

TAPPING MUTUAL AID, LAY RESOURCES IN CHRONIC DISEASE MANAGEMENT*

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ABSTRACT

The modal type of health problems in “developed” countries, chronic illness, presents difficult problems of care-management. It is increasingly recognized that for both patient and family, psycho-social issues are especially important and often transcend bio-medical treatment needs. Role-readjustments, life-style alterations, everyday problems of “normalization,” self-concept, self-management, practical information, and emotional-social support become salient in the patients’ maintenance of social functioning. In these aspects, participation in self-help groups, which exist widely in the chronic conditions, has been shown to have effective values for the chronically ill and their families. Such mutual aid groups, whether formed and conducted within formal institutions, like hospitals or independent community organizations, provide continuous care on the psycho-social issues. Such care will be illustrated by examples drawn from recent research and the speaker’s current study of patients with systemic lupus.

It has been clear for some time that the chief problems affecting the health of populations in advanced countries are the chronic diseases, which account for some 75 or 80 % of current morbidity and mortality. It is also clear that personal behavior, as summed up in the term “lifestyle,” is highly involved, in interaction with the physical and social environment, in both the causation and management

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of chronic long-term diseases or conditions. The examples of coronary artery disease, cancer, and hypertension are most familiar in this respect.

Studies of the *immediate* psychological reactions that occur when a particular chronic illness has been diagnosed are abundant. The conceptualization of these studies reflects mainly a crisis-theory orientation. From this standpoint, patient and family-member perceptions and fears regarding the illness, treatment regimens, and prognosis, and their concerns to provide for medical care and other material problems, are viewed as temporary reactions that disturb psychological homeostasis. Based on Selye's classical stress paradigm, patient/family responses to chronic illness are analyzed in terms of the processes of perception of threat, resource mobilization to meet it, and the diminution of the presenting crisis through adaptive behavior.

Only a few researchers, have looked at the *longer-term* issues that arise once the immediate crisis has past: these are issues of patient and family adaptation to changed circumstances, needed changes in social roles and family organization; the patient's needed life-style alterations including daily regimen and habits, social interactions; vocational activity.

In contrast to acute or short-term illnesses, chronic diseases significantly alter everyday behavior on a continuing basis.

Lavietes summarized its nature and effects: "Chronic illness is marked by long duration and frequent exacerbations. . . . It is frequently present long before becoming evident, and more often than not, it is irreversible . . . the usual course is progressive deterioration, although it is often slow. For the bulk of chronic illnesses there is no cure; fortunately there are often useful palliative resources. Chronic illnesses give rise to much disability, loss of earning capacity, need for medical care, and perhaps even more important, a decrease in the quality and fullness of life. For many patients, the onset of chronic illness forces an awareness of a permanent defect, however slight it may be, and the need to learn how to live with something less than the perfection which has been taken for granted."

The primary requirement in chronic illness behavior then is adjustment: the individual has to adapt his/her lifestyle and daily social functioning to a less-than-normal health status. Among the health and social problems are: the management of medical crises and regimens; the control of symptoms including pain; the re-ordering of time; the management of social isolation; the processes of "normalization," the often changed relationships with family members and vocational status. For adaptation to be accomplished, psycho-social strategies to meet these problems must be continually worked on, tested and modified.

Two additional characteristics of chronic diseases are also worth stressing. First, they involve uncertainty and unpredictability. *Prognosis* is often uncertain, making it difficult for those affected to make long-range plans. For younger patients, who have important life decisions before them, this may constitute an additional burden, as in the case of female lupus patients' reproductive decisions.

Second, chronic diseases are frequently multiple in character; a single condition may lead to others, as in the cases of the frequent connection of cardiac and renal failures of lupus with kidney and CNS disease.

These additional aspects contribute to the reality that chronic diseases disrupt the lives of patients and their families, to a far greater degree than do short-term, acute illnesses.

The need to adjust to the demands of a medical regimen and to physical limitations often requires radical re-organization of the patient's lifestyle, commitments, aspirations, and activities. Since the prognosis may be indefinite, the patient cannot drop out of normal activities *temporarily*, but must make major changes in the way life is conducted. These changes bring large costs to patients and their associates.

Household routines have to be re-ordered to accommodate the patient's limitations, the use of special equipment, the demands of symptoms, the scheduling of the regimen.

Patients often face the need to adjust their work lives to the demands of the disease. Even if the patient can continue on the job, the effects of the illness and treatment on his/her time, energy and mental state may not be understood or accepted, and an employer may be unwilling to make scheduling or work-load adjustments.

Patients also pay a high price for chronic illness in the form of social isolation from friends and community activities.

Two bodies of research are very important in understanding both the etiology of chronic disease and methods of overcoming it.

The first concerns vulnerability. From many studies, the finding emerges that persons who lack stable and satisfying social supports, i.e., those who are isolated have the highest risk of morbidity and mortality in the major conditions. For instance, rejection of ethnic minorities by the dominant majority in their neighborhood; high sustained rates of residential and occupational mobility; broken homes or isolated living circumstances often result in significant deprivation in meaningful social contact.

Now, what can we do about this knowledge? Cassel concluded his paper with recommendations that embody the use of self-help approaches: "With advancing knowledge, it is perhaps not too far-reaching to imagine a preventive health service in which professionals are involved largely in the diagnostic aspects—identifying families and groups at high risk by virtue of their lack of fit with their social milieu and determining the particular nature and form of the social supports that can and should be strengthened if such people are to be protected from disease outcomes. The intervention actions then could well be undertaken by nonprofessionals, provided that adequate guidance and specific direction were given."

Researchers concerned with factors that help individuals cope with stress are increasingly focusing on social support. Individuals suffering from malignant

disease, physical disability, death of a close friend or family member, rape, and job loss have all been found to adjust better when they receive social support. For example, Gore found that unemployed men who felt unsupported had more symptoms of illness, and were more depressed than unemployed men who felt supported. High levels of depression are frequently found for individuals with low levels of social support. Berkman and Syme, in a prospective study, found that people who lacked social ties had higher mortality rates than did those with social ties.

Prevention of both physical and mental illness is related to improving how people feel about themselves, and one way of achieving this is by enhancing their social ties and connections. In the mental health field, these ideas received full expression in the Report of the President's Commission on Mental Health (1978), as well as in the Reports of the White House Conference on Handicapped Individuals (1977).

The second group of findings come from basic research in the fascinating field of psychoneuroimmunology (PNI).

The social support literature has almost ignored the subject of *immune responses*, but there is evidence that disruptions in social networks can impair or suppress the immune system;—emotions and other psycho-social responses influence neuroendocrine functioning and immunity. *Life situations characterized by alienation and social isolation have been correlated with respiratory infections, arthritis in children and adults, asthma increased corticosteroid levels, etc. Thus, social stressors may depress host defenses.*

Both these sets of findings show that it is essential that health workers help provide social support systems for the chronically ill, if they are deficient or non-existent.

This has been borne home to us by our study of lupus patients.

That study had two aims: 1) to examine how patients recently diagnosed with lupus cope with everyday problems of living, and adjust to this serious, potentially disabling chronic illness; and 2) to study the impact of peer self-help support groups on patients' adaptations to life problems in a newly acquired, or newly diagnosed chronic illness.

Briefly, we found 1) a close association between episodic lupus "flare-ups" and social stresses and 2) a beneficial effect on most aspects of adaptation to the illness through regular participation in a self-help group, composed of and led by peers.

The application of such data—from this and other research—in planning preventive and educational activities in human service programs has been insufficiently realized and carried out. The studies highlight the essentiality of *recognizing, fostering, and consciously using informal support groups of all types, including self-help groups*, as indispensable resources in aiding troubled and ill people to cope with life pressures and crises. Such informal groups perform services of emotional and material sustenance, present peer models of successful

coping, aid in the establishment of positive self-concepts through education and reinforcement in problem-solving and self-management skills. They provide opportunities for the open sharing of problems in a non-threatening atmosphere. In all these aspects and at all periods of the life-cycle, they present unusual but easily-realized possibilities for the prevention and amelioration of personal social disease, possibilities different from those offered by professionals.

Human service professionals should regard such groups not as some kind of threat, or undisciplined competitors, but as collaborators and partners. *The lay resource is the oldest, most widespread, and easiest to use resource that we have in fighting the effects of chronic disease.*

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