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### THE NON-ORTHODOX CANCER THERAPY MOVEMENT: EMERGENT ORGANIZATION IN HEALTH CARE CRISIS

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#### ABSTRACT

The ideology and organization of the non-orthodox cancer therapy movement are analyzed as social constructions in an area of professional ambiguity and failure. The movement articulates, integrates, and orders the personally and socially disabling consequences of health care failure in cancer. The protest activities of the movement are characterized by political opposition to medical "orthodoxy" and "monopoly." The challenges of the non-orthodox movement are generally ineffective, non-legitimated, or coopted. Yet, in providing conceptual and organizational frames for the disordering consequences of medical failure and in establishing a politically polarized deviant position in relation to conventional practice, this movement socially organizes and isolates various problems in cancer health care that threaten the institutional dominance of professional medicine. The emergence of this movement is discussed as an illustration of the social organization and management of crisis.

#### Medical Crisis and the Alternatives to Disorder

Today, in the United States, cancer is the second leading disease killer. Over 1,000 people die of cancer each day, and statistics indicate that the number of fatalities increases each year (Cairns, 1975). Cancer occurs in two out of every three families, one out of every four individuals, and kills one out of every six (American Cancer Society, 1976a). A review of recent developments in the "war on cancer" reports that "not only have there been none of the breakthroughs we're always promised, but...there really has been little if any progress in cancer treatments since the mid 1950s" (Von Hoffman, 1975). As the fundamental questions of the origins and pathology of cancer remain unanswered or disputed, social policy is deficient in the development of effective and comprehensive programs for the prevention, control or cure of cancer. On the individual and family level, medical interventions frequently fail to "cure" patients, lead to terminal prognoses, and may compound the fear, hopelessness, and anxiety associated with cancer. Sociologically, the disorientation and dissidence arising from the unresolved problems of cancer threaten basic values, behavioral norms, and institutional conceptions of order (Douglas, 1970; Kleinman, 1978). As the consequences of cancer are personally disruptive and socially disordering, the emergence of conceptual and institutional re-orderings alternative to the perceived failures of conventional medicine is basic to the development of the non-orthodox cancer therapy movement.

The non-orthodox cancer therapy movement, of which Laetrile advocacy is only a single popularized example, involves lay individuals, maverick scientists, marginal practitioners, and non-professional "health" organizations. In protesting the inadequacies of conventional medical approaches to cancer, the movement seeks to promote, distribute, and legalize unproven and unrecognized cancer treatments in direct opposition to the licensing and modality restrictions fundamental to the institutional dominance of the medical profession. Materials for the ideological and organizational analysis of this movement are derived from participant observation in several associations advocating and implementing the principles of alternative cancer treatment. Supporting information was obtained from the journals of the American Medical Association and the American Cancer Society, related Federal and other documentary materials, and from personal interviews with organizers, advocates, patients, and practitioners active in developing or responding to the movement.

The major sociological principle involved in the analysis of the non-orthodox movement reflects Douglas's (1970) conception of the necessity for the social ordering of disease. On a patient level and under conditions of perceived medical failure, the movement provides an alternative system of beliefs and practices supporting personal re-integration. On a social level, the movement as a counterinstitutional formation organizes protest resulting from exposed inadequacies in the professional and political management of cancer.

Significantly, health care insurgency, potentially involving mass disaffliation and political revolt, is contained and limited by the movement's emphasis on unapproved, illegitimate therapies. Social protest developing from the cancer crisis is disconnected from political mobilization for institutional change and is channeled into advocacies for questionable "victim" centered therapies. In effect, the non-orthodox movement, with its promotional treatment interest and its ideological insularity, develops few if any significant changes in the social organization of cancer on the national level, and, more importantly, sustains dissidence in politically ineffective and discredited deviant polarizations subordinate to professional medical authority.

Overall, we observe how the unstructured consequences of social crisis in an area of professional dominance are managed and politically neutralized. Threatening dissent and other divergent discontinuities of the cancer crisis are chamneled, tracked, and regulated by the non-orthodox movement in politically marginal contexts subordinate to the dominant power structures. With disorder and dissent organized and isolated in a repressed and repressive social movement, disruptive conflict and contradiction in the professional and institutional management of cancer is contained and reduced.

## The Ideological Order of the Non-Orthodox Cancer Therapy Movement: Personal Re-integration and Social Pathology

Given the confusion, mystery, and fear often associated with cancer (Sontag, 1978) and the apparent hopelessness in many cases, cancer patients become especially vulnerable to fringe practitioners and non-orthodox approaches that promise to meet needs left wanting

by conventional medicine. Patients "terminated" by the medical profession, or otherwise "turned off," turn to fringe practitioners hoping not only for cures as "strawgraspers" (Cobb, 1958), but also for the emotional and social support provided by these practitioners and the organizations which may represent them (Bernard, 1963; Garland, 1961 Inglis, 1965; Whitehurst, 1974).

While a list of over 200 unrecognized, unapproved cancer therapies that are reported to "work" may be compiled (Brown, 1968), only a dozen or so of these methods are prominent or accessible. The various fringe methods and health sects constitute a broad spectrum of alternative approches and practices, and differ considerably in style, content, and orientation. Many are characterized by underground, deviant social contexts, while others are remote hold-overs from folk and traditional medicine, and still others involve eclectic combinations of innovative and "scientific" rationales. Non-orthodoxy in cancer includes nutritionists grounded in materialist and natural rationales, chiropractors, acupunturists, Laetrilists, as well as faith healers, spritualists, psychics, and the metaphysicians of various energy systems.

To the novice, the pluralism of the diverse methods and claims is often confusing and ambiguous. For cancer patients and families experiencing the stress of terminal prognosis, introduction to non-orthodoxy may be initially quite confusing. Each method, however, in encompassing a knowledge system that re-orders and re-orients the personal and social calamities of cancer, can be "explained" technically and metaphorically. Indications include specific references to rationales, applications, and alleged rates of success. These knowledge systems embody a variety of clinical, social, and political articulations and develop a world of meanings that constitute significant ideological re-constructions of reality which serve ultimately to root and organize patients and families in altered personal relations and in movement activities (Behar, 1976).

activities (Behar, 1976).

The vacuum of effective scientific knowledge and medical practice has made possible, and perhaps necessary, the development of alternative explanations and interpretations of cancer (Petersen and Markle, 1979b). In the non-orthodox movement, "theories" of cancer engage alternative paradigms of the nature of disease and its relation to the social order. Cancer is projected, identified, and resolved ideologically as a social pathology or "social disease." Douglas's (1970) observation of the necessity for the social meaningfulness of disease is applicable to the efforts of the non-orthodox movement to ideologically transform cancer from disease to social theory. Political de-legitimation of the movement and the consequent "deviancy" of its members involves therefore not only medical rejection of alleged clinical quackery, but reflects attempts by established power structures to repress and discredit the movement's incompatible and conflicting world views.

Initially, this ideology characterizes and rejects the American Medical Association, the Federal Food and Drug Administration, and most cancer research as an established cartel, fundamentally exploitative of the "cancer industry." Conventional practice is viewed as an enormously ineffective "rip off" of the uneducated and naive public. Despite substan-

tial failure, physicians allegedly work to maintain the <a href="staus quo">staus quo</a>
in cancer treatment because of vested interests in the "industry."
Surgery is viewed as destructive "cutting" and "butchery"; chemotherapy as "poisoning"; radiation therapy as "burning." Indeed, in this conspiratorial perspective, most physicians are viewed as incompetent, licensed "quacks," and the A.MA. as a totally corrupt organization protecting elite priviledges and lucrative mystifications (Brown, 1968; Caum; Haines, 1976; Hoffman; IACVF, 1971; Kittler, 1963; Lowrey, 1971; Morris, 1977; Rorvik, 1976). On the other hand, "non-toxic" therapies such as Laetrile, Hoxsey, Krebiozen, and various other methods are actively promoted and demanded.

In relation to a world view of the social order, proponents in the movement define cancer as a "social disease" or as a "disease of civilization." Primitive, undeveloped societies are presented as cancer free such that the "real" causes of cancer are to be found in the economic and industrial processes of modern society. The environment of the "advanced" world is viewed as thoroughly polluted: carcinogens exist in the air we breathe, the food we eat, the water we drink, and contaminate most areas of everyday life. The "natural" world, subject to industrial pollution, unrestrained economic exploitation, and political corruption, is thus conceived as a destructive, pathological environment with cancer as its most characteristic product.

In its most intense negative formulations, the non-orthodox ideology reflects a general consciousness of "cultural despair." Critical assessments of the cancer "epidemic" are related to (1) the moral confusion of contemporary society, (2) the debasement of traditional institutions, (3) the diminishment of human freedom by bureaucratic systems of collective control, (4) the destructiveness of governmental and industrial priorities, and, of course, (5) the deterioration of natural, health securing environments. Reduced to its simplest terms, the non-orthodox ideology focuses on the alienation, anomie, and alleged illegitimacy of the major institutional "establishments" of contemporary society. This ideological radicalism is effective in solidifying a meaningful and coherent re-articulation of cancer in relation to personal victimization through social pathology.

While cancer is portrayed as a "social disease," and it is alleged that technological industrialization and political corruption determine the cancer complex, therapeutic responses are geared to the promotion of questionable and generally ineffective patient-centered bio-chemical approaches. The individual patient is isolated for therapy, specifically implored to "de-pollute" or "de-toxify" bodily impurities, and to refuse "toxic" therapy as unnatural, destructive, and immuno-suppressive. Sociolgical diagnoses and "theories" function as ideological abstractions in the movement, while practical applications center on individual and subjective life-style adaptations, especially patient-centered commodity

consumption.

Beyond therapeutic individualism, the non-orthodox movement idealizes resolutions to the cancer complex is the social imagery of a reformist "return to nature." This somewhat nostalgic and mythical appeal to recapture the alleged innocence, purity, and vitality of traditional, communal society is as consequential politically as it

is realistic. While advocates certainly cannot return to the traditional folkways of a romanticized <u>gemeinschaft</u>, their adherence to organic, natural, vegetarian, and other unadulterated diets reflects a shadow-like attempt to reproduce the natural world through the imitation of "primitive" diets. Again, the healing practices are individually based and involve no political action.

based and involve no political action.

In summary, publicly represented "theories" of cancer causation are most often commentaries on industrial chaos and political corruntion. For those patients and families who need to condition their experience of pain and loss within a meaningful framework, a framework perhaps not available in the medical prognosis of terminal incurability, the phenomenal world of the non-orthodox therapies offers a context of rules, perspectives, values, and interpretations which may support a sense of integrated moral existence. More than "strawgrasping" for dubious clinical alternatives, patients, relatives, and friends become subject to sets of experiences and interpretations which help to authenticate their adjustments to personal calmity.

Politically, however, the ideologies of cancer therapy, couched in socialgenerality and vague imagery, remain theoretically abstract and support no substantial movement mobilization. Socially engaging critiques become vehicles not for directed political transformation but rather for the promotion of alternative clinical practices. The potential of the movement for social change, as implied in expressed ideologies, is neutralized by an emphasis and almost exclusive pre-occupation with individual problems. Thus, without a central political praxis directed toward institutional change, and with a continuing official discrediting of its dubious clinical and ideological promotions, the non-orthodox cancer therapy movement resides in a nether world of marginality, illegitimacy, and institutional impotence.

#### Movement Organization: Polarization and De-Legitimation

Promotional activities of the non-orthodox movement are coordinated by national "health" organizations. Five major associations act to inform the public and the cancer patient of the "suppressed" truth about non-orthodox cancer therapies that "work." The organizations develop socially effective networks for the distribution of practices and beliefs that specify medical inadequacies in cancer therapy and identify accessible alternatives. In addition to claiming that conventional medical treatment is clinically iatrogenic within the context of broader ideological theories of cancer, these organizations support legislative initiatives to establish "Freedom of Choice" in cancer care such that patients and "doctors" be permitted to pursue whatever promising treatments they wish without interference from the government or medical profession.

The International Association of Cancer Victims and Friends, Inc., (IACVF) is one of the largest and oldest organizations involved in the promotion of Laetrile and other non-orthodox approaches to cancer. The organization reports a membership of approximately 20,000 and has 50 local regional chapters throughout the United States, Canada, and Australia. Income generated by membership is supplemented and substantially

increased by the extensive sale of publications, convention activities, advertising, private donations, and foundation grants. In "Suburbia," a local chapter of the IACVF, with approximately 400 members, provides cancer patients, relatives, and other health minded individuals with information and directives about cancer specifically regarded as fradulent "quackery" by the medical profession. Other major organizations in the movement are: The Committee for Freedom of Choice in Cancer Therapy, The Cancer Control Society, The Foundation for Alternative Cancer Therapies, and The National Health Federation.

Leaders and other volunteers in the IACVF and its sister organizations claim to have had cancer that they were able to "cure" or "control" through the use of one or more of the non-orthodox therapies. Many ex-"terminal" patients give powerful dramatic testimony to the efficacy of the non-orthodox methods and the vileness and failures of A M A enderged medicine. On the least shorter level and failures of A.M.A. endorsed medicine. On the local chapter level, cancer patients and relatives who attend a meeting of the IACVF are exposed to sets of incentives and opportunities for non-orthodox therapy that are uniquely optimistic, comprehensible, and emotionally and socially responsive and supportive. With political explanations given for the suppression of the methods within the context of the general ideology, many patients are convinced, may seek out alternative methods, and begin an initial yet deepening conversion to the non-orthodox way. Patients travel to Tijuana for therapy, smuggle contraband drugs across the border, convert to "natural" food regimens, conceal treatment information from their regular physicians, and use "illegal" methods locally. Publicly, the chapter functions to present "educational" lectures which are generally thinly veiled promotions. On another, more interactive level, the chapter creates a context for patient recruitment and for the informal yet persuasive sharing, directing, and controlling of information and practices about illegal or quite marginal medicine.

The Laetrile case is illustrative of movement organizational controls and the development of ideological and clinical promotions. The Laetrile "connection" includes many scientists, physicians, "doctors," distributors, political publicists, foundations, clinics, and "health" organizations in a complicated, international network of vested interests, controlling structures, ideological media bases, and "service" deliveries. The emergent "underground railroads" of the non-orthodox movement in developing the ideological and practical availability of Laetrile reach into a sundry assortment of "suppliers," "cancer victims," and "friends," and pass through numerous cities, states, and countries. It is estimated that in the United States alone, Laetrile has been used by over 70,000 individuals. For patients and others vulnerable to the promotions of non-orthodoxy, the organizing structures of the movement make accessible practical alternatives and provide integrated incentives for social conformity among recruits and advocates (Petersen and Markle, 1979a; Markle, et al., 1978).

Yet, non-orthodox organizations and underground networks are only marginally viable in an arena historically and politically dominated by the American Medical Association. In establishing its "orthodox" domain, professional medicine has systematically relegated interests

and practices it chooses not to represent or support to marginal, deviant, and "quackery" status (Kaufman, 1971; Shryock, 1947). The continuing de-legitimation of "alternative," "unproven," "unrecognized, and "non-orthodox" competitive health care practices, approaches, and "sects" is thus a well established political activity of the medical profession. Indeed, the American Medical Association's advancement as a professional organization parallels its capacity to discredit "unorthodox" methods, criminalize their practitioners, and generate belief in the singular legitimacy of allopathic health care.

In specific reference to the non-orthodox cancer therapy movement, the American Medical Association and the American Cancer Society have consistently been active and determined in denouncing the alleged fraudulent quackery of the IACVF, Laetrile and <u>all</u> other "unproven methods of cancer management." Reporting on the IACVF, the American Cancer Society (1976b) states:

This organization attacks medicine such as the American Medical Association, the American Cancer Society, the Food and Drug Administration and the National Cancer Institute for their orthodox approach to the management of cancer.

The IACVF is associated with an "underground railroad" whereby cancer patients from all over the United States are directed to Mexico for treatment with readily available worthless methods.

Similarly, the American Medical Association (Kotulak, 1975) indicates that among the most prevalent health frauds promoted today are:

<u>CANCER TREATMENTS</u>--As authorities put pressure on the phony cancer treatments, many are moved across the border to Mexico. These patients are offered Laetrile and other disproven treatments such as Krebiozen, the Hoxsey treatment, and the Koch treatment. <u>The International Association of Cancer Victims and Friends</u> has been set up to recruit frightened cancer patients from the U.S. and Canada to patronize the Mexican clinics. (emphasis added)

Additionally, movement organizations have been a target of state and federal actions typically involving border arrests, smuggling indictments, conspiracy trials, crackdowns on Laetrile operations, and suits of member physicians and doctors for non-licensed or illegal practice. One indictment of Laetrile traffic, peripherally involving the IACVF and directly involving leaders of the Committee for Freedom of Choice, consisted of 187 separate counts, 19 major conspirators, and dozens of unindicted co-conspirators (Holles, 1976). In effect, the non-orthodox movement is subject to intense medical discrediting and legal suppression.

Interestingly, in this social conflict, the medical profession, with its claims of unilateral, singular legitimacy and with its private practitioners entrenched in the orthodoxy of the profession, is not immune to criticism. Increasingly, conventional medicine is subject to the attacks of critics who report on the continuing failures of ineffective cancer therapy and an unresponsive delivery system. Organizations such as the IACVF, in developing and promoting a critical ideology of medical "monopoly," have capitalized on public and private disenchantment with the medical profession, and have succeeded in organizing patients, families, and legislators in non-orthodox orientations that most medical professionals, the American Medical Association, the National Cancer Institute, and the Federal Food and Drug Administration consider illegitimate and fraudulent.

Yet, in the medical profession's construction of a rationalized health system, it has achieved a powerful bureaucratic and ideological dominance that is only slightly modified by these external assaults and criticisms. The public order of medicine, to the extent that it is ideologicallylegitimated, bureaucratically maintained, legally protected, and technologically capitalized, is considerably unresponsive to the challenge of critics, especially when these critics are defined as opponents located in "deviant" non-orthodox health "sects." The IACVF and the non-orthodox cancer therapy movement effect very little fundamental change either legally, morally, or institutionally their interests and practices remain eccentric, deviant, and fundamentally discredited.

#### Conclusion

The polarized structure of this social conflict is extremely indicative in analyzing the institutional managment of health care crisis. The polarization maintains the external boundaries of professional medicine and yet allows for the internal cohesion of an alternative world view. Disorder, discontinuities, and dissidence arising from professional failure in cancer are organized, structured, and socially re-integrated by the ideological and organizational constructions of the non-orthodox movement. The medical profession is thus relieved of some of its potentially disruptive failures by a tracking system which is both outside of its legitimate area of responsibility and is made politically impotent by the continuing de-legitimation of the non-orthodox movement's alleged deviant quackery. The first consequence of the tracking is to provide a safety-valve for the outletting of dissidence, while the second consequence is to reduce the efficacy of external attempts for institutional change.

Additionally, while the non-orthodox movement suffers the fate of illegitimacy, deviancy, political eccentricity, scientific discreditation, and general institutional impotency, its emphasis on patient-centered, individual modalities and therapies distorts its perspective on genuine social alternatives. Radical challenges to the medical profession's organization of health care which might require a fuller investigation of the political economy of the cancer complex on a variety of ecological, social, and cultural levels are neutralized

by the vague metaphors and abstractions of the ideological rhetoric. In exploiting individual victimization, the movement has opted for

freedom of choice in commodity consumption and not for health care insurgency directed toward fundamental social change.

The dynamics of cancer management are a significant illustration of social ordering. Movements mobilized in times of crisis may or social ordering. Movements modifized in times of crisis may serve to channel and track divergent discontinuities developing from perceived societal failures and, in effect, provide a social regulation. This regulation, appearing as a self-contained control system and occurring outside the limits of professional legitimacy, may be both internally repressive and externally repressed, and consequently consistent with the continuing dominance of elite power groups.

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