Beyond Scientific Controversies: Scientific Counterpublics, Countervailing Industries, and Competing Research Agendas

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## Abstract

Health advocacy organizations can be conceptualized on a continuum from an interest group pole, which generally does not challenge mainstream assumptions about etiology and treatment, to a social movement pole, which often challenges the dominant epidemiological paradigm and calls attention to undone science. A scientific counterpublic can emerge when researchers and clinicians, generally located in subordinate positions in the scientific and therapeutic fields, advocate broader policy reforms that would provide support for the evaluation of undone science, such as novel etiologies and therapies. In the case of advocacy for complementary and alternative medicine (CAM) approaches to cancer, the counterpublic has sometimes been in opposition to the pharmaceutical industry, especially its traditional emphasis on cytotoxic chemotherapy, and in alliance with the countervailing nutraceutical industry. Although the CAM cancer counterpublic articulates a call for reform and claims to support a broad public interest in gaining access to a new generation of less toxic treatments, the articulation of an alternative public interest is not innocent of sectional interests. When a scientific counterpublic is successful at gaining funding for undone science, epistemic modernization of the research field occurs, as happened with the historical change in government funding in the U.S. that was associated with the creation of the National Center for Complementary and Alternative Medicine. The historic change in the research field coincided with liberalization of the regulatory field, in which nutraceuticals were made more widely available in both stores and medical practices. However, there were limits to the changes. Of 147 completed studies funded by NCCAM between 2001 and 2011, only 2 were clinical studies of a CAM cancer therapy, even though the contestation over CAM cancer therapies was an important motivation for the founding of NCCAM. The one, significant, head-to-head study of a chemotherapy and CAM therapy (enzymes for pancreatic cancer) resulted in the breakdown of trust between the CAM and conventional research teams, with subsequent allegations and investigations. Implications for the study of neoliberalism, citizenship, and health advocacy are discussed.

The role of patient associations, health movements, and other actors outside the medical profession and associated research community has changed dramatically during recent decades. To some degree, the changes are broad ones that affect science in general: as the technological complexity and industrial diversity of societies has increased, the scientific field has become both more important politically and more politicized. Social movements and civil society organizations have been drawn into political conflicts about the regulation of both new and old technologies, and they have politicized issues of therapeutic choices and research agendas. At the same time, the relations between the scientific field and industry have also changed, because new professional specialties and new industries also seek to influence research agendas. The growth of industrial funding and the allure of revenues from patents have also provided scientists with the incentives to respond to industrial needs; however, some medical researchers have become aligned with health reform movements and patient advocacy organizations, and their involvement tends to enhance and politicize divisions within the scientific field over research agendas.

This study adopts a perspective on patient advocacy movements and medical research that is based on political sociology of science and technology (Frickel and Moore 2006, Moore et al. 2011). Central concepts from the sociology of science as an institution are important, such as differential career attainment and competition for recognition, remains important, as does the central finding of the sociology of scientific knowledge, that the making of scientific knowledge is socially shaped or negotiated. However, the focus of attention in a political sociological perspective is on power differentials and the relations between the scientific field and other social fields (such as the medical profession, civil society, the pharmaceutical industry, and the state). In this project I focus particularly on the meso-level construction of scientific research fields rather than the micro-level of specific knowledge claims, on the unequal power relations between challengers and incumbents in the therapeutic and research fields, and on the relationship between the sociology of scientific knowledge and the sociology of scientific ignorance. This paper will outline a conceptual framework, present case study materials based on one health reform movement, and then discuss the broader theoretical implications.

### Background Concepts and Framework

Epstein (2008) has noted that there are various ways to classify patient advocacy organizations; the focus here is on the relationship to health policy, corporate power, and social change. From this perspective, one can think of health advocacy organizations as forming a continuum from traditional interest groups, which attempt to increase research resources and therapeutic access, to reform movement organizations, which challenge mainstream approaches to disease and treatment and draw attention to the politics of research agendas and therapeutic choices.

Advocacy organizations close to the pole of traditional interest groups attempt to increase research resources and therapeutic access for a social segment, such as persons afflicted by a particular disease. The disease may be a common one, such as breast cancer or AIDS, or a rare one, for which resources and treatment options are limited because of the demographics. In either case, the primary goal with respect to research funding is the allocation of resources. Resources may come from the reallocation of existing health-related resources or from a reallocation of resources to the sectors of health research and care from other social fields. In either case, medical specialists and pharmaceutical companies may advise and encourage advocates to lobby funders to free up resources. Conflicts tend to arise over treatment options as defined by the mainstream of the researchers and health-care providers.

At the other pole of health-related advocacy, health movements challenge the dominant frameworks of disease categorization, etiology, and/or treatment. For example, patients

suffering from an unrecognized disease face not only an issue of funding allocation but also a controversy within the research community over the etiology and even existence of the disease. With respect to contested disease etiology, patient advocacy organizations that seek more research into environmental causes of a disease find themselves at odds with what Brown has called the "dominant epidemiological paradigm" (Brown 2007). Likewise, advocacy organizations may also contest treatment options and seek greater funding for research on (and greater access to) therapies that are outside the medical mainstream. The contestations over treatment options are often linked to different etiologies, but the two types of contestations can be distinct. In other words, advocacy groups can share the dominant etiological paradigm while rejecting the mainstream approaches to treatment, or vice-versa. There can also be radically different theory-treatment packages, which in turn are associated with complementary and alternative medicine (CAM) professions.

Both the interest group pole and the movement pole of health advocacy draw attention to specified ignorance or non-knowledge, that is, areas of potentially fruitful future research that could be completed (Merton 1987, Gross 2009). At the interest group pole, the articulation of non-knowledge tends to define the future research agenda in ways that are consistent with mainstream researchers, and hence their view of non-knowledge is "positive" or desirable both for the advocacy group and the mainstream research community. In contrast, reform movement organizations tend to draw attention to future research areas that mainstream researchers and associated industrial groups (the leaders of the medical profession and dominant corporations in the pharmaceutical industry) reject as negative non-knowledge. Thus, a conflict emerges over the identification of systematic pockets of non-knowledge that are created by the shared assumptions of the dominant agents in the research and industrial fields. Elsewhere we have discussed this form of non-knowledge as "undone science" (Frickel et al. 2010; Hess 2007, 2011; Woodhouse et al. 2002). There is also an element of what Gross calls "nescience," that is, a form of scientific ignorance that is only knowable in retrospect, after a surprise. However, due to the impossibility of seeing nescience in advance, this form of scientific ignorance does not play the same role in the politics of agenda-setting as does the specified ignorance of positive and negative non-knowledge.

Whereas in the interest group type of advocacy organization, the partnership is among civil society organizations, mainstream researchers, and corporate funders, in the reform movement type of advocacy organization, the partnership is often with some combination of scientists outside the maisntream, alternative or CAM clinicians, and countervailing industrial firms such as nutraceutical organizations. When scientists "go public" with their claims about epistemic gaps and systematic non-investigation of research leads and hypotheses, they form a counterpublic, often in alliance with civil society organizations (Hess 2011). When the aspirations of the counterpublic receive acceptance by the mainstream of the research field, and the new research agendas receive funding and legitimacy, a process of epistemic modernization occurs (Hess 2007). In other words, the research field becomes open to reforms of its research priorities, methods, and conceptual frameworks based on the inclusion of the perspectives of previously excluded groups. The change can lead to a situation in which undone science, as identified by civil-society reform organizations, gets done. However, one can also find examples of marginalization and intellectual suppression, which can lead into the dynamics of backfire (Debourne 2008; Martin 2007, 2010).

Networks of reform-oriented civil society organizations and dissenting researchers tend to lack the resources to mount a successful challenge to the dominant epidemiological and therapeutic paradigms. However, if the counterpublics form coalitions with countervailing industries, their political power increases. In the case of the CAM cancer counterpublics discussed below, the countervailing industries provide resources such as research institutions and peer-reviewed publications from the CAM professions and funding from the nutraceutical industry. Although there is an element of grassroots organizing and democracy in the counterpublics, their political power is contingent on building alliances with countervailing professions and industries (see also Hess 2013).

Although these conditions of counterpublics and countervailing powers are likely to be general across a wide range of science-oriented reform movements in societies that have parliamentary institutions and high levels of influence by private capital on the political system, the case study that follows will focus on a specific health reform movement in the United States. This approach is methodologically distinct from the quantitative methods that tend to characterize the sociology of science as an institution and also from the detailed examination of the construction and deconstruction of specific knowledge claims that is characteristic of the sociology of scientific knowledge. Instead, the methodology focuses on the long-term, mesolevel of the broad historical transition of the field. Within the STS field, the approach is closest to the long-term historical case studies of technological systems analysis, such as the work of Hughes (1987) and transition studies (e.g., Geels 2002, 2007). More generally, the concept of social fields as quasi-autonomous but inter-connected social spaces of contestation informs the methodology. The historical narrative is divided into two sections based on a periodization divide during the 1990s. The research is based on years of interviews, conference participation, participation in patient advocacy events, and extensive reading of both the popular and scientific literature. The long-term warrant of ethnographic research has enabled a picture to develop of the transition of the field that was not evident when the research first began during the 1990s.

#### The CAM Cancer Field in the Twentieth-Century United States

During the period prior to World War II, the fields of cancer etiology and treatment in the United States were more open and pluralistic than today. Although the theory that cancer was an infectious disease like tuberculosis was widely accepted before World War I, slowly other etiologies emerged with studies of environmental toxins (e.g., coal tar), viruses, and genetic predisposition. During the first half of the twentieth century, there was little evidence of cancerrelated patient advocacy organizations or other types of civil society advocacy work in either the United States or Europe. However, there were networks of scientists and clinicians who had developed theories of cancer etiology and treatment approaches that offered an alternative to surgery. Among the prominent networks were supporters of the theory of bacterial etiology, who developed therapies that included antimicrobial interventions such as vaccines and dietary changes. This network of researchers included William Coley and Thomas Glover, and it survived after World War II principally in the networks that developed in support of the work of Royal Raymond Rife and Virginia Livingston (Hess 1997). Another prominent and influential early approach was the treatment of cancer advocated by John Beard, who believed that proteoloytic enzymes produced by the pancreas held cancer cells in check (Moss 2008a, 2008b).

After World War II, chemical weapons became the basis for the new generation of cancer chemotherapy drugs, and the credibility in the mainstream medical community for that vaccine and enzyme therapies declined. However, during this period the field of complementary and alternative medicine (CAM) approaches to cancer diversified, and there were more extensive networks of clinicians and patients. A prominent network was support for the therapy Krebiozen, which was based on a substance isolated from the serum of horses that had been injected with the bacterium *Actinomyces bovis*. The therapeutic claims were highly controversial, but at its peak during the 1950s, the network included political and labor leaders as well as doctors. Emmanuel Revici and Max Gerson, two European émigrés, attracted networks of clinicians and patients in support of their complex nutritional and biological regimes. Some prominent herbal therapies, notably the Hoxsey and Essaic formulas, also attracted networks of patient advocates (Hess 2004, Moss 1996).

In most cases, solid clinical evidence in the form of peer-reviewed studies was absent, and health authorities prosecuted practitioners. At the high end of scientific credibility, Livingston

and her fellow researchers published in peer-reviewed journals, and Revici and Gerson were medical doctors who conducted scientific research and found linkages between nutrition and cancer that later became more widely accepted. In contrast, the herbal formulas came from folk medicine backgrounds, and although the therapies attracted a following of patients who claimed to have been successfully treated, they lacked the same level of scientific research credibility. Even more controversial were the Krebiozen supporters, who were plagued by widespread claims of fraud. Some of the networks were able to establish clinics, generally in Mexico, which enabled a degree of institutionalization that was able to survive the death of the founder (Hess 2004, Moss 1996).

A patient-based health social movement emerged in support of laetrile, a food-based pharmacological intervention for cancer that was claimed to be toxic only to cancer cells. The laetrile phenomenon was the source of formal advocacy organizations, some of which survive today. In 1963, the laetrile patient Cecile Hoffman founded the International Association for Cancer Victims and Friends (the word "Victors" was later switched for "Victims"), and she partnered with the Tijuana-based physician Ernesto Contreras to obtain therapy in Mexico when it was not available in the United States. The Contreras Oasis Hospital eventually grew into one of the largest of the Tijuana cancer treatment centers. Over time the International Association and the Contreras Oasis Hospital diversified to support a wide range of CAM cancer therapies. In 1973 the Los Angeles chapter of the association formed the Cancer Control Society, which hosted and continues to host an annual meeting that brings together cancer patients with CAM practitioners. Beginning in 1984, the conference also provided tours of the Tijuana cancer clinics, including those associated with the Gerson, Hoxsey, Rife, laetrile, and other CAM approaches (Hess 1999).

A galvanizing moment in the development of the CAM cancer therapy movement was the prosecution of the physician John Richardson. Because he was a member of the John Birch Society, his prosectution triggered the mobilization of an estimated 500 chapters and 30,000 supporters of the legalization of laetrile (Culbert 1974, Markle and Peterson 1980). Michael Culbert, another patient advocate leader and cofounder of the International Council for Health Freedom, noted in an interview with me that the laetrile movement was not monolithically rightwing, because it also included hippies and countercultural supporters (Hess 1999). Despite the diversity of political viewpoints of the laetrile movement during the 1970s, there was a strong libertarian stream in the CAM cancer therapy movement in the United States. That stream continues today in expressions of concern with government control of medicine and electronic record keeping (e.g., Citizens Council for Health Freedom 2011). Another source of support for laetrile and CAM cancer therapies in general was the National Health Federation, an organization founded in 1955 to promote more open markets for vitamin supplements and unconventional medical therapies (Markle and Peterson 1980). Furthermore, in 1977 the firing of Ralph Moss, the assistant public affairs director of Memorial Sloan Kettering Cancer Center who exposed the cover-up of successful laetrile experiments, added another dimension to the laetrile movement, because he went on to found a patient support and educational organization, Cancer Decisions, and to become a leader in calls for scientific support of research into CAM cancer therapies. His book The Cancer Industry, originally published in 1980, chronicles the problems in clinical trials for laetrile and other CAM cancer therapies, and it discusses the suppression that clinician-researchers faced during the 1970s and 1980s (Moss 1996). He also became a student of German cancer clinics and the leading American expert on the options available for patients who have the resources to travel to Germany.

Laetrile was not the only CAM cancer therapy that was emerging during the 1970s. There were also networks of clinicians, researchers, and patients in support of the work of Linus Pauling and Ewan Cameron on vitamin C and cancer, Michio Kushi on macrobiotics, Joseph Gold on hydrazine sulfate, Stanislaw Burzynski on antineoplastons, and Lawrence Burton on immuno-augmentative therapy. During the early 1980s the cancer research community responded to the laetrile and Vitamin C claims by conducting clinical trials that had negative results, but CAM cancer therapy advocates claimed that the studies suffered from fatal design flaws (Hess 1999, Moss 1996, Richards 1981). Because the CAM community was not included in the design and execution of the clinical trials, the resulting experimenters' regress only fanned the gulf between the two communities.

In 1986 Congressman Guy Molinari joined with patient advocates and forty other Congressional representatives to ask the Office of Technology Assessment of the U.S. Congress to call for an investigation into bias against CAM cancer therapies, partly in response to the repression of immuno-augmentative therapy (Office of Technology Assessment 1990). Patient advocate Frank Wiewel, whose father was a Burton patient, led a march on Washington against the suppression of CAM cancer therapies and was the original requestor of the OTA study (Hess 1999). A group of CAM advocates led by journalist Robert Houston tracked the errors in the subsequent report and called for corrections (Hess 1999). The report evaluated existing research on a wide range of CAM cancer therapies and became a battleground for conventional and CAM cancer researchers. The publication of the report is sometimes mentioned as one of the reasons why the Office of Technology Assessment was closed, but it also served as a trigger for Congressional reforms that led to the establishment in 1991 of the Office of Alternative Medicine of the National Institutes of Health. In 1998, amid charges that the office was too soft on alternative medicine, it was restructured as the National Center for Complementary and Alternative Medicine (NCCAM).

# Epistemic Modernization and Liberalization

Prior STS research on CAM cancer therapies has focused on the period before the 1990s (e.g., Markle and Peterson 1980, Richards 1981), and a new historical perspective is now possible given the lapse of time since the first STS studies. During the 1990s two significant changes occurred in the development of the field of research and therapies for CAM and cancer. The founding of the Office of Alternative Medicine (later NCCAM) marked a regime change in which the integration of CAM therapies was to proceed based on evidence. Thus, a new era of epistemic modernization was supposed to occur, in which the integration of CAM and mainstream therapies would become possible based on scientific research. The change coincided with the professionalization of CAM providers, especially naturopaths with degrees accredited by the Council on Naturopathic Medical Education and also acupuncturists who were gaining licensing accreditation. Researchers representing CAM professions were added to the NCCAM advisory board, including a naturopath, an acupuncturist, and a chiropractor in 2011. Cancer patient advocates, including one whom we interviewed for *Women Confront Cancer*, also were allowed to join the advisory panel of NCCAM, at least for a period (Wooddell and Hess 1998).

In general, the integration of CAM research coincided with a complementarization process, that is, the focus of research on complementary rather than alternative uses of CAM cancer therapies. Furthermore, in a process akin to bioprospecting among indigenous herbal medicines, the dominant networks of the research and therapeutic fields colonized the CAM field by taking ideas and subjecting them to a filtration process that translated them into patentable pharmaceutical products. There are numerous examples, including the ideas of William Coley (who is now recognized as the father of cancer immunology even if his therapies have long been rejected) and the idea of antiangiogenesis. In the translation from, for example, shark cartilage to an antiangiogenesis drug, the biological product was simplified and rendered capable of passing a test of evidence based medicine (Hess 2006).

The complementarization process also included the integration of CAM researchers, especially those associated with research and education institutions, including schools of naturopathic and chiropractic medicine. On the surface, there was a significant change from the era of the Mayo Clinic trials for Vitamin C and laetrile, which excluded CAM researchers and

physicians from participation in the design and execution of the trials. However, the new conditions for research also put the therapy through a filter that has a bias against alternative modalities in favor of complementary modalities, and against the total, individualized protocol in favor of a standardized therapeutic unit such as a drug or food supplement. Advocates of alternative approaches were told to prove their therapeutic mettle with clinical trials, but the funding was very restricted for the research. NCCAM did not fund direct, head-to-head research on alternative cancer therapies versus conventional therapies. Guidelines of equipoise (projected equivalent benefit for patients) made it ethically impossible to offer, for example, the herbal formula Essiac and standard chemotherapy as competing arms in a clinical trial. The exception was patients with a very poor prognosis for whom conventional therapies have little efficacy, such as pancreatic cancer patients, but with that population it is possible that nothing will work well.

The research agenda at NCCAM can be tracked via its funding record and the results of funded studies. The analysis in Table 1 is focused on results from NCCAM-funded studies, because it provides a more comprehensive picture of the research agenda over a ten-year period, and it is also possible to gain a better picture of the nature of the research and direction of results. From the summary in Table 1, one can see that cancer is only a relatively small percentage of the data set of completed research results. Even though cancer affects more than one-third of the population, it is the topic of only about 9 percent of the 147 completed studies in this data set. Furthermore, within the group of 13 cancer studies, most of the research is on prevention, subclinical efficacy, or behavior. Shark cartilage is the only CAM cancer therapy for which results were available. Both studies tested shark cartilage in a complementary modality, and both had negative results (the first was stopped early due to low patient adherence and no apparent benefit). Although shark cartilage was widely hyped and was the basis of both positive subclinical results and conversion into antiangiogenesis drugs, it was hardly one of the main lines of CAM cancer therapy. With respect to the main lines of CAM cancer therapy (proteolytic enzymes, autogenous vaccines, the Gerson diet, the Revici lipids, immuno-augmentative therapy, antineoplastons, Vitamin C, laetrile, hydrazine sulfate, and the herbal formulas such as Essiac), little more is known about clinical efficacy in 2011 than in 1991, when the Office of Alternative Medicine was founded. Even Vitamin C, for which the Mayo Clinic trials substituted an oral dose for intravenous injections (a crucial design flaw according to CAM advocates because high plasma levels could not be attained), remained unfunded. In other words, while there was a blossoming of research on a wide range of diseases and some research on cancer, the fundamental questions raised by the history of conflict remained undone science.

Year	Ν	Cancer Prevention	Cancer Treatment	Cancer Population
2011	18	-Vitamin E, clinical	0	CAM provider use
2010	30	-Gingko Baloba, clinical	+White tea, subclinical; -Shark cartilage, clinical; +Green tea, subclinical	0
2009	30	0	+Acupuncture and cancer pain, subclinical	0
2008	44	+Probiotics, clinical	+Massage and patient mood, clinical	CAM provider use
2007	8	0	0	0
2006	12	-Vitamins C & E, meta	-Vitamins C & E, meta	0
2005	2	0	-Shark cartilage, clinical	0
2004	2	0	0	0
2003	0	0	0	0
2001	1	0	0	0

Total	147	4	7	2
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Table 1. Summary of Cancer-Related Research Results, 2001-2011 (+ = positive results)

(National Center for Complementary and Alternative Medicine 2012)

The one exception to the pattern of undone science (the systematic non-research of alternative modalities of CAM cancer therapies) was the head-to-head clinical trial of an enzyme-and-supplements therapy in the lineage of John Beard, which was originally funded by the National Cancer Institute at the instigation of Nicholas Gonzalez, a physician who had trained at the Memorial Sloan Kettering Cancer Center. The case of Nicholas Gonzalez is especially important because it was originally heralded as representing a new era of cooperation and integration, and it allowed a direct comparison of his therapy with chemotherapy for inoperable pancreatic cancer patients (that is, the Gonzalez therapy was not tested as additional to chemotherapy). The equipoise limitation, which generally restricted direct comparisons of a conventional chemotherapeutic cocktail with a CAM cocktail, could be met because the life expectancy was low, and the survival benefit from the conventional therapy was also very low. However, ten years later, Gonzalez found to his surprise that the study had been published in the Journal of Clinical Oncology without any correspondence with him or the other lead investigator (Chabot et al. 2009). He initiated an investigation and alleged that the recruited patients for the nutrition arm were not comparable to the control arm of the clinical trial, that the claim that the chemotherapy patients did better than the Gonzalez patients was unfounded, and that the lead investigator had financial ties to the chemotherapy drug used in the trial. The NIH office responsible for investigating the trial concurred that the arms were not comparable. As Gonzalez wrote:

My colleague Dr. Linda Isaacs and I initially approached this project with some enthusiasm, believing it to be a wonderful opportunity to bring the conventional academic world and "alternative" researchers, so often at odds, together for the benefit of science and for patients suffering terrible illness. But as the years passed we came to realize with some disappointment that there was no new dawn breaking, no new age of cooperation between the academic and alternative universes, that the same biases against treatment methods developed outside of the mainstream still reigned supreme, and that scientists and physicians at the highest levels of academia would do anything, even change the truth to prove an unconventional therapy has no value (Gonzalez 2009).

In short, the one, high-profile, NIH-funded direct comparison of a major alternative cancer therapy against a standard chemotherapeutic agent in the control arm ended in the same kind of accusations that had characterized the clinical trials for other alternative cancer therapies, such as Vitamin C and laetrile. Little had changed since the 1980s. Gonzalez's experience shows quite clearly the limitations of the epistemic modernization of CAM research. The outcome became well known in the CAM communities, and it confirmed the general belief that cancer therapy was the most firmly guarded area of biomedical orthodoxy and the perception that NCCAM was not willing to wade in those waters. The results of the Gonzalez trial and the data on the funding patterns suggest that although the research field has changed significantly since 1991, there are also fundamental continuities that have not addressed the issues of undone science in the CAM cancer research field.

The second historical change during the 1990s involved the liberalization of therapies. With respect to cancer treatment, some medical doctors began to include CAM therapies in their oncology practices under the new term "integrative medicine," and hospitals also began to offer integrative cancer care. CAM therapies available in the hospital settings were generally limited to mind-body therapies such as yoga and to nutritional counseling, and people with whom I

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spoke in those centers indicated that their physical location and social position were very marginal. In the late 1990s, the Center for Mind-Body Medicine at George Washington University and the National Cancer Institute began sponsoring conferences on "comprehensive cancer care," where the new approach to integrative cancer treatment provided a different vision of CAM cancer therapies from those of the Cancer Control Society, which was connected with the alternative cancer therapies of the Tijuana clinics. The conferences included patient advocates and did not exclude the "alternative" side of CAM cancer therapies, but the sessions also clearly showcased the evidence-based medicine paradigm and the practices of integrative oncology. In these practices, patients generally received conventional chemotherapeutic and/or immunological treatment along with access to mind-body therapies and counseling on diet, supplements, and lifestyle changes. They gained access to complementary therapies as long as they followed the conventional drug regimen.

The limited liberalization of the therapeutic field occurred at roughly the same time as the liberalization of the dietary supplements industry. Prior to the passage of the Dietary Supplements and Health Education Act (DSHEA) of 1994, food supplements existed in a liminal regulatory state between food and drugs. The Food and Drug Administration adopted the view that vitamins and dietary supplements were drugs if they exceeded a potency of greater than 150 percent of the Recommended Daily Allowance, but those regulations were reversed by the Proxmire Amendment of 1976. In response, the Food and Drug Administration used its regulatory authority over food additives to limit the availability of food supplements. DSHEA clearly classified food supplements as food, and it allowed manufacturers to make limited health claims (such as structure and function support), but it did not allow them to make disease claims (Bass 2011). For practical purposes, DSHEA placed supplements outside regulatory oversight from the Food and Drug Administration unless they could be proven to be unsafe, but manufacturers of supplements could only make claims about structure and function, not about the efficacy of supplements for the treatment of diseases. In effect, the existence of a disease claim associated with a supplement, rather than a material or design boundary, distinguished food from a drug under the law. The act had been widely supported by the nutritional supplements industry as well as CAM advocates. However, some consumer advocacy organizations and the pharmaceutical industry criticized the act for exposing consumers to worthless expenditures on supplements, and periodic battles flared up in the U.S. Congress between opposing coalitions.

Similar conflicts emerged at the global trade level in Codex Alimentarius regulations for food supplements. Although the Codex guidelines are technically voluntary, the World Trade Organization recognizes them in resolving trade disputes, and Codex guidelines are likely to have increasing influence in global trade policy (Halfon 2010). An enduring concern is that the U.S. may harmonize its supplements law with Codex, which has tended to follow the stricter, European approach. CAM advocates and the nutritional supplements industry in the United States and some other countries worry that the change would render illegal the over-the-counter sale of high-dose supplements by converting them into prescription drugs that would either be extremely costly or simply unavailable because of the lack of regulatory approval. Nutritional advocacy organizations and the dietary supplements industry have been especially vigilant of attempts to harmonize American regulations to Codex. The U.S. government's Food and Drug Modernization Act of 1997 contains anti-harmonization language, and at the urging of advocacy organizations, language that would have facilitated harmonization was stricken from the 2010 Food and Drug Modernization Act (Alliance for Natural Health 2010).

The concern among CAM and "health freedom" advocates with harmonization has some empirical support in the experience with the North American Free Trade Act. Patients have been going to Mexico for CAM cancer treatment since the 1960s, and it is in Mexico that they can gain access to the alternative end of the spectrum of CAM cancer therapies. (Of course, access to this end of the spectrum contains both the risks of lack of efficacy and the potential, albeit often small, for a positive response when conventional options are ineffective). The number of clinics in Tijuana grew during the 1980s and 1990s, but the North American Free Trade Agreement also made possible the Mexico-United States-Canada Health Fraud Work Group, or MUCH, which closed some of the Tijuana clinics. Although some clinics closed permanently, they proved resilient, and in 2011 at least twenty clinics were still functioning in Tijuana. However, business had slowed due to the recession and the rise of kidnappings and other forms of violence, which have nearly ended the city's tourism industry (Moss 2005, 2011). Furthermore, the liberalization of the therapeutic field in the United States also meant that for some patients the integrated therapies offered in the United States were adequate. Patients generally lack the knowledge to distinguish among the different forms of CAM cancer therapies, so unless they are very well read, they will not be able to distinguish the complementary therapies available in American integrative practices from the alternative therapies available in the Mexican clinics, not to mention the considerable overlap between the two based on the legal status of food supplements in the U.S.

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Due to liberalization of the therapeutic field, the locus of health advocacy has shifted. The patient advocacy organizations that were so active at the height of the laetrile, Vitamin C, and immuno-augmentative therapy controversies have not disappeared but have shifted their attention toward more routinized activity such as holding conferences and providing patient support services. Likewise, the alternative practitioners have not disappeared but increasingly have been displaced by a continuum of health-care practitioners who offer a range of CAM therapies, but mostly on the complementary side of integrative care. With the rise of evidence-based integration and the liberalization of the supplements market, advocacy work has shifted to the preservation of the relatively deregulated nutraceutical market against attempts by coalitions of pharmaceutical companies, consumer advocates, and some medical professionals to reduce availability.

Although scientific controversies continue and the problem of undone science for alternative cancer therapies remains unresolved, the liberalization of access to therapies and supplements has been accompanied by a new type of engagement with science and the public. The Alliance for Natural Health USA has sponsored campaigns to limit the regulatory authority of the Food and Drug Administration with respect to health claims for food supplements. For example, the organization worked with Congressman Ron Paul, who was also a presidential candidate for the Republican Party nomination in 2012, to support various amendments that would enable the manufacturers of food supplements to make a broader scope of disease claims. The "Stop Censoring Medical Science" campaign includes the proposed Free Speech about Science Act, which would allow manufacturers of nutritional supplements to reference peer-reviewed scientific studies about the health effects of the supplements and would prevent the Food and Drug Administration from using those health claims to trigger a change of status of the supplement from food to drug (Alliance for Natural Health USA 2012). For example, growers of cherries or manufacturers of supplements based on cherries currently cannot make reference to peer-reviewed studies that suggest that the consumption of cherries may reduce heart-attack risk. The law would enable manufacturers to publicize peer-reviewed studies, but it would preserve the right of government agencies to intervene to stop false and misleading claims. Here, the historical question of science and the public good, the right of patients to have the undone science done so that they know what works and does not, is amplified by a second question: the right of the supplements industry to make public the results of evidence-based medicine to nutraceutical consumers. It also raises the question of what constitutes a peerreviewed publication from a legal perspective.

### Discussion

A significant strand of work on science, technology, and health has utilized the concept of biological citizenship to analyze historical changes such as the ones described here. From this perspective, advocacy for CAM during the period before the 1990s invoked a rights-based citizen, who demanded freedom of access to medical therapies, to a more choice-based citizen, who is faced with a bewildering combination of CAM and conventional therapies under the tent of integrative medicine and a liberalized market of nutraceuticals. The contrasting modalities of changes might be compared with a rights-based form of biological citizenship, in which patients or victims use their biological condition to legitimate demands for rights of access to health care, and a form of biological citizenship based on biomedical potential, consumer hope, and individual health (Petryna 2002, Rose 2007, Wehling 2011). Similar changes have been noted elsewhere in studies of neoliberalism, such as the growth of the entrepreneurial self and the emergence of health practices as a field of consumer choice (Moore 2011, Ong 1999).

Although the concept of changes in health-related citizenship can help to identify underlying cultural shifts in the forms of health advocacy, it needs to be articulated with a broader institutional analysis of changes in relations between patient advocacy and industry. The field of patient advocacy has undergone dramatic changes in which industrial sponsorship has elevated some organizations to a dominant position in the advocacy field while also changing the forms and goals of advocacy (Baggott and Forster 2008, Batt 2012, Jones 2008, O'Donovan and Glavanis-Grantham 2005). As a result, organizations that retain a more critical perspective on the dominant epidemiological and therapeutic paradigms tend to occupy a subordinate position in the advocacy field, a pattern that has occurred in various types of social movement fields, from health advocacy (Batt 2012) to hunger advocacy (Poppendieck 1998) to environmental advocacy (Dowie 1995). It is among the subordinate positions in the civil society fields of advocacy organizations that one finds articulations of general political citizenship founded on action based on the public interest rather than rights anchored in a biological condition. In this situation, the mode of operation is less an interest group that seeks to have more resources (for a particular disease, or greater access to a particular drug) and more that of a reform movement in which there is a broader goal of social change.

However, the enactment of citizenship in this circumstance is not reducible to the ideal of the "moi commune" or "rational-critical" discourse in the traditional of utopian, Western, democratic theory. The counterpublic that emerges in the case of CAM politics is not innocent of sectional interests. Although patient advocates and CAM-oriented researchers articulate a general social reform goal—a more democratic politics of therapeutic evaluation and access— that goes beyond the interest group politics of advocating for greater resources for one social segment over another, the CAM counterpublic is also aligned with countervailing professional groups and industries, which have their own sectional interests. Just as elites articulate a public interest that is in alignment with those of the dominant political and industrial organizations, so the counterpublic articulates an alternative public interest that has its own sectional alignments. In other words, alliances among mainstream advocacy organizations, mainstream researchers, the medical profession, and the pharmaceutical industry enter into conflict with alliances among CAM advocacy organizations, researchers, professions, and countervailing industries such as the nutraceutical industry.

Thus, I am not arguing that those in the dominant position in the fields of health research, care, and policy cannot articulate a public interest; they do with clarity. Elites from the industrial field tend to form alliances with political, scientific, and civil society elites to ensure that an articulation of official public interest is generated that is aligned with the sectional interests of the industrial elites. In the case of cancer there is an alignment of the leading medical associations, mainstream cancer charity and advocacy organizations, leading scientific researchers, and the pharmaceutical industry in favor of an approach to treatment that is based on patented drugs that are tested singly or in small pharmacological cocktails in clinical trials. The dominant networks constitute an official public that articulates the grounds and limitations of narratives of cancer treatment and disease, based on a spectrum of choices that have been certified as scientifically valid and medically safe and efficacious. They work well with the

interest group pole of patient advocacy organizations, which accept the dominant etiological and therapeutic paradigms (and often receive large donations from the pharmaceutical industry), and they tend to limit political conflict to the allocation of resources within that field or over increases of resources to that field. The official view of the cancer research agenda has strong merits, because on the surface it is grounded in evidence-based medicine, and the scientific field is charged with providing another source of neutral arbitration of disputes.

In a pluralistic state, competing coalitions present their arguments for policy changes in a relatively neutral setting (a legislative committee and an executive agency), and the public representatives evaluate competing claims and make decisions. Thus, conditions of competition and neutral decision-making by government units charged with acting in the general public interest make it possible for sectional interests and articulations of public interest to coincide, because they provide information that a neutral arbiter can evaluate. However, as political sociologists have documented, governments do not generally operate according to a classical, pluralist model. In the case of CAM research that is sponsored by the American government, there are layers of prioritization: away from cancer-related research in general, within cancer research away from clinical trials, and within clinical trials away from the head-to-head study of alternative therapies.

Counterpublics emerge from the subordinate positions of social fields (government, industry, civil society, science) to contest epistemic claims, political ideologies, and policy directions of official publics. Although counterpublics are often linked to historically excluded groups in society (e.g., hourly labor, women, and ethnic minority groups), the connection is historically contingent and can include networks of people who occupy relatively privileged social addresses but are in the subordinate position of the social fields that they inhabit (Fraser 1997; Harding 1998, 2008; Hess 2011). A scientific counterpublic emerges when a scientist or group of scientists located in a subordinate position in the scientific field step out of their role as scientists and enter other social fields (such as the media, government, civil society, and industry) to advance an alternative arrangement of knowledge agendas in the scientific field as better serving a broad public interest.

In the case of advocacy for CAM cancer therapies in the United States, there is full counterpublic of researchers, clinicians, patient advocacy leaders, nutritional companies, political officials, and health freedom organizations. Like the official public of the cancer establishment, the networks are not innocent of sectional interests. The clinical field has seen the growth and professionalization of CAM providers, and the therapeutic field has seen the growth of the nutritional supplements industry. Both pose a challenge to the medical profession and the pharmaceutical industry, and the skirmishes over professional and industrial position take place over a long time horizon in multiple fields, including regulatory policy, legislation, patient recruitment, research agendas, funding priorities, and the interpretion of research design and results. Although not innocent of sectional interest, the counterpublic also advances an agenda for research and policy based on its opposition to the vision of public interest articulated by the official public. Thus, one does not conclude that patient advocacy organizations represent the public interest in opposition to the sectional interest of the mainstream of research and clinical practice. Instead, both the counterpublic and official public construct a vision of public interest that is aligned with their sectional interests. Indeed, battles also occur within civil society between mainstream organizations such as the American Cancer Society and CAMoriented clinicians and advocacy organizations.

The counterpublic also draws attention to undone science, that is, science that is systematically blocked because it is in conflict with the research agendas of the dominant agents in a scientific research field and associated industrial fields (e.g., the chemotherapy orientation of the cancer therapy research field, oncology profession, and pharmaceutical industry). For the counterpublic, research into CAM cancer therapies is a form of positive non-knowledge, whereas during the early period of the CAM-mainstream relationship, the official

public viewed the CAM challenge as negative non-knowledge, a worthless and unproven approach based on dubious science. Not only were alternative cancer therapies not worth the investment of public research resources, but the practice of CAM cancer therapies also represented a threat to the public interest, because some of the therapies were potentially dangerous. Even if the therapies were generally recognized as safe, they represented an opportunity cost because innocent cancer patients could be bilked of their money and miss the opportunity for potentially life-extending conventional therapies. The fact that the history of the CAM cancer field does have its share of hucksters and unproven folk remedies, even as it has brilliant scientists such as Revici, suggests that the construction of a threat to public interest has some backing. In other words, with respect to CAM cancer therapies, there is a risk of both Type 1 and Type 2 errors.

In summary, the historical changes described above as the epistemic modernization of the CAM cancer research field and the liberalization of policy governing therapeutic and nutraceutical markets include reconstructions of notions of citizenship but go beyond them. The relationship between the two publics and articulations of the conditions of public good also changed. During the post-liberalization period, the older "hard line" approach of anti-alternative medicine has not disappeared, but it has become moderated by the limited acceptance of CAM based on the filtration criterion of evidence-based medicine, which enables some complementary modalities of CAM cancer therapies to enter into conventional practice as integrated medicine. Funding appears for research on CAM therapies, and the repressive strategy appears to give way to a more integrative strategy. Leaders of CAM professions are brought into the funding process, such as the Advisory Council of the NCCAM, and papers are published in peer-reviewed literature. Patients are allowed to have their vitamins and yoga as long as they take their drugs, too.

However, the liberalization of the therapeutic field occurs on the terms of the dominant agents in the field. Biomedical integration proceeds slowly and in a limited way, much as other forms of integration occur (such as the slow process whereby men of the dominant ethnic groups have admitted some ethnic minorities and women into management positions). The funding priorities of the official public continue to marginalize and even discredit alternative modalities for cancer treatment. The result of medical integration is "A" deletion in the CAM, so that it tends to become "COM" (complementary only medicine). Just as radical feminist and minority activists had to leave their radical politics on the doorstep of entry into the corporate world that embraced "integration" as a social policy, so CAM advocates must leave their alternative aspirations on the doorstep of entry into the biomedical mainstream. There is little funding available to test the prospect of alternative cancer therapies, and the blockage is legitimated by an ethics system that limits clinical trials to situations of equipoise of benefits to patients. For clinicians who do not accept the yoke of complementarization, repression continues. (Their stories are chronicled in an ongoing column in the Townsend Letter for Doctors and Patients by Marcus Cohen.) In short, there is a process of incorporation (of CAM into the mainstream) and also of transformation (of CAM into COM). As I have shown elsewhere, these dynamics of complementarization apply to other alternative industrial movements, specifically to a subtype of those movements that I have studied as "technologyand product-oriented movements" such as organic foods, open-source programming, and solar energy (Hess 2005, 2007).

Although both epistemic modernization and therapeutic liberalization have been limited, the historical change has been accompanied by a decline in the high levels of popular mobilization that occurred during the laetrile period. To some degree the historical change is a product of the success of the reform movement. The liberalization of the cancer therapy field and vitamin supplements means that the field is both more diverse and less polarized than it was during the 1960s and 1970s. Patients have access to a wider range of both conventional and CAM therapies, and patients who wish to gain access to a more complete range of

alternative therapies can go to Mexico, Germany, or other countries. Clinician-based patient advocacy organizations sometimes mobilize to support a particular doctor when faced with prosecution, but the general patient advocacy organizations play a broader role in holding conferences and educating patients about options. If a significant regime change were to occur, with multiple crack-downs on multiple practitioners, it is possible that the patient organizations would become quickly mobilized. Thus, a general conclusion is that the change of epistemic modernization and therapeutic liberalization has been accompanied by a relative quiescence of patient advocacy organizations. They have not disappeared, but they are not mobilized in the more directly political ways that were evident before the 1980s.

The social movements literature includes studies of the effects of social movements, and one of the conclusions of the research field is that it is not always easy to determine a causal relationship between mobilizations and policy outcomes (Guigni 1998, Amenta et al. 2010). In some cases, governments have responded by establishing post-market monitoring or holding consultation exercises, but it remains to be seen how much change such programs will effect (Böschen et al. 2011). In the case of CAM cancer therapies in the U.S., on one level there has been a substantial change since the 1980s, but on another level nothing has changed.

The CAM cancer case is of general interest to the study of social movements, civil society, and science because it suggests the need to pay more attention to the role of countervailing industries. It disturbs the idea of industrial cooptation of social movements by suggesting that attention could be focused more on the coalitions of civil society organizations, scientists, and different industries. Without the constant surveillance of the nutraceutical industry, it is likely that the relatively open access that American consumers enjoy for food supplements and that CAM clinicians and patients have to high-dose supplements for therapeutic purposes would quickly evaporate. These are the conditions of democracy in a society in which political power is heavily influenced by the visions of public interest that are formulated by large industrial corporations. Democratic contestation in a corporatocracy implies that counterpublics may achieve limited political success, but they are more likely to do so when they can take advantage of countervailing industrial power.

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