.6-3.8	10	13	.3
Emotional					
Being supported/approved	3.38	3.3-3.6	12	13	.4
Feeling freer to express feeling	3.52	3.4-3.7	10	9	.2
Expressing compassion	3.47	3.4-3.6	12	13	.2
Talking about my child	3.61	3.5-3.7	12	13	.2
Social identification					
Meeting similar others	3.78	3.7-3.9	11	9	.3
Feeling part of a larger group	3.48	3.3-3.8	10	13	1.9
Self-empowering					
Developing self-confidence	2.78	2.4-3.2	10	13	1.1
Being helpful to others	3.46	3.2-3.8	10	13	2.8@
Learning to be a leader	2.46	2.1-2.9	11	13	1.9
Being active in medical care	2.68	2.3-2.9	12	10	.6

One way analysis (ANOVA) of F-test of differences in means statistically significant at the .05 (@) or .01 (*) level of confidence

markedly with reports from the U.S. parents. This finding provides evidence of the strong ties to the medical-psychiatric system and to the long-range nature of their child's illness that characterizes parents of young mentally-ill persons. While the data indicate that parents of mentally ill children studied in Israel do not generally share their feelings with their social network, they also indicate a substantial amount of emotional support, but little practical help, received. Table 5 reflects these parents' reports that almost all life changes occurring over the course of the period since diagnosis are in the negative direction, with a slight exception in the area of personal empowerment and a more substantial positive potential for action.

In contrast to the dominant theme of privacy evident in this sample's coping styles, the support group appears to be a major source of emotional assistance. Reports of group activities, coming only from active group members, emphasize emotional support activities as the primary activity and information-dispersal about treatment advances as the secondary agenda for these groups of parents of mentally ill children. Table 6 presents these involved parents' reports of the benefits they derive from their participation in the self-help groups. Social identification stands out as the benefit reported most often, and it probably represents the value of finding and considering oneself part of a larger group of persons experiencing a difficult social and personal situation.

Practical coping skills and aid also are consistently reported as benefits from self-help group participation. Other categories of benefits are either less vital, or mixed and ambiguous reports about them are provided.

Parents of children with mental illness who are active members of self-help groups view their experience with their child's illness, and with the self-help group, quite differently than do parents who are not involved in the group. Active parents more often seek help from others, cope more actively, are more involved in other voluntary activities, and report actually receiving more help from a variety of sources. They also report more positive (or less negative) life changes, especially in terms of the potential to be self-empowering through action for change in their environment.

Parents in Families of New Immigrants. A second set of self-help groups in Israel involved parents of families who were new immigrants to Israel. The coping strategies reported by these parents demonstrate a very active, family-based approach to dealing with stresses of immigration and resettlement. Emotional support and action-taking help are dominant, echoing the expectation that new immigrants, while not threatened or saddened by the loss of a child, must deal with a variety of practical challenges. In general, the reports of life changes over time by these parents are in the positive direction, despite the physical stress and emotional disruption of resettlement, and the threat to physical health and

estrangement from old friendships that parents report accompany it. Positive growth is seen in reports of satisfaction with family life and in general, and in one's personal (perhaps national as well) identity. The sense of increased empowerment accompanying the feeling of being able to accomplish things, to establish personal control over one's life, and to join others in doing so, stands out as another major positive change.

Table 7 indicates these parents' report of their views of the importance of involvement in other voluntary organizations active on social issues. A high level of importance is attached to such participation, reflecting a general eagerness to play a role in solving national and local problems and influencing policy decisions.

The two groups of parents in families of recent immigrants to Israel are comprised of South Americans and North Americans (U.S. and Canada), respectively. While the South Americans do not report frequent self-help group activities, they do report having received more emotional and practical benefits from their group. This finding echoes the U.S. reports, indicating that perceived benefits of group membership are not necessarily a function of the frequency or even the specific nature of group activities. The needs of the older, less-educated South American group may be greater, and thus the self-help group's capacity for helpfulness greater, than in the case of the group for North Americans.

TABLE 5: PARENTS OF CHILDREN WITH MENTAL ILLNESS' REPORTS OF CHANGES IN THEIR LIVES

Changes	Percent reporting		
	Better	Same	Worse
Health			
Physical health	2	58	40
Health compared to others	0	74	26
Life satisfaction			
With life in general	2	20	78
With family life	4	40	56
With friends	0	50	50
Personal identity			
Sense of who I am	2	81	17
Mental health	2	32	66
Action potential			
Sense of what I can do	27	49	25
Willingness to join others to change things	42	48	10
Sense of personal control	0	41	59

TABLE 6: REPORTS OF THE BENEFITS OF SELF-HELP GROUPS FOR FAMILIES OF CHILDREN WITH MENTAL ILLNESS

Benefits	Percent reporting receiving			
	Much	Some	Little	None
Informational				
Getting information	13	30	22	35
Understanding treatments	13	22	26	39
Learning the staff	4	4	35	57
Learning my "rights"	9	13	30	48
Practical coping				
Coping with child's problems	48	35	13	4
Coping with family problems	30	17	26	26
Learning to cope differently	29	29	29	13
Emotional				
Feeling freer to express feelings	42	29	17	13
Expressing compassion	0	4	17	78
Talking about my child	44	39	13	4
Social identification				
Meeting similar others	79	13	4	4
Feeling part of a larger group	75	13	4	8
Self-empowering				
Developing self-confidence	8	25	46	22
Being helpful to others	67	21	4	8
Learning to be a leader	0	8	17	75
Being active in medical care	8	8	13	71

TABLE 7: IMPORTANCE OF INVOLVEMENT IN VOLUNTARY AND CIVIC AFFAIRS FOR PARENTS IN FAMILIES OF NEW IMMIGRANTS

Involvement dimension	Percent stating importance as:			
	Very	Somewhat	Little	Not at All
Importance of involvement in national affairs	64	22	13	0
Importance of involvement in city issues	73	22	5	0
Importance of involvement in neighborhood affairs	76	16	16	2
Importance of involvement in problems like your own	79	13	6	2

Comparative Analyses of Different Family Crises
and National Cultures.

Since parents in the two nations studied are experiencing different cultures as well as different family crises, we compared the two United States samples and the two Israeli samples, as well as the aggregate samples from the two nations (Chapter V). These comparisons illuminate differences and similarities between the two samples of parents within each nation, focusing on their views of and experiences with their self-help groups, and also paint a clearer picture of how the two different national cultures and socio-economic systems may impact on all parents.

Parents of Children with Cancer (PCHCA) and Parents of Murdered Children (POMC). In these analyses, we generally divided the PCHCA sample into parents of living children (PLC) and parents of deceased children (PDC), in an effort to increase our understanding of whether the differences between the PCHCA and POMC samples were a function of the different experiences of cancer and murder, or of the death versus the chronic illness of a child. Most of the significant differences in coping styles among these U.S. parents occur between the POMC sample and the two sets of the PCHCA sample, with POMC taking a more private, less public approach to coping with the death of their child. In terms of the helpfulness of various sources of support, the POMC report more support from neighbors and

lawyers, and less from close friends and family members than do the two PCHCA sets of parents.

The two sets of parents whose children have died (PDC and POMC), also resemble each other in some ways, such as reporting that funeral directors and the parent support group are especially important sources of support. These two sets of parents also rank quite highly the supportive role of their surviving children, indicating the maintenance of their own parental role and their own special identity as parents of deceased children. Despite these similarities, the amount of support and help reported by the PDC is still greater than that reported by the POMC, perhaps signaling the greater negative social effect of the stigma of childhood murder as contrasted with cancer.

Examinations of the differences in group activities between the PCHCA and the POMC reveal that PCHCA groups engage in more group maintenance, social planning, and fundraising. While POMC groups raise some money and more often work for institutional change, they primarily use group time to talk about personal feelings. However, Table 8 reflects very few significant differences between the PCHCA and the POMC parents in terms of reported benefits they receive from the self-help groups. This is in sharp contrast to most reports about coping, about social support, about life changes, and about group activities from these samples. In both sets of groups, meeting with other parents who have experienced a similar life

crisis is rated as the most important benefit. One major difference occurs with regard to coping with a child's death, a benefit reported in greater degree by parents of all children who died than by parents of children who are living, and in greater degree by parents of murdered children than by parents of children who died from cancer. In addition, parents of murdered children report more benefit from learning who the staff (police and court) is than do parents of children with cancer (medical). Parents of deceased children with cancer report less benefit from new information about the problem than do either of the two other samples.

The data suggest a universality of experience in benefitting from self-help groups among parents facing different family crises. The magnitude of the difference in these family crises cannot be belied; it stands out clearly from other tables and other data considered in this paper. But these data suggest that differences germane to the individual experience of childhood cancer and murder may be overwhelmed by the common needs parents experience and the common resources and benefits that self-help groups offer.

Table 9 indicates different groups of parents' reports of the changes in their lives as a function of their experience with their child and family crisis. Coded so that higher numbers indicate a more positive change, the data indicate that

**TABLE 8: COMPARATIVE REPORT OF SELF-HELP GROUP BENEFITS
FOR PCHCA (PLC, PDC) AND POMC**

Benefits	Mean report of benefit		
	PLC	PDC	POMC
Informational			
Getting information about problem	3.63	2.92	3.39@
Learning the staff	3.08	3.00	3.45@
Learning my rights	3.21	3.08	3.20
Practical			
Coping with family's problems	3.08	3.08	3.01
Learning to cope differently	3.29	2.92	3.18
Coping with death of child	2.93	3.23	3.65*
Emotional			
Being supported/approved of	3.38	3.23	3.41
Talking about my child	3.69	3.54	3.62
Expressing compassion	3.56	3.31	3.49
Feeling freer to express feelings	3.48	3.31	3.54
Social			
Meeting similar others	3.73	3.58	3.81
Feeling part of a larger group	3.46	3.31	3.53
Self-empowering			
Developing self-confidence	2.98	2.83	2.95
Being helpful to others	3.23	3.58	3.50
Learning to be a leader	2.68	2.69	2.55
Being active	2.77	2.92	2.82

Statistically significant difference at the .01() and 0.5(@) level of confidence, respectively, using the F-test of means in a one-way analysis of variance (ANOVA).

**TABLE 9: COMPARATIVE REPORTS OF LIFE CHANGES FOR
PCHCA (PLC, PDC) AND POMC**

Changes	PLC	PDC	POMC
Health (physical)	3.80	4.10	3.70
Life satisfaction	2.20	2.00	1.53*
Satisfaction with others	4.69	4.10	3.57*
Personal identity	1.92	2.32	1.58*
Social action	2.46	2.66	2.41

*Statistically significant difference in means at the .01 level of confidence, using an F-test of means in a ONE-WAY ANALYSIS OF VARIANCE (ANOVA).

parents of children with cancer generally report more positive changes as a long-term result of their family crisis experience than do parents of murdered children. With regard to the satisfaction items (general life and others--family/friends) there is a linear trend evident, with parents of murdered children reporting the most negative results, parents of living children the most positive, and parents of children who died from cancer in the intermediate position.

Parents of Mentally Ill Children (PMIC) and Parents in Families of New Immigrants (PFNI). The two Israeli samples also exhibit some interesting similarities and differences. PMIC report significantly less public and more private coping strategies than do PFNI; they more often avoid thinking about problems related to their child's illness and more often keep their feelings to themselves. When they do elect to go outside of themselves to share their feelings and concerns they are more likely to seek professional help. PMIC parents also report more help from other parents of ill children than do their Israeli immigrant counterparts. PFNI, on the other hand, are much more public and active in both their coping and help-seeking strategies. As might be expected, these same parents, who have voluntarily chosen immigration and resettlement, report more positive life changes than do parents of mentally ill children. Thus, the data quite clearly represent the different realities of the two experiences of these Israeli groups of parents.

Table 10 indicates that there also are substantial differences between the two Israeli samples in terms of the incidence of various activities of their self-help groups. PMIC activities focus on sharing and dealing with feelings, while PFNI activities are more oriented toward raising resources for needy immigrant families, conducting social events and maintaining their own group, a source of new relationships for all of the immigrants.

These two samples of Israeli parents also differ in the extent to which they view civic involvement as important. PFNI rate such involvement highly, given their obvious desire to integrate into the affairs of their new country, while PMIC often are so engulfed in the daily management of their child's illness that they seldom feel free for or interested in formal civic involvement.

United States (PCHCA and POMC) Parents and Israeli (PMIC and PFNI) Parents. Given the substantial differences in social service systems and cultures in the two nations, we expect Israeli and U.S. parents to experience their respective crises differently, even taking into account the differing nature of the crisis each parent experiences. U.S. parents, Table 11 suggests, cope by sharing their feelings more and more publicly seeking help than do Israeli parents. The totals for public coping by U.S. parents and by Israeli parents consistently differ significantly.

TABLE 10: REPORTS OF THE INCIDENCE OF ACTIVITIES OF
SELF-HELP GROUPS FOR PMIC AND PFNI

Activity	Mean reports of activity incidence	
	PMIC	PFNI
Informational/educational		
Discuss recent advances in treatment	2.63	2.51
Sharing/dealing with feelings		
Talk about family stresses	3.30	2.11*
Talk about personal feelings	3.28	2.29*
Deal with emotional issues	3.39	2.44*
Funding-raising		
Raise money for needy families	1.65	3.00*
Social events		
Plan to get together socially	1.72	3.93*
Visit parents at home	2.00	3.07*
Making change		
Give feedback to staff	2.30	1.82@
Plan to change the system	1.67	1.88
Maintenance		
Plan group activities	1.44	3.84*
Discuss recruitment of new members	1.62	2.72*

Statistically significant difference at the .01(*) or .05(@) level of confidence, respectively, using the F-test of means in a one-way analysis of variance (ANOVA).

TABLE 11: COMPARATIVE COPING STYLES OF U.S. AND ISRAELI PARENTS
AND OF PARENTS FACING FOUR TYPES OF FAMILY CRISES

Style	U.S.			ISRAEL			F SCORE	
	PCHCA	POMC	TOTAL	PMIC	PFNI	TOTAL	(X4)	(X2)
Private vs. public styles								
Talk about things to someone	3.43	3.30	3.37	2.42	2.69	2.56	21.9*	61.5*
Seek help from friends	2.95	2.73	2.85	1.72	2.00	1.87	28.3*	78.5*
Seek information from friends	2.80	2.67	2.73	2.18	2.28	2.23	7.2*	20.3*
Active vs. passive styles								
Avoid thinking about problems	2.47	2.61	2.54	2.73	2.63	2.70	1.1	1.6
Accept things as they happen	3.30	3.14	3.22	3.00	3.09	3.05	1.7	2.9
Use of professionals								
Seek professional help	2.72	2.28	2.52	3.62	1.39	2.43	53.5*	.4
Family focus								
Talk as a family	3.28	2.57	2.94	2.60	2.96	2.78	10.6*	1.5
Share feelings with spouse	3.29	2.93	3.12	3.17	3.08	3.13	1.9	.0

Statistically significant difference at the .01() level of confidence, using one-way analysis of variance (ANOVA).

and the PCHCA and POMC parents' reports of public coping are always higher than either of the PMIC and PFNI. Moreover, with regard to parents' reports of talking about things to someone, the differences in coping between the two types of family crises in which parents are involved in the U.S. are very small (3.43 v 3.30), and (2.42 v 2.69) so the differences between the two types of Israeli parents. As a result, here we can be relatively confident in attributing the difference to national/cultural factors. Although there often also appear to be substantial differences by type of crisis (see F score X4 crisis) care must be taken to determine whether these figures primarily reflect reports relevant to a single crisis, two crises occurring in different nations, or two crises occurring within a single nation.

The picture with regard to active coping styles is quite different, with no substantial differences occurring either with regard to type of family crisis or national culture. No differences are apparent on a national cultural level with regard to the use of professional help either, although there are very significant differences among parents facing the different types of crises; PMIC utilize professional help a great deal (3.62) and PFNI very little (1.39), with PCHCA (2.74) and POMC (2.28) in intermediate positions. Coping that focuses on the family also demonstrates mixed results, with U.S. and Israeli parents in general coping quite similarly (2.94 v 2.78 and 3.12 v 3.13), but with PCHCA and PFNI talking

much more as a family (3.28 and 2.96) and POMC and PMIC doing so much less.

With regard to the amount of support received, with the exception of action-taking help, U.S. parents report receiving significantly more support than do Israeli parents, and this is true in terms of sources of support as well as kinds of help (Gidron, Chesler and Guterman, 1988). On a number of dimensions of life change over time, U.S. parents also report more positive changes than do Israeli parents. However, this particular finding is most likely due to the extremely negative responses of PMIC, which is a reflection of the ongoing daily pain of their own and their children's situation.

Table 12 indicates that a great many significant differences occur in frequency of self-help group activities, both in national cultural comparisons (see totals and F scores x2 nations) as well as in comparisons among types of crises (see F scores x4 crises). The strongest national cultural differences in self-help group activities occur in the areas of getting information about treatment relevant to the crises, sharing emotional issues and feelings, and making changes, with parents in the U.S. groups reporting significantly more of each of these types of activities. Differences in the reported incidence of fundraising appear to be more a function of the nature of the family crisis than of national cultural differences. In almost every one of these situations parents in both U.S. groups (PCHCA and POMC) report more of each kind

of activity than do parents in the Israeli groups (PMIC and PFNI). In addition, however, immigrant families appear to experience much fewer of these kinds of activities than any other group, including their Israeli compatriots who are dealing with the crisis of a mentally ill child. Thus, we see evidence of activity differences as a function of the type of family crisis with which groups are dealing, as well as with regard to the national culture.

The items involving social events and group maintenance activities indicate no significant international differences, although there are significant intranational differences (e.g. PCHCA v POMC and PMIC v PFNI). In the case of fund-raising activities for needy families, the Israeli parents report being involved in these events slightly more often than do U.S. parents, but this is probably a function of the very high activity level in groups of parents of new immigrant families (PFNI=3.00, compared to PMIC=1.72, POMC=1.59 and PCHCA=2.48). Similarly, with regard to social events the very high level of immigrant group activity, coupled with the very low level of activity in groups of parents of mentally ill children, make the national comparisons quite suspect. It appears that these differences are primarily accounted for by the nature of the family crisis rather than by the national culture itself.

A very clear national cultural difference is reflected in parents' reports of the roles professionals play in these different groups. Both U.S. samples, PCHCA and POMC, report

TABLE 12: COMPARATIVE REPORTS OF THE INCIDENCE OF ACTIVITIES
IN SELF-HELP GROUPS FOR U.S. AND ISRAEL PARENTS

Activity	U.S.			ISRAEL			F SCORE	
	PCHCA	POMC	TOTAL	PMIC	PFNI	TOTAL	(X4)	(X2)
Informational/educational								
Discuss recent advances in treatment, enforcement, etc.	3.08	3.29	3.19	2.63	2.51	2.57	12.2*	32.8*
Sharing/dealing with feelings								
Talk about family stresses	3.50	3.40	3.45	3.30	2.11	2.69	42.4*	56.1*
Talk about personal feelings	3.12	3.51	3.31	3.28	2.29	2.77	25.1*	24.7*
Deal with emotional issues	3.21	3.26	3.23	3.40	2.44	2.91	14.6*	9.6*
Fund raising								
Raise funds for needy families	2.48	1.59	2.06	1.65	3.00	2.33	31.1*	4.2
Social events								
Plan to get together socially	3.00	2.0	2.66	1.72	3.93	2.84	70.5*	1.7
Making change								
Give feedback to staff	2.52	2.57	2.54	2.30	1.82	2.06	7.9*	17.4*
Plan to change the systems of care	2.10	2.89	2.48	1.67	1.04	1.78	24.9*	31.6*
Maintenance change								
Plan group activities	3.17	2.36	2.78	1.44	3.84	2.66	92.4*	.9
Discuss recruitment of new members	2.52	2.06	2.30	1.62	2.73	2.19	13.8*	.8

*Statistically significant difference at the .01 level of confidence, using the F-test of means in a one-way analysis of variance (ANOVA).

the following professional roles as most common:

Refer new parents to the group
Provide information
Refer parents for special help
Consult with the group on problems
Advocate the group's existence and
function.

The following roles, on the other hand, are reported as least common:

Train parents in how to lead the group
Set the agenda for the group
Plan group activities
Supervise the group's operations.

In marked contrast, parents in both Israeli groups report the following professional roles as most common:

Lead the group
Set the group's agenda
Plan group activities

And the following roles as least common:

Raise or provide funds
Attend social functions/activities.

Where professionals in the U.S. groups commonly play advisory or consultative roles, and desist from controlling or supervising functions, the reverse often is true in the Israel groups. Professionals in Israeli groups were reported as much more vital to group leadership and maintenance, while U.S. groups reported their roles as more advisory and advocacy-oriented. Thus self-help groups in Israeli appear to be much more dependent upon professional direction than are those in the U.S. This does not mean the U.S. groups operate without or in opposition to professional assistance, but that assistance

is delivered in a very different manner than in Israeli settings. These findings are consistent our original suggestion that the more elaborate and professionally staffed social service system in Israel would extend into active professional and even governmental leadership of self-help groups. In the U.S., with a less extensive social welfare and social service apparatus, and with a strong tradition of voluntary activity, self-help groups appear to be more autonomous from professional control and direction, while still collaborative.

All these national cultural comparisons are incomplete, however illuminating and provocative. Future analysis will focus on the interaction between type of crisis and nationality, hoping to use MANOVAs (among other procedures) to determine the relative impact of these two variables on parental responses.

Conclusions

The data generally support the assumption that U.S. and Israeli parents experiencing a family crises have different preferences and experiences regarding their support resources and environments. U.S. parents are substantially more public in their coping strategies and report receiving greater amounts of help from a greater variety of sources. The evidence that U.S. parents receive more help is consistent with their adoption of a more public coping style; the effort to reach out

for and receive help from others both solicits and accepts a wider variety of social support from more sources.

The expectation that self-help groups serving the two national sets of parents would utilize similar programs and internal support processes is only partially supported by the data. The two nations' groups differ in terms of the incidence and priority of some specific group activities. In addition, members' reports of self-help group benefits do differ between nations, with U.S. levels of benefit somewhat higher, but this is true of almost all forms of social support reported by U.S. and Israeli parents. On the other hand, the rank ordering of benefits does not vary appreciably across all groups studied, once again suggesting a universality to the self-help group experience. Meeting others in a similar situation is universally reported as the single most important benefit, with talking about my child and coping with my child's problem consistently close behind.

Since only the PCHCA and PMIC samples included non-members of self-help groups, only those data could be used to determine whether life change reports varied according to group involvement. PCHCA parents involved in a self-help group report more positive changes in their lives, more help from the self-help group and less assistance from the social worker, than do non-involved parents. PMIC parents who are involved in the self-help group also report more positive (or in their case less negative) life changes, and more help of various kinds,

from more varied sources. All these differences appear to be positive, verifying the value of self-help group participation for members, and also suggesting their value for most parents experiencing a family crisis.

Group structures and activities were found to be not as relevant as membership and involvement in a group of one's choice, as indicated by reports of group benefits. The evidence seems clear that the activities of various groups differ, as do parents' reports of the amount of help they receive from other parents experiencing a similar family crisis. However, the benefits reported by parents in the PCHCA and POMC groups do not generally differ significantly by virtue of the organization, activities or leadership of the specific group in which they are involved. Membership and involvement in a group of one's choice, rather than the structures or operations of an aggregate of groups, seems to be the critical variable. While further analyses are required, this finding suggests that meeting and identifying with others in a similar situation, and thus gaining feelings of personal and social empowerment may be the generic benefit that underlies any of the particular benefits of mutual support and self-help group involvement.

The two national sets of parents' different views of the roles of professionals and of state services is clearly confirmed by the data. Advocacy/consultant roles are played primarily by professionals in the U.S. groups and Israeli

professionals primarily lead, set the agenda and control developments in their self-help groups. This finding reflects the differences in the structure and operations of the social service systems and human service agencies in the two national cultures. The Israeli tradition of socialism, and its more far-reaching social service and medical system, provides greater professional resources to aid parents in families in crisis, and the Israeli conception of appropriate roles is consonant with that ideology and structure. Over time, parents become dependent upon this professional assistance, and, as a result, even the definition of a self-help group, usually considered a semi-autonomous parent activity, has come to include active professional leadership and direction. In the U.S., with a much less extensive social service system, fewer professionals are available to work with parents of families in crisis. In addition to this difference in resource availability, the American tradition of volunteerism venerates autonomous or semi-autonomous citizen organization, sometimes even to the exclusion of professionals who do not embrace collaboration and coalition-development.

We indicate throughout the final report that many more data analyses, of a progressively more complex and sophisticated character, are planned for the months ahead. This report describes most of the data collected and some of our analyses to date, primarily in a preliminary fashion. Nevertheless, the findings are quite informative and provocative, justifying additional attention to these issues.

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