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UMI
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To my grandmothers
nonna Apollonia the *curandera*
nonna Irma the *guerrillera*

To Helen Michalowski
sister, comrade, inspiration

To Mumia Abu-Jamal
¡para que viva!

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Laura Corradi

Malignant Profit.

The Debate Over Genetics and Environmental Causes of Cancer Among
Scientists, Women Survivors and People of Color

ABSTRACT

This dissertation develops a sociology of cancer by looking at the actors involved in the struggles over definitions of cancer causation and primary prevention strategies. I interviewed sixty actors in the cancer arena in different U.S. sites: women survivors, scientists, and people of color.

The scientific debate over the causes of cancer presents two competing systems of explanation: the (dominant) genetic paradigm and the (emerging) environmental paradigm, which polarize the scientific community. Scientists are also divided over lifestyle factors: some believe they are mostly a matter of individual choice; others believe they are socially constructed.

This dissertation also look at the development of cancer activism as a new social movement against the production of cancer. It is composed of women cancer survivors who contest the role of passive victims historically assigned to them, lesbian groups, indigenous populations, environmental justice activists, scientist/activists, popular epidemiologists.

Activists tend to agree that environmental causes of cancer are neglected in most of the scientific discourse. Furthermore, they criticize the cancer establishment for a 'blame the victim' attitude when it comes to lifestyle factors -- and claim that too little attention is devoted to prevent environmental causes of cancer. Activists, as well as scientist/activists also express concern about the social and political implications of genetic research.

This dissertation shows an emerging public perception of profit as an obstacle in environmental health issues -- and specifically as an obstacle in the primary prevention of cancer. Some scientists see the profit made by the tobacco industry as a main obstacle to cancer prevention; others include in their analysis all human-produced carcinogens and conceptualize a wider connection between the production of cancer and the profit system.

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PREFACE

Capitalism As Production Of Death and Body As a Place of Resistance. Three Postulates.

Accumulation of wealth at one pole is ...
at the same time accumulation of misery,
the torment of labour, slavery,
ignorance, brutalization
and moral degradation at the opposite pole,
i.e., on the side of the class that produces
its own product as capital.¹

We all are taught to think about the rise and the expansion of capitalism in Europe as a victory of progress against the darkness of the Middle Ages.² We learn that capitalism was a great revolutionary force, which had the power to defeat old feudal orders and build new social relations. We are taught to associate capitalism with scientific discoveries, technological inventions, great migrations to new exotic lands. The concept of capitalism evokes images of heroic subjugation of nature by men -- and the liberation of an immense productive potentiality.

But when we look at advanced capitalism today, we see a world system³ that is destroying and overcoming itself, while destroying the material resources -- natural, human, social -- and ultimately the possibility itself of living and reproducing on the planet. What we often do not see is that capitalism has been, from its very beginning,

¹ K. Marx, *Capital: A Critique of Political Economy*; Vol. 1, Viking Penguin, London, 1976, p. 799.

² "The 'superstitious' Middle Age rarely persecuted any witches; and never in the 'Dark Age' are mass trials and executions to be found. (...) What fears instigated such a united policy of genocide? Why so much violence and why were its prime targets women?" S. Federici, "The Great Which Hunt," in *The Maine Scholar*, N. 1, Vol. 1, Fall 1988, pp. 31-52.

³ I. Wallerstein, *Class Conflict in the Capitalist World-Economy*, State University of New York, Binghamton, 1976; W. Goldfrank (editor), *The World System of Capitalism: Past and Present*, Sage, Beverly Hills CA, 1979; J. Borrego "Metanational Capitalist Accumulation and the Emerging Paradigm of Revolutionist Accumulation," in *Review*, Vol. 4, N. 4, Spring 1981, pp. 713-777.

an unsustainable mode of production -- and that capitalism does not bring generalized well-being, not even at its inception. As Dalla Costa (1995) writes, capitalist development has always been "unsustainable" because of its human impact.

All one needs to do is to take the viewpoint of those who have been and continue to be killed by it. A presupposition of capitalism's birth was the sacrifice of a large part of humanity, mass exterminations, the production of hunger and misery, slavery, violence and terror. Its continuation requires the same presuppositions.⁴

In reproducing itself, capitalism creates various forms of slavery -- i.e., unpaid work. The first is predicated upon the sexual division of labor. Not everybody is a "free worker," under capitalism: the system creates women as unwaged workers in a wage economy.

Particularly from the woman's point of view, capitalist development has always been unsustainable because it places her in an unsustainable contradiction, by being an unwaged worker in a wage economy and, hence, for that reason, denied the right to an autonomous existence. And if we look at the subsistence economies -- continually besieged, undermined and overwhelmed by capitalist development -- we see that capitalist development continually deprives women of the land and water which for them are fundamental means of production and subsistence in sustaining the entire community.⁵

We know that capitalism⁶ kills, in direct and voluntary ways: war, famine and genocide of whole populations; slavery,⁷

⁴ M.R. Dalla Costa, "Capitalism and Reproduction," in *Capitalism, Nature, and Socialism*, Vol. 6, N. 4, December 1995, (forthcoming).

⁵ Ibidem.

⁶ Here the term capitalism is meant to include both forms: market capitalism and state capitalism. Since domestic modes of production are presently subsumed and functional to capitalist accumulation, I refer to capitalism as a world system whose main feature is the one of reproducing profit. In so called "socialist countries" there was indeed creation of surplus - which was re-distributed by the state with criteria different from those leading market capitalism states.

⁷ While it is known that slavery preceded - and allowed - capitalist accumulation in the United States, authors often omit the fact that proto-

imprisonment, and the death penalty. Capitalism also kills in many indirect ways: through exploitation, by working people to death; by producing poisonous emission during the valorization process which are dangerous to people's health, sometimes fatal.

By legitimizing the "necessary sacrifice" -- Gambino would say -- of categories of people in order to reproduce this social and economic system as such, capitalism -- under the form of a military/industrial/service complex -- is responsible for people dying at work as well as at war -- for deaths due to scientific experiments, human risk assessments, and environmental crimes.

Either we agree with the common belief that a system by definition has no ethics -- only agents -- or we make an ethical judgement based on the system's values, social relations, and economic priorities. Capitalism, under the form of a military/industrial/service complex produces negative effects which diminish the health of people, and because this is done for profit, then we see capitalism as a system that "values profit above bodies."⁸ In the long view of history, a system based on inequality, racism, and the oppression of women, a system that produces fear and greed, will be judged for its crimes -- for the deaths of those who become "expendable."

I am going to introduce three postulates that are fundamental concept for this dissertation. These postulates are not just assumptions, nor are they hypotheses. They can be considered the political and sociological intuitions, theoretical elements that have inspired this work.

The first postulate is that under capitalism people die untimely and avoidable deaths. The second postulate is that --

capitalism made use of slavery in Europe and that today the same process is visible in developing countries. See: S. Federici, L. Fortunati, *Il Grande Calibano, Storia del Corpo Sociale Ribelle nella Prima Fase del Capitale*, [The Great Caliban. History of the Rebellious Social Body in the First Stage of Capitalism], Franco Angeli, Milan, 1984.

⁸ As Carolyn Martin Shaw posited in a personal communication.

keeping at the same level the development of productive forces -- a different mode of production and distribution whose priority would not be profit, will cause fewer untimely and avoidable deaths.

If in place of capitalism there was a mode of production and distribution whose priority was the creation of use values -- instead of exchange values -- this would give more life and more happiness to people. In a system not oriented to profit but oriented to social beings' needs and abilities, people would live longer and better.

Such a system does not exist anywhere -- but history tells us of many attempts to abolish capitalism, which have had (as common denominator) the will of overcoming class division, exploitation and the oppression of some social beings by others. We do not have a different situation to compare with and refer to; we do not have any formula or prescription, any alternative models already applied somewhere in the world. I think it is necessary to produce some theoretical reflections in our scholarly work, by using an inductive method -- and trusting our sociological intuition -- what Gramsci called "common sense."

In the first place, if there were no opposition between the social character of production and the private character of accumulation -- in other words, if production wasn't oriented to profit-making -- many hazardous productions would not even exist, and goods would last longer and have more social utility. In a virtual context free of capitalistic competition, the workplace would not be a place where human energy is squeezed out of some for the benefit of others. The places where goods are produced would not be as risky as they are for the workers' health and often for their communities.

In the second place, if wealth were evenly distributed among the producers, the general standard of life would be better for those social strata displaying the major risk of illness and the highest rates of mortality. It is not difficult to envision industrialized countries without homeless and unemployed people; and non-industrialized

countries no longer subjected to the systematic robbery of their resources.

In the third place, if the commodity form -- inescapable characteristic of capitalistic modes of productions, and pervasive, since it penetrates (in different degrees and ways) social relationships, even those considered personal and private -- and the separation between manual and intellectual work were overcome, we can theorize that social beings whose function have been reified, split, dissociated by capitalism, would re-compose themselves and have a more fulfilling and balanced life, working for the realization of their talents and aspirations as whole social individuals. So many illness and deaths are produced by unhappiness, stress, lack of love for life -- all elements which exploitation inevitably creates.

The third postulate of my theory regards the common awareness of a "permanent tension between the requirements of the economy and the requirements of a healthy existence."⁹ Critical literature suggests that under capitalism, *any progress in health should be regarded as coincidental*. As McKinley wrote, "medicine under capitalism will never contribute to improvements in health unless such improvements facilitate an acceptable level of profit"¹⁰

The increasing consciousness of a structural contradiction between profit and health -- in a context of increasing untimely and avoidable deaths -- stimulates political growth among those who are hit with or at risk of life-threatening diseases.

The body seems to become a physical and symbolic limit to capitalism:¹¹ human labor is both what enables and constrains¹² the

⁹ B. Turner, "Capitalism, Class, Illness," in B. Turner, (editor), *Medical Power and Social Knowledge*, Sage, Newbury Park ,CA, 1987, pp. 172-196, p. 172.

¹⁰ Introduction to J.B. McKinley, *Issues in the Political Economy of Health*, Tavistock Press, New York, 1984, p. 8.

¹¹ I will not develop this postulate in my dissertation, I am presenting it as a sociological intuition, which needs more research in order to be proved.

extraction of surplus value. There are limits to capitalist extraction of surplus labor: the requirement that labor can reproduce itself. Besides this tension between the needs of capitalism to increasingly extract surplus from the labor force employed and the needs of the labor force to reproduce itself -- a tension widely explored by political economists -- there is a second contradiction, conceptualized in the eco-marxist thought,¹³ which has to do with the limits of "nature."

By destroying natural resources at increased speed, capitalism also diminishes the capacities of human beings to reproduce. This process affects indigenous populations at the geographical margins of capitalist accumulation -- where domestic modes of production still are allowed to exist as providers of raw materials and fresh labor force, for which no pre-productive nor post-productive costs will be paid. This process also increasingly affects the center of the empire - - where technological revolutions have created margins within the centers: third-world conditions visible in the capitalistic metropolis.

The sacrifice of those who are expendable is not always a direct action, yet it can be seen as part of the process of containment and removal of the undesired or unproductive labor that the system does not need.¹⁴

As all organic disorders, conflict can be cured by science. But the hidden anxiety of all organic views of society is primarily not scientific but practical: a social body must always be able to contain or resist a conflicting individual or social group, whether with social bonds or with coercion. No representative of the social body -- from the Corporate Finance Committee or from the Central Planning Bureau -- has so far been able to answer a simple, most personal, and least private question that has been,

¹² "Nature" as a condition of production - including both human and non-human nature - can be seen as the entity that enables and constrains capitalist accumulation. See Alan Rudy, "On the Dialectics of Capital and Nature," in *Capitalism, Nature, and Socialism*, Vol. 5, N. 2, June 1994, pp. 95-106.

¹³ J. O'Connor, "Capitalism, Nature, and Socialism: A Theoretical Introduction," *Capitalism, Nature, and Socialism*, N. 1, November, 1988.

¹⁴ As Mike Rotkin suggested.

increasingly, the starting point of irreconcilable collective action: "Why does it have to be me who is sacrificed?"¹⁵

What is happening with the production of cancer is that increased awareness of the human costs of this development also challenges the cultural reproduction of capitalist relations. The cultural hegemony of the dominant classes is threatened by the "counter-subjectivity"¹⁶ of people of color and women resisting the social production of cancer and the scientific control of the body.

¹⁵ F. Gambino, "The Significance of Socialism in the Post-War United States," in J. Heffer, J. Rovet (editors), *Pourquoi n'y a t-il pas de socialisme aux Etas-Unis?/ Why Is There No Socialism in the United States?* Editions de l'Ecole des Hautes Etudes en Sciences Sociales, Paris, 1987.

¹⁶ Term suggested by David Minkus. Here I am using "counter-subjectivity" to indicate forms of oppositional consciousness.

INTRODUCTION

This dissertation develops a sociology of cancer by looking at the actors involved in the struggles over definitions of cancer causation and prevention strategies. In this work, I do not consider the controversies over institutional or alternative therapies, surgeries, and rehabilitation. My analysis focuses on different representations of cancer etiology and primary prevention, and the different priorities and strategies under scrutiny today. These representations, priorities and strategies have social and economic implications.

The first chapter of this dissertation provides the theoretical frame and background of this work. Suggestions have been borrowed from different fields and disciplines. This research is located at the crossroads of three sociological areas: the Sociology of Science, the Sociology of Death and the Sociology of New Social Movements.

The first chapter also offers conceptual tools for a reading of specific new counter-subjectivities, such as those of cancer survivors who contest the role of passive victims historically assigned to them. Cancer activism is a social movement against the production of cancer. This movement does not have one single ideology or practice, but many; it doesn't have one subject but many: white middle class women with pink ribbons, blue collars, heretical scientists, popular epidemiologists, lesbian witches, indigenous populations, Green environmentalists, Black and Brown activists of the inner cities. The internal cooperation of the cancer movement is balanced against constant tensions due to class and race diversities. Shared experience helps different segments of the cancer movement to cooperate on common grounds, despite divisions on political issues, strategies and goals.

The second chapter discusses the relevance of this research and takes the reader through the different stages of conceptualization and re-negotiations of direction. While starting from a Marxist

feminist background, the research also reflects a critical perspective on Western science as formulated in Afro-centric theory and Native-American philosophy, in recent developments in feminist theory and epistemology, and in suggestions from deconstructionism.

In this chapter I outline the empirical research and its goals. Given the impossibility (not in principle, but because of the different ways data on deaths are recorded) of empirically demonstrating that capitalism produces untimely and avoidable death, the research moved its original focus toward social representations as an intermediate level between theory and reality. The second chapter also offers a description of the methodological tools I used to sociologically understand different perspectives expressed in the cancer arena today, including contested areas of meaning, connections between causes of cancer, perceived failure to prevent cancer, and capitalistic profit. I interviewed sixty actors involved in the cancer arena in different U.S. sites: scientists, women survivors, and people of color. Then, I analyzed the content of their statements, in order to understand different perspectives and commonalities.

The third chapter introduces the scientific debate over the causes of cancer and looks at two competing systems of explanation: the genetic paradigm and the environmental paradigm. The chapter also analyzes how scientists are divided over lifestyle factors. Scientists who believe that genetic predisposition plays a main role in cancer causation tend to conceive of lifestyle factors in terms of individual choice. Scientists who believe environmental carcinogens are the main causes of cancer, believe that lifestyle factors -- such as diet, age of pregnancy, cigarette smoking -- should not be considered matters of individual responsibility. In different degrees, they acknowledge that people's lifestyle choices are affected by economic status and by social environment.

This chapter offers an account of what the interviewed scientists said about the role of genetics in cancer etiology. Besides the distinction between those scientists who rank genetics as a main cause of cancer and those who look at environmental carcinogens,

there are scientists who advocate a dialectical approach between genetics and environment, taking into account the interactions between these two entities.

In addition to an examination of the scientific debate, this chapter also analyzes statements provided by cancer activists on genetics and cancer. Some activists find hope in the results of the current investigations and experiments on DNA; while other activists are concerned with the social and political implications of genetic research. These activists are also skeptical of genetic research because so far it has proven to be fruitless.

The fourth chapter discusses different concepts of the environment and environmental causes of cancer, and presents the terms of the scientific debate over thresholds of tolerance, multiple exposures, risk assessments, and risky behaviors. Scientific thinking about the environmental causes of cancer is located on a continuum. At one pole environmental carcinogens are seen as negligible, while at the other pole environmental carcinogens are seen as a main cause of cancer. The chapter also presents the points of view expressed by activists, who tend to agree that environmental causes of cancer are neglected in most of the scientific discourse.

The fifth chapter considers how class, race and gender are not adequately accounted for in contemporary explanations of cancer incidence. Materials published by institutions such as the American Cancer Society and the National Cancer Institute are examined. This chapter also explores the construction of an ethnic perspective on cancer causes and prevention by looking at two different institutions in the Native-American community in Oakland, California.

The sixth chapter introduces the reader to the cancer movement, analyzing its roots, features, goals, strategies, and contradictions, including an account of its composition and leadership in terms of class, race, gender, and sexual preference. The chapter offers perspectives from Black women's cancer activists and an analysis of the ways in which cancer activism is affecting the

scientific community. The chapter ends by considering connections between cancer activism and the environmental justice movement.

The seventh chapter concludes the dissertation. Here the interviewees express their ideas about the connections between cancer causation and the profit system. In this chapter I focus on the scientists' discourses because they articulate more diverse views than activists when talking about profit and cancer. At the very least, the scientists interviewed see the profit made by the tobacco industry as an obstacle to cancer prevention. Other scientists tend to include in their analysis all human-produced carcinogens; they make a wider connection between the production of cancer and the profit system.

Some reflections about the literature on ethics and profit introduce this chapter, in order to better explain the issues raised by the scientists whose statements are analyzed. At the end, I present parts of the interview with cancer scientist/activist Sandra Steingreber and, in Appendix 20, the testimony of two cancer lawyers who shed light on a legal system that makes it difficult to implement environmental prevention policies, when the economic profits of powerful corporate polluters require it.

Cancer can be seen as a metaphor for late capitalism: an incurable illness that can be prevented. This dissertation supports the postulates stated in the Preface: that capitalism produces untimely and avoidable illness and death,¹⁷ and that increased

¹⁷ The term capitalism also includes those experiments of proletarian dictatorship that resulted in different forms of state capitalism. As Goldfrank pointed out in an e-mail conversation, the alarming decline of life expectancy in the USSR/Russia shows a link between environment and health. Of course, USSR/Russia represents a parody of industrial capitalism, without the "safeguards" of working-class organization, inter-capitalistic competition, a parliamentary system with semi-democratic elections, a semi-free press, and an "independent" judiciary. A state-capitalism system not necessarily does protect its citizens more than a market-capitalism system. However, if the state has to pay for the illnesses produced by the private sector, in its blind search for profit, the state is more effectively an agent of control where

awareness about this production of illness and death creates resistance in the social body. Even though the empirical research I carried out cannot be considered a "scientific" proof that capitalism produces death, it shows an emerging public perception of profit as an obstacle in environmental health issues -- and specifically as an obstacle in the primary prevention of cancer.

illnesses are produced - as it happens in Europe and, for different reasons, in Cuba.

Chapter 1

THEORETICAL LOCATIONS

1.1. Theoretical Backgrounds: Marxism, Feminism, Working Class Intellectuals and Located Knowledge.

My theoretical framework mostly consists of the body of works produced in the areas of Marxism, feminism, and their recent eco-developments.¹⁸ In this section I am going to situate my background and myself as a researcher in relation to the project. I believe it is important in social sciences to produce a disclosure of such a relation between subject and objects of the research -- a relation which I would be more comfortable in defining as an interactive process among subjects.

This chapter begins with some autobiographical notations. I believe the social scientist has some duties of "correctness" toward the reader. Given that neutrality in social sciences -- as well as in natural sciences -- is a much debated topic, I feel the need to state where am I coming from in terms of intellectual formation -- and to expose some of the personal/political motives situated at the basis of both my theory and empirical research.

This chapter ends with the explanation of two inscriptions -- or "corrections" -- I found necessary to make in what is academically recognized as a Marxist-feminist field. The first regards a different standpoint on the scholarly contributions from the intellectual area

¹⁸ J. O'Connor, "Capitalism, Nature, and Socialism: A Theoretical Introduction," in *Capitalism, Nature, and Socialism*, N. 1, November, 1988, pp. 11-38; J. O'Connor, "Political Economy of Ecology," in *Capitalism, Nature, and Socialism*, N. 3, November 1989, pp. 5-14; M. Mellor, "Eco-feminism and Eco-socialism. Dilemmas in Essentialism and Materialism," in *Capitalism, Nature, and Socialism*, Vol. 3, N. 2, June 1992, pp. 43-62; E. Mingione, "Marxism, Ecology, and Political Movements," in *Capitalism, Nature, and Socialism*, Vol. 4, N. 2, June 1993, pp. 85-92.

of deconstructionism; the second includes the theoretical approaches forwarded by thinkers involved in race and gender studies.

I am also providing some reflections about the nature of research and intellectual work in terms of status and location in the social division of labor, and the attempt to historicize the division between manual and intellectual work.¹⁹ The frame I am providing for an understanding of scientists as producers of intellectual labor is not systematic and is not intended to be exhaustive. Rather it should be read as suggestions that need further development.

My Marxist-feminist approach is not the product of academic efforts: it was built in the realm of praxis as the result of my life path. Before getting my high school degree (by attending adult programs) I was a factory worker, a janitor, a waitress, a chambermaid, a phone operator, a typist, and a full-time hospital caretaker of geriatric patients for three years. Becoming an intellectual was not my concern when I started studying Marx and feminist writings.

I grew up in an environment -- the proletarian left in the North of Italy, where these ideas were circulating. I started working in a factory, on the production line, when I was 16. I have been fired several times, for my activism and for insubordination.

Once my first African-American friend -- working class *losangelino* -- asked me if I could recall the time when I was working in the factory, and remember something -- among my deeds -- that was inappropriate for a manual worker and more appropriate for an intellectual. His question was based on the assumption that -- at a certain point -- a manual worker might start doing things that pushes him/her away from the working class environment. I still do not know if that assumption is right or wrong.

¹⁹ This part of the manuscript is located in Appendix 1; it consists of some reflections on the subject.

I started my blue-collar career in 1977. I worked in several factories: an electronic assembly plant, a wood furniture factory, and a swimming pool company. The last was a food factory. I still remember when we got "tenure" in that job. Most of the young women, almost all teenagers like me, were really happy: One said: "Now I am settled down for life." I was in panic. The idea of spending the rest of my life in that place was a nightmare.

I told my friend this story. After a few months of working there, I had been moved from one place to another -- for "discipline" -- so I knew almost all departments. One day I was working in on production line called the "carousel"... It was the worst place of the factory, where they used to send trouble makers and the rhythms of the production line were just awful, you couldn't even breathe at your pace -- your body was sweating and your mind was drugged. After months of doing always the same movement with your hands, you couldn't feel yourself as a human being, as having some dignity. I thought that I was sinking toward the bottom. I felt the desire of nurturing my brain, learning new things, before turning into a monkey. Going back to High School? Isn't it too late? I am almost 20 years old -- I told myself.

I don't think I was very different from the other workers ... There were some differences between me and the majority of them. Most already had children, while I was single and I had the time and the energy for being a militant in the union, in a political group of the new left, and an activist at a people's radio station.

But most of the time I was feeling just like one of them and even now I am more prone to see the common points, the common feelings, fears, struggles. I learned that nobody accepts being exploited. But not everybody is in the position of being able to say no, losing her job every year and starting all over again. The majority of my co-workers didn't have the opportunity to read books, go to meetings, watch movies or participate in local cultural events: they didn't have the energy or the time.

Often, at work, when the job-rotation allowed me a place where I could talk with other women, I gave them history lessons, about what I was learning. I always loved history, and poetry, I lectured them about the World Wars, the Soviet Revolution ... I read Majakowski during the lunch break and I can still remember the face of Flavia listening, absorbing ... But I didn't think I was doing something inappropriate for the factory and appropriate for intellectual labor: I thought it was part of my job as unionist and feminist.

One day I started to have the fantasy of becoming a journalist and writing real stories about how people live and are exploited, about the struggles and the smiles of women, those dreams that never become true, those lives so normal and so poetic.

I fulfilled my dream ten years later: I went back to interview my co-workers and I wrote about them. I was working on my dissertation, and found that many of those women were still in the same place, looking much older than I did, consuming their bodies and giving up their desires.

Being working class has given me a great opportunity: being able to speak the language of everyday life, being able to communicate with people, to translate sophisticated concepts into concrete tools for the transformation of reality, tools for the self-empowerment of people. Sometimes I feel that people like me -- who come from the hell of a production line -- have the energy not just for learning what we are supposed to, but also some capacity to criticize it and to create subversive forms of knowledge.

We know there are many issues of class, ethnicity, and gender in a re-appropriation of intellectuality from the bottom. The realm of philosophy was the dominion of white males from the aristocracy -- later from bourgeoisie, now from the middle class. If I am a woman, a proletarian, a person of color, a foreigner, I am socially constructed with a lack of the self-confidence necessary to be comfortable as a thinker. In other words, I am not in the position of taking for granted my ability to produce theory -- while I will take

for granted that I can be trained for any kind of waged manual work.

1.2. Theoretical and Practical Inclusions

Many in the progressive *milieu* are convinced that a critique of philosophy and science is necessary today. I think that this critique can be successful only if it comes from the bottom, from working class activists, from feminist organizers, from minority leaders.

When Marx wrote in his famous last *Thesis on Feuerbach* -- "The philosophers have only *interpreted* the world in various ways: the point however is to *change* it" -- he was calling for a commitment, among those who produce ideas, to act upon the real world and be an aware part of material processes.

I would like to add something -- since this process needs to go both ways. While asking the philosophers to enter into social praxis, we also should break those gates that keep the majority of people far from the realm of intellectual production. This means that we need to create the conditions and the space for the theoretical contribution of people who have been relegated to manual work, domestic unwaged labor, segregated neighborhood, and cultural ghettos.

Until the "outsiders" are allowed "in", we will be missing an important contribution, as concerned social scientists: we absolutely need the particular energy of those who look at society from the bottom -- as Patricia Hill Collins pointed out -- to assault dominant paradigms and oppressive theories.

In my research two variations have been necessary in the Marxist-feminist perspective I adopted. The first is to use deconstruction more as a method than as a theory. Since my goal was more to subvert categories than to neutrally relativize them, I played with deconstructive tools *within* a Marxist-feminist framework.

Deconstruction cannot be restricted or immediately pass to a neutralization [of two concepts]: it must, through a double gesture, a double science, a double writing -- put into practice a *reversal* of the classical opposition *and* a general *displacement* of the system. It is on that condition alone that deconstruction will provide the means of *intervening* in the field of oppositions it criticized and that is also a field of non-discursive forces (...) Deconstruction does not consist in moving from one concept to another, but in reversing and displacing a conceptual order as well as the non-conceptual order with which it is articulated.²⁰

I made the choice to not counterpoise the contribution of some post-structuralists, post-marxists, post-modernists and historical materialism. My choice is rooted in the fact that most of their works -- regardless the authors' claim -- can be read as variants or further developments within the theory they criticize.

Marxism needs a theory of the subject. The subject in Marx is historically determined: it is a subject produced and reproduced in specific social relations. Even though Marx made very clear that history is, *in primis*, a history of class struggle, most Marxist thinkers, implicitly or explicitly, have stressed the aspect of social, economic and ideological determination of the subject. Such a focus on the the realm of "objective forces" didn't leave much space for reflection on subjective identities until recently.

Precisely, what has been neglected is an analysis of the development of a revolutionary subject: connections still need to be theorized between the individual, immersed in his/her everyday life, and the politics of radical transformation of the existent mode of production and distribution.

I believe most post-marxist thought is not antagonistic to Marxism, but complementary.²¹ In the same way most of post-structuralist contributions are still children of De Sassoure. As recently pointed out by Stuart Hall -- the deconstructionists are still historical materialists.

²⁰ J. Derrida, "Signature Event Context," in *Glyph*, N.1, pp. 172-197, 1977, p. 195.

²¹ See: L. Corradi, "A Sociological Reading of Lacan," Qualifying Essay, Board of Studies in Sociology, University of California, Santa Cruz, 1992.

This does not mean the *nouvelle philosophes* shouldn't be recognized for the important merit of starting to look at different levels of power relations, social practices and collective actions. In many of them it is not unusual to find (in embryo) some answers to questions emerging while re-reading Marx with non-dogmatic eyes.

The second "correction" I made in my Marxist-feminist background is based on contributions coming from the interdisciplinary field of race & gender studies, to be juxtaposed and integrated with the category of class in our sociological analysis. This operation can be described -- by using a popular definition forged by Niklas Luhmann -- as a process of complexification of the paradigm or model of explanation.

The objective centrality of race, class, and gender divisions in our societies -- and consequently in the sociological analysis -- has informed my work both theoretically and empirically, as categories of examination, explication, critique and connection.²²

The conceptualization of race, class, and gender as a combined unity, and an integrated synthesis, originated specifically from the intellectual experience and cultural production of women of color.²³ Yet, everybody is affected by these categories in our everyday life as well as in our scholarly analysis as sociologists in advanced capitalistic countries.

As Margaret Andersen and Patricia Hill Collins wrote, race, gender, and class are interlocking categories of experience that affect all aspects of human life and are the basis for many social problems. Cancer is among them, and the race/class/gender prism has been a necessary tool through the whole work.

Some of my tasks were relatively easy: one doesn't need an impressive theoretical background to notice that cancer scientists are largely men, overwhelmingly white and upper-middle-class; while

²² P. H. Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, Unwin Hyman, Boston, 1990.

²³ M.L. Andersen, P.H. Collins, (editors) *Race, Class, and Gender. An Anthology*, Wadsworth Publications, Belmont CA, 1992.

activists come from different socio-economic strata, are mostly women, ethnically more diverse, and politically connected with people of color on issues of environmental justice and cancer prevention.

The notion of class was central in my work. I applied it in a relational way, as a double interface to describe who gets hit by environmental causes of cancer and why. Gender and race can be understood as both factors that contribute in determining class, and as relatively autonomous factors that explain sociological variations where class showed to be an inappropriate or insufficient conceptual tool.

Specific discourses should be articulated when it comes to religion, age, sexual preferences. I didn't have a model for these categories of analysis. My approach was to connect these issues to the main ones, where possible. The reasons why lesbians might be more at risk include gender-related economic factors, such as poverty -- which affects area of residency, type of job, nutrition, tobacco and alcohol use, level of stress, and other cancer risk factors -- including not having children.²⁴ Furthermore, the belief of higher breast cancer ratio of lesbians *versus* heterosexual women cannot be discussed without critically looking at the complex of social mores interposed between a lesbian and her desire to mother.

1.3. Theory of the Subject Versus Rhetoric of the Passive Victim.

The ideology of the passive victims -- whether women, people of color or oppressed 'others' -- is a negative ideology. When Marx wrote in "The Eighteenth Brumaire" the famous statement *women make their own history but not of their own free will* -- pointed out that lower classes in general can practice their right to choose only under given circumstances and restrictions

²⁴ In the medical establishment lesbians are believed to be more at risk for breast cancer because of not having children. However, this is a belief based on prejudice, since lesbians do have children.

(which are economically and politically determined) he was describing a reality: that we are "socially constructed" -- so to speak.

What Marx wrote needs to be understood in the frame of the polemic against the neo-hegelian left: his emphasis on economic and political factors that shape ideas and visions of the world was meant to contrast the neo-hegelian discourse based on the assumption that consciousness is autonomous from such social forces. Yet, Marx wasn't a determinist -- as opposed to some of his followers. I think that denying to Marxism any notion of agency is wrong. Marxism couldn't have been such an important base for social revolutions and rebellions of the oppressed -- if it was a disempowering theory: it was Marx who said that we should go beyond the negation of the negation: toward the positive on itself positively founded.²⁵

In my research I wanted to outline the role of those actors -- often referred to as "passive" (or "weak" in the Italian philosophical debate) who are implied by actions in a specific arena. The actions taken in that arena -- regardless of the actors' organization and other contingent aspects -- will have consequences on them and on the internal equilibrium of the arena itself.

Both Gambino and Stoller encouraged me to go beyond a discourse on the production and distribution of cancer -- which would have given to this work more of a political economy approach. In different ways they helped me to exit the *cul de sac* of the objective analysis of reality, and focus on the contradictions as processes that change reality itself. Their questions directed me to pay more attention to those who are resisting the production of cancer, to the subjects -- women, people of color, scientist/activists - - as agents, instead of just objects of macro processes they can't control.

I met the necessity of including the actors' representations of the world I was investigating -- the specific *Weltanschauungen* each

²⁵ On the concept of agency, see: M. Rotkin, *Class, Populism, and Progressive Politics: Santa Cruz California, 1970-1982*, Dissertation, University of California at Santa Cruz, 1991.

activist constructed about cancer causes and prevention -- among the multiple visions required to understand a phenomenon in a non hierarchical way. This can be done, as Clarke and Montini pointed out in their work on the debate about RU486,

by not analytically recapitulating the power relations of domination, analyses that represent the full array of situated knowledges related to a particular phenomenon turn up the volume on the quiet, the silent and the silenced.²⁶

Focussing on listening to those voices that are usually "closeted" has a reality effect -- an impact that cannot be ignored by the social scientist. In fact, they argue, "some voices are empowered through our own sociological (re)representation processes that recognize and acknowledge, whereas others may metaphorically be forced out of the closet".

Clark and Montini believe the process of empowering is intrinsic to the research process itself. It doesn't necessarily imply the precise choice of standing by the side of the oppressed.

By the very scholarly act of representing most or all of the actors in print, we are turning up the volume on the less powerful actors, empowering them in the arena ... by following a current controversy, we are feeding it.²⁷

Every social actor is the bearer of a local knowledge -- or situated knowledge²⁸ -- a category sociologists and other social

²⁶ A. Clarke, T. Montini, "The Many Faces of RU486: Tales of Situated Knowledges and Technological Contestation," in *Science, Technology, & Human Values*, Vol. 18, N. 1, Winter 1993, p. 45.

²⁷ Ibidem, p. 69.

²⁸ C.W. Mills, "Situated Actions and Vocabularies of Motive," in *American Sociological Review*, Vol. 5, N. 6, 1940, pp. 904-913; P.H. Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, Unwin Hyman, Boston, 1990; D. Haraway, "Situated Knowledges: the Science Question in Feminism and the Privilege of Partial Perspective," in *Simians, Cyborgs, and Women: the Reinvention of Nature*, Routledge & Kegan Paul, London, 1991, pp. 183-201; J.H. Fujimura, "On Methods, Ontologies, and Representation in the Sociology of Science: Where Do We Stand?" in *Social Organization and Social*

scientists have been debating since the forties. Situated knowledge is not a fixed category; rather it is a fluid one, since it derives from the actors' identities. Actors' identities acquire consonances when they refer to what Mead named a "universe of mutual discourse"²⁹ - and Adele Clark calls "communities of discourse and practice."³⁰

The overall *modus operandi* of the cancer establishment is perceived -- especially by activists -- as oozing with concern for profit. In different degrees and ways, activists display a common anger against this situation, often characterized as unacceptable. The threat to their own lives -- and the lives of people they love -- gives to this struggle a character of an extreme battle.

A pair of Lacanian concepts can be used at this point.

1. Cancer activists perceive the science of cancer research as a *despotic signifier* because of both its form and content. Cancer research has an esoteric character and -- as most of the science produced -- it is not meant to be understood by "profanes." Its language -- like most of the scientific language -- is an element of exclusion and repression in which structures and settings of dominion are crystallized.
2. Cancer research focuses on individual predisposition and behavior -- which is perceived as a "blame the victim" approach by cancer activists and their supporters. The *subversion of the subject* presupposes important elements of collective identity construction. Lacan refers to a subject socially constructed in toto. He also criticizes the role of the specialist/expert by using the concept of "reciprocity of the process" which would be pivotal in a

Process: Essays in Honor of Anselm Strauss, D.R. Maines, A. de Gruyter (editors), New York, pp. 207-48.

²⁹ See also: C. Ellis, M. Flaherty (editors), *Investigating Subjectivity: Researching Lived Experience*, Sage, Newbury Park CA, 1992.

³⁰ A. Clarke, "Social Worlds/Arenas Theory As Organizational Theory," in *Social Organization and Social Process: Essays in Honor of Anselm Strauss*, edited by D.R. Maines, A.de Gruyter, New York, pp.119-158.

democratization of science.³¹ An antagonistic subjectivity according to Lacan is the distinctive trait of someone who knows what his/her desire is -- and connects/expresses it at the collective level.³²

The necessity of a counter-control on the signifiers is strategic. It is the task of social movements to begin the process. These operations have a great effect anywhere in the social body, since the definitions of reality strongly affect reality itself and the direction of its own development.

The desire for life expressed by cancer activists -- like any desire in Lacan -- presents elements of subversion and introduces germs of radical change inside controlled structures of signification. The struggle of cancer activists has been capable of directing *elan vital* into medicalized circuits disciplining bodies and minds.

1.4. A Movement Emerging From the Realm of Social Praxis

The cancer movement is not based on a political ideology but on a commonality of situation -- the ill body -- and shared needs. As I will demonstrate, it emerges from a social demand that couldn't find institutional answers. The social physiology of cancer activism is, at first, one of an interest group whose goal is to pressure politicians, scientists, and the media on a wide spectrum of issues.

Several social movements studies helped me to formulate questions and hypotheses -- and gave me the instruments for an early understanding of cancer activism. Being caught in the

³¹ A call for "liberation research" is emerging from different social groups: economically disadvantaged communities, people of color struggling against environmental racism, women survivors and scientist/activists involved in the production of popular epidemiology. M. Bakati Kuumba, M. Keita, "Liberation Research: A Weapon in the Hands of the Oppressed," *As The South Goes*, Vol. 2, N. 1, Winter 1995.

³² Experiments in this direction - like Maud Mannoni's community in Bonheil sur Mer - developed processes of subjective ruptures, self-legitimation and autonomy in the social fabric. See: M. Mannoni, *Education Impossible*, (avec la contribution de Simone Benhaim, de Robert Lefort et d'un group d'etudiants) Editions du Seuil, Paris, 1973.

explosion of cancer activism was "serendipitous." When I wrote my dissertation proposal, in 1992, cancer activism was -- as I indicated in the title -- a "sprout of resistance." In the last 3 years it became a movement and I could witness the process inside out.

Cancer activism has a double character: from a subjective point of view it could be explained as a post-modern new movement rising from identity aggregation. Yet, many of the goals of cancer activism undermine the ethical and economic legitimacy of the profit system. I am referring here to the banning of all proved carcinogens, the "zero tolerance initiative" and other goals that are politically connected with the environmental justice movement and the activities of scientist/activists concerned with environmental and occupational health. These goals of the cancer movement can be theoretically inscribed within the frame of anti-capitalistic movements -- since they are objectively antagonistic to the reproduction of profit.

Yet, the "objective location" of the cancer movement alone does not explain to us important features of this social phenomenon. The cancer movement started as the reaction of women survivors to a setting of en/gendered violence: the violence of silence and dismissal -- a violence women know too well -- the violence of the privatization of their illness, the patriarchal attitude of the medical establishment, and its paradoxical conservatism.

Those who first organized the resistance were very often lesbians. They gained the leadership in several U.S. cities because of their competence in women's health, their expertise in political activism and in the practice of empowering women -- and because of the caring attitude lesbians bring in the women's community.

Furthermore, if symbolically women's body is a territory of state control and "protection" -- the lesbian body is also a stranger and hostile territory, a body that carries the marks of unacceptable difference. Lesbians -- because of their identity *and* their body less accessible and likely to be manipulated -- suffered particular stigma

and discrimination by the medical profession and by the cancer establishment.

The supposed high incidence of breast cancer among lesbians is explained often by their not having children, not having nursed, being overweight or hormonally unbalanced. These causes are implicitly assumed to be related to lesbian sexuality.

Using feminist theoretical tools, the cancer movement can be analyzed as another step in the struggle for self-determination. When cancer activism was only women-based, this could have been possible. Yet, in the dissertation proposal I pointed out how cancer was not -- despite the activists' claims -- a woman's issue. Among my arguments there were basic facts, such as that men overall get more cancer than women, economically disadvantaged minorities get more cancer than whites, and lower classes more than upper classes.

As we shall see, cancer activism became a powerful stimulus for the environmental movement to reconceptualize nature including humans -- and to focus on people's health, since it is connected with the protection of endangered animal species, rainforests, and the general equilibrium of the eco-system.

Theoretical contributions that gave me insights are from authors who studied contemporary social movements: the Italian Alberto Melucci, the Frenchman Alain Touraine, the Polish Michail Vivieorka, the Jewish-American Barbara Epstein, the African-American Robert Bullard, as well as the "classics" like Neil Smelser's work and the contemporary literature on new social movements.³³

Where does the anti-cancer movement fit in the panorama of resistance, struggle and subversion? The movement is too young to

³³ A.D. Morris, C. McClung Mueller, *Frontiers in Social Movement Theory*, Yale University Press, New Haven, CN 1992; E. Larana, H. Johnson, J.R. Gusfield (editors), *New Social Movements: From Ideology to Identity*, Temple University Press, Philadelphia, 1994; S.M. Buechler, "Beyond Resource Mobilization. Emerging Trends in Social Movements Theory," in *Sociological Quarterly*, N. 2, Vol. 34, 1993, pp. 217-235; R.H. Williams, "Constructing the Public Good. Social Movements and Cultural Resources," in *Social Problems*, Vol. 42, N. 1, February 1995, pp. 124-144.

take the risk of comparisons with anti-war or anti-nuclear movements or parts of them. The connections I draw in the chapter on the cancer movement are mostly with the environmental justice movements and some fragments of mainstream environmentalism.

In this work I will not try to predict the future of the cancer movement -- if it is going to become part of a global movement for environmental health and reproductive rights, or if it is going to remain mostly a U.S. phenomenon. However, if I can express an intuition, I believe that environmental illness -- and specifically cancer as the main one -- is going to become a main issue in the communities of color, among sacrificed minorities, poor whites, women of different social classes -- and eventually will become one of the areas of resistance of people and concerned scientists against the "new world order" in the capitalistically advanced countries and in the areas of reproduction -- in the centers as well as in the margins of the empire.

1.5. The Intersections Between Critique of Science, Sociology of Death, and Sociology of the New Social Movements.

In this work I attempted to use an interdisciplinary approach and I looked for the possibilities of combining paradigms often perceived as conflictual: Marxism and post-modernism, feminism and Afro-centrism -- in order to develop epistemological pragmatism. I will discuss these issues in the chapter on methodology.

In the process of understanding the debate around cancer causes, I digested a quantity of public health studies, treatises of epidemiology and toxicology, and many essays on primary prevention. In the early stages of my research I even approached literature on Ergonomics and other eclectic readings.

I used authors who are not sociologists such as the economist A.O. Hirschman -- in order to understand the modality of voice/exit in cancer activism -- and the New Age theoretician Deepak Chopra -- to learn how to look at the body in a less Western way.

Several sociological fields have been especially relevant in my research: in this chapter I will discuss some contributions from the Sociology of New Social Movements, the Sociology of Science, and the Sociology of Death. My work has been inspired also by other sociological fields I explored during my doctoral training -- such as Environmental Sociology, Medical Sociology, and the Sociology of Health.

From the *sociology of science* point of view, the research produced more questions than answers. I decided not to present some (compelling) conflicts discovered during the research -- which would have taken me far from the research project.

I will present the conflict about what is considered to be a carcinogen and what is not, what is claimed as a safe exposure and what is not, because it has to do with the polarization between the scientists who believe cancer is produced by environmental carcinogens and those who believe otherwise.

This conflict could have been compared to a parallel (new) one: what is considered to be cancer and what is not. Definitions of cancer change: in the same way thresholds of tolerance are manipulated -- and "adjusted" to the new situations -- also the definition of what is a "malignant expression" or "cell aberration" change: some forms of cancer are not considered as such any more.³⁴ Discovering issues like these was of great interest to me. I decided not to include them since they are related to pathology and detection -- while my research considered only issues related to etiology and primary prevention.

³⁴ Some of the reasons why this happens - as in the case of threshold of tolerance and the changing definitions of cancer - is to reassure people. With the instruments also the words change: e.g. some kinds of cancer become CIN; and scholarly papers are produced questioning if we should say to the patient that CIN *is* a cancer, because of the depressive effects this can have on the person. Recently papers started questioning if we should really consider CIN as a cancer - since it is so diffused and, in about half cases, it is not lethal.

Some of the issues of detection overlapped etiology: the polemic over mammography is one of the examples. I didn't include in the dissertation my work on the debate around mammography, since I would have had to include a discourse around other detection technologies as well.

The choice of a detection method is socially constructed: the same way that non-Western cultures detection process tend to be non-intrusive, in Western societies, competing methods seem to win on the basis of their intrusiveness and on the use of high technology -- the latter considered as a guarantee of precision. The supremacy of a method is stated considering its cost-effective qualities, often without considering the damage related to the use of such technologies.

Many natural and social scientists in the past and today argue that science is not neutral. It can't be: science embodies stratifications and inequalities that largely reflect those present in any specific society. In Western countries and areas of "mature capitalism" -- as Jurgen Habermas would say -- such systems of stratification and discrimination follow lines of class, race, gender, sexual preferences, age.

Evelyn Fox Keller examined the mythlike belief that science is emotionally and sexually neutral by deconstructing scientific metaphors and stereotypes. She criticized much philosophy and sociology of science by looking at the different ways in which the foundations and the structure of science are patriarchal and sexist.

Interestingly enough, one of the arguments Evelyn Fox Keller makes to support her thesis -- the "masculinity" of objective thought -- is borrowed from the sociologist Simmel, who pioneered research in our discipline exploring "minor" fields, considered to be women's domain, such as the sociology of fashion. Keller suggests that we

should not take seriously the idea that if were more women to engage in science a different science might emerge.³⁵

The perspective and the kind of arguments Evelyn Fox Keller produced from a gender point of view can also be applied when looking at race/ethnicity and from the standpoint of heterosexist critique: the structure, values, and priorities of science are not going to change just by increasing the number of people of color involved or by facilitating the access to sexual minorities. The same can be said for the access of working class people in scientific disciplines.

Class plays a central role in the construction of science. Under capitalism, science has the role to serve -- with some degrees of autonomy -- the interests of the dominant classes. Gramsci, in his prison's notebooks raised a question that remains largely unanswered: what use can be made of "bourgeois science"?

Marcello Cini, Physics Professor at the Universita' La Sapienza in Roma theorized how the elaborations of workers' knowledge are crucial in the construction of a 'new science.' For Cini the main task of the 'new scientist' is questioning the neutrality and the reliability of this science. Cini refers to Maccaccaro's work -- a milestone in the working class movement for occupational and environmental health of the late sixties and early seventies:

Medicine cannot be trusted as neutral any more, and any illusion about this point should not be tolerated. Losing itself with the capital or saving itself with the labor: this is the only choice medicine has -- not a moral one, but a scientific and practical one.³⁶

³⁵ E. Fox Keller, "Gender and Science," in S. Harding, M.B. Hintikka (editors), *Discovering Reality. Feminist Perspectives on Epistemology, Metaphysics, Methodology, and Philosophy of Science*, Reidel Publishing Company, Boston, 1983.

³⁶ G. Maccaccaro, *Classe e Salute*, [Class and Health], Feltrinelli, Milan, 1973. [My translation]

The critique of science carried out by Maccaccaro didn't deny there are margins of autonomy in the production of science -- and some possibilities of a "progressive use" of capitalistic science.

Giulio Maccaccaro and his team of scientists/activists became part of the leadership in the Italian occupational and environmental health movement of those years: in their books they analyzed two processes having dialectical unity: the medicalization of politics and the politicization of health.

The first process was explained as a class choice made by capital, the second as an opportunity for the working class. At the end of the sixties Maccaccaro's group theorized the factory as the place where the maximum degree of health hazard is produced for the whole society. The Italian working class revolts of the late sixties had a strong focus on health issues: salary was considered as negotiable -- health wasn't. As documented in several issues of the *Journal Medicina Democratica*, collective struggle for collective health is having an impact on the whole mode of production because it questions the rationality of the system itself.

The "rationality of the system" is a crucial point: the more the system tries to legitimate its rationality as 'objective', the more it becomes evident how vicarious it is to the interests of those in power. Among the indicators they mention:

1. the capitalistic structuration and organization of labor and society;
2. the criminalization of absenteeism, which tends to mask the continuous perpetration of the robbery of collective health;³⁷
3. the concept of 'compatibility', which tries to support the subordination of health to the needs of profit;
4. the abdication toward public and private capital in the matters of programming and management of health.³⁸

³⁷ In the Seventies absenteeism became a militant form of protest and a mass antagonistic behavior against exploitation and the assault on health.

³⁸ G. Maccaccaro, *Classe e Salute*, Feltrinelli, Milan, 1973, p. 232.

The journal *Medicina Democratica* was published by concerned physicians, scientists and intellectuals and it became a forum for the discussion about the role of science and capital's long term trends. In re-reading them, I found some of the roots of my theorizing capitalism as production of death.

Nobody can give guarantees about the eternal existence of human beings on the earth. Other species have disappeared, human beings themselves might cease to exist.³⁹

The scientist's choice in Maccaccaro's thought could not be one of compromises: while the working class was displaying an historical compactness around the slogan "la salute non si paga" [our health has no price] -- these scientists and intellectuals took a militant stand:

We cannot work for the health of people if we do not make a very precise choice of class. And it is true that, until when we -- physicians, politicians and intellectuals of medicine and politics -- do stay in the compromise between the social parts, we are not working for the liberation and the health of people.⁴⁰

This team of scholars agreed that there are reforms which are not possible under capitalism. For this reason they considered health as strategic -- an uncompromising ethical and political issue.

We cannot really implement a Health Reform if we do not deeply *change the social context that contradicts such a reform*. In health as well as in society in general, power relationships are those which count. When power relationships are those among classes, it is the class struggle -- not the compromise -- what will decide what is going to happen."⁴¹

³⁹ F. Di Jeso, "Riflessioni su un progresso che inquina e sul regresso della qualita' della vita," [Reflections about a polluting progress and the worsening of the quality of life], in *Medicina Democratica*, n. 59, December 1986.

⁴⁰ G. Maccaccaro, *Classe e Salute*, [Class and Health], Feltrinelli, Milan, 1973.

⁴¹ G. Maccaccaro, *La medicina come strumento di controllo in Cile*, [Medicine as an instrument of control in Chile], Feltrinelli, Milan 1976. [My emphasis].

The "burden of proof" and the "level of threshold" about carcinogens was already a field of discussion. Benedetto Terracini, and Maccacaro considered carcinogens as substances acting at the molecular level and interacting with the DNA. The level of concentration in the environment cannot be the focus of scientific debate because the very presence of one or two molecules already imply a risk.

They came up with a proposal: MAC zero. This perspective of radical prevention has been recently re-issued in U.S. by the Zero Toxic Alliance and the Union of Concerned Scientists.

Terracini and Maccacaro proposed as conclusive the results of carcinogenicity on other organisms as possible carcinogens for humans -- against the multinational corporations who want people to pay for "comforts of modern life" they can't even access. Their conclusion was that there is no acceptable risk and the goal of primary prevention should be the one of securing that no man-made substances enter the environment without having been proved as safe. The degrees in which this happens has to do with class relations.

Maccacaro pointed out that focussing on primary prevention does not negate the importance and the effectiveness of secondary prevention and epidemiological surveillance. The end of his work expressed an early concern about the export of hazardous productions and waste in third-world countries.⁴²

I can date early cancer activism -- a strike against cancer in a chemical factory (IPCA) located in the north of Italy -- at the beginning of the seventies. Cancer was among the concerns of the occupational health movement, in Italy as well as in U.S. and other

⁴² I chose to quote Italian authors in this section - even though U.S. studies in Public Health by Vincente Navarro and others pointed out many common themes. The reason is twofold: the first is because of the anticipatory character of the work produced by Maccacaro's group; the second is an acknowledgment of the importance of their heritage in my political and sociological background.

countries, before becoming a women's issue and an environmental justice issue in recent years.

Today cancer activists are making a difference in the environmental movement, by bringing the body into the ecological discourse. As in the Native-American theory, humans are re-located as being part of the environment. Not the owners of nature but "a ring of its chain."

Body should be central to any theory of social action. What I can say as a sociologist is that the body is determined by the needs and the articulations of the mode of production, by the social inscription of gender, color and sexual preferences, and by phenotypical variations.⁴³

We can theorize as a further determination a rupture of conceptual unity between the healthy body and the sick body -- especially after AIDS has changed public consciousness on the matter in Western socio-economic formations.

The early practice of the cancer movement was a struggle to gain attention. Women showed their breastless chests and shocked the public with its horrifying absence, the marks of scars. Cancer activists correspond to what Julia Kristeva (the only woman thinker in the *tel quel* group) defined *sujet en proces*: they produced an "excess" -- or a subversive matter -- which indicated to the social scientists the beginning of a struggle or, at the very least, a contended ideological site. Often cancer activists perceive to have less time left, in their life, to make a difference, for such *proces* is sped up to the nth power -- the same way it happened with AIDS activism.

The cancer activists' challenge to the cancer establishment is a challenge about knowledge, body and agency. By contesting medical authority in a specialized field such as cancer etiology, women and people of color are asserting their capacity to produce knowledge of a

⁴³ Variations that account (and constitute a synthesis of) geno-typical characteristics and socially constructed differences.

certain sort, and their right to be part of decision making processes that will ultimately affect them.

The practical critique forwarded by women and people of color represents a valuable contribution to a new paradigm in priorities, methods and goals. Needless to say, in their desire, public health should be considered a top priority. This is what a new social movement is trying to achieve -- in different degrees and forms.

If we look at the sociological literature produced on *new social movements* in the U.S. we can notice a distinction between studies on specific movements and studies providing theories about movements. The former analyze the struggles of working class, women, people of color, sexual minorities, the anti-war protests, and the civil rights movements. The latter area of studies, more theory-oriented, gradually moves from its origins in the field of social psychology and collective behavior⁴⁴ toward the analysis of the social structure, its economic and political problems, seen as factors at the bases of social movements.

In other words, after the Fifties were over, collective movements could be seen for what they are: social phenomena having social origins. The scholarly production in this field -- having lost the aura of "pathologization" and the focus on the 'irrationality of collective behavior' -- could gain political respectability with structural analysis on the relationships between elites and masses, on the systematic deprivation of specific communities, and with studies about the dynamics of revolutionary groups that decide to challenge institutions and their definitions of reality. Most of these sociological contributions can be grouped as either *Durkheimian* or *Weberian* -- the former emphasize factors like industrialization and social control, the latter focus on cultural aspects and the sources of authority.

⁴⁴ Among these studies we can find much of the Chicago School's production, with contributions of Blumer, Parsons and Gustav Le Bon.

After the social movements of the sixties the theoretical production started to include studies on the internal dynamics of social movements, their ability to mobilize resources, the constancy of discontent and mobilization, the explosions of "insurgencies" and the patterns of cooptation.⁴⁵

The literature on "new social movements" emerges in the Europe of the Eighties, and is favored by a rapid spread in the U.S.. Many of these studies are based upon Antonio Gramsci and Hannah Arendt -- some of them include the contribution of theoreticians such as Nikos Poulantzas and others who we cannot consider as sociologists *tout court*, but whose scholarly and political thinking have deeply affected our discipline both in Europe and in United States. From the prestigious Ecole des Haute Etudes, Alain Touraine announced the end of mass movements based on politics and economics and the birth of identity aggregation. He was in part wrong: the success of Touraine's ideas in the European academic world coincided with revolts for bread a few miles south -- on the other side of the Mediterranean. The two components -- political economy and identity politics -- still continue to co-exist when it comes to social movements and often seem to be complementary.

In the case of anti-nuclear mobilizations in Europe we could witness the overlapping of economics, politics, and identity aggregations having a cross-sectional character in terms of class. The mobilization included the reformist Communist and Socialist parties - - as institutional representatives of the majority of the working class -- different segments of the New Left, feminist groups, pacifists, yoga practitioners, sexual minorities, the green petit bourgeoisie, and the red revolutionaries.

In the analysis of Eastern European movements -- such as Solidarnosc in Poland -- looking just at cultural and religious issues was inadequate: it didn't take into account important structural

⁴⁵ D. McAdam, J. McCarty, M. Zald, "Social Movements," in N. Smelser (editor), *Handbook of Sociology*, Sage, Newbury Park, 1988, pp. 695-737.

issues and socio-economic transformations that were in large part at the roots of those movements. Once again, superstructural analysis disconnected from the consideration of material conditions of life demonstrated its inadequacy.

Alberto Melucci⁴⁶ looks at new social demands and new social movements based also on identity -- and his view is sophisticated and comprehensive. He theorizes that these new formations are symptoms of a nascent mode of production: they can cause a structural change because they are the expression of something that does not function at the structural level.

Melucci integrates the awareness of economics and political issues with the analysis of desire, body, the collective unconscious, and social identities resisting rationalization. His works are pivotal for a Marxist theory of the subject and for a discourse around body as a place of resistance and subversion.

In the framework suggested by Melucci, I would locate also Jean-Francoise Lyotard and Stuart Hall, the first for his work around meta-narratives -- whose function is to hide social and economic inequalities -- and the subversion of what is called democracy; the second for his consideration of the process from the point of view of the subjects who need to be seen as collective -- following oppressive lines that divide people by class, gender, race/ethnicity and sexual preferences.

Barbara Epstein's intuitions around the ways in which intellectuals affect the political arena⁴⁷ and their role in the rise of new social movements are at the basis of my reflections on the cancer movement and on the effects that can be generated from the researcher's action of amplifying a social phenomenon in progress by

⁴⁶ A. Melucci, "The New Social Movements: A Theoretical Approach," *Social Science Information*, N. 19, 1980, pp. 199-226. A. Melucci, "The Symbolic Challenge of Contemporary Movements," *Social Research*, Vol. 52, N. 4, 1985, pp. 789-816.

⁴⁷ B. Epstein, "Rethinking Social Movement Theory," in *Socialist Review*, Vol. 20, N. 1 pp. 35-66.

investigating on it. This interaction between intellectual research, framing and speculation, and the development of the considered phenomenon is a field of knowledge that needs more attention and systematic study.

I want to conclude this section on the sociology of new social movements by mentioning a stimulating body of recent U.S. literature on social movements, which express the tendency to overcome the separation between theoretical studies and models, and empirical analysis of real movements. In Robert Bullard's works on the environmental justice movement we can notice a co-existence of both components: a new movement is analyzed within a new conceptual frame -- a new theory is supported by new empirical data.⁴⁸

Another example is constituted by the black women's movement in this country and the scholarly production emerged with the movement itself. Despite the academic marginality of oppositional thinking and practices expressed by black women in this country -- which at first can be perceived by a foreign scholar as an unexplained "absence," a missing topic -- and despite much anti-intellectualism in the black community, these works and some of those focussed on the third world are surviving hostile environments and expressing the potentiality of a new paradigm -- which looks at systems of oppression in an analytically integrated way.⁴⁹

⁴⁸ This issue is discussed in section 6.5.

⁴⁹ B. Hooks, C. West, *Breaking Bread: Insurgent Black Intellectual Life*, South End Press, Boston, 1991; T. Morrison, *Race-ing Justice, En-gendering Power*, Pantheon Books, New York, 1992; S. Mitter, *Common Fate, Common Bond: Women in the Global Economy*, Pluto Press, Wolfeboro, 1986; C. T. Mohanty (editor), *Third World Women and the Politics of Feminism*, Indiana University Press, Bloomington, 1991; A. Ong, *Spirits of Resistance and Capitalist Discipline: Factory Women in Malaysia*, SUNY, Albany, 1987.

From a *sociology of death* perspective, my work covers an area quite neglected in this sub-discipline.⁵⁰ Death represents an important perspective and an instrument of analysis in order to:

- re-define what is health, under capitalism and deconstructing the different ways in which the processes of body-consumption -- which allow capitalism to reproduce itself -- take place;
- re-infuse awareness about limits;
- re-elaborate a position about sustainability, allocation of resources, waste of both raw materials and work;
- re-conceptualize property and privileges, and the physical and intellectual sacrifice of parts of the social body.
- re-establish the meaning of collective and individual practices, toward a theory of the subject that refers to humans also as part of nature.

Within the sociology of death, the "radical wing" is represented by those authors that joined together for two anthologies on "Horrendous Death"⁵¹. They seem to go to the root of the problem, and to work for overcoming the causes, while the psychology of death, and part of the sociology of death, only studies the effects and the possibilities that individuals (and also groups, like in the studies on Holocaust) have in coping with other people's deaths and the prospect of their own death. Moreover, while the bulk of thanatology is studying death on a microsocial level (the dying person, the bereaved, the suicidal) they focus on types of death at the macrosocial level.

The stress on *collective action*, in the second volume of the anthology, even though it is partially directed to the formation of pressure groups (whose referents are, by definition, public

⁵⁰ L. Corradi, "Re-defining a Field: The Sociology of Death," qualifying essay, Board of Studies in Sociology, University of California, Santa Cruz, 1992.

⁵¹ D. Leviton (editor), *Horrendous Death, Health and Well Being*, Hemisphere Publishing Corporation, New York, 1991; D. Leviton (editor), *Horrendous Death and Health: Toward Action*, Hemisphere Publishing Corporation, New York, 1991.

institutions) place some effort in dealing with grass roots activity.

I believe we are going to witness, in the near future, radical movements somehow connected with the right to health/reproduction/life and *macro* variables and resources such as air, water, food. Even though these movements exist at a virtual or embryonic level they have the potential of generating important consequences. Movements grounded on vital needs -- since such an issue is global -- can become global movements.

The *Horrendous Death* theoreticians focus on the particular danger that has been labeled "horrendous-type death" and the goal of the authors is to contribute in health-educating people of every country to present imminent dangers. Examples include death as a result of chemical and biological disasters, pollution and poisons in water and food, destruction of the environment (e.g. the biosphere), undernutrition, conventional and nuclear wars.

These forms of death are all *capitalism related*. "Horrendous deaths" are man-made, premature and often unexpected and usually affect large populations. These forms of death are often tortuous, have no socially redeeming value and are usually denied by individuals as a potential cause of their own death or the death of their loved ones (especially children and grandchildren).

These causes of death can be prevented and eliminated only in a collective and worldwide effort. The threat and actuality of horrendous-type deaths are a *global community health problem* and on the forms in which the global community can mobilize its resources to defeat this common threat.

I think that there is an increasing -- awareness among large strata of the population in the capitalistic countries about the necessity to reallocate the resources in a different way. Some empirical studies started to be done on this subject. In Great Britain, the Gallup poll asked people the following question: "Which do you think is more important: protecting the environment or keeping prices down? In 1982, 50% of those polled said protecting

the environment. Three years later they were 60% and in 1988 the 74% answered that the environment was more important.⁵²

Another indicator of the increased concern is the growth of studies on the percentage of children in industrialized countries born with congenital defects caused by chemicals in food, water, air, or by exposure to ionizing radiations.

The three main categories in which "Horrendous Death" is conceptualized are:

- Horrendous deaths *type I*: are those intentionally caused (wars but also: racism, mass murder grounded on group hatred, starvation caused by people etc.).
- Horrendous deaths *type II*: are not intentionally caused, but are the "natural" effect of capitalistic exploitation of nature and human beings. More precisely, these kind of deaths are resulting from "upsetting the homeostatic balance of the earth or its self-sustaining reproductive capacity"⁵³ (see: toxic chemical, electromagnetic pollution from radar, microwave and other telecommunication systems, nuclear fuel, pesticide, herbicide, destruction of forests, desertification, reduction of the ozone layer, and toxic waste, etc.).
- Horrendous deaths *other types* are not intentionally caused: cancer, coronary heart disease, illness related to stress, Alzheimer's disease, AIDS. These causes of deaths affect large number of people.

Besides the health and well being costs, special attention is given in presenting the economic costs of horrendous-types death at the national and global levels. For instance, in 17 eastern states of the USA it is estimated that "air-borne acid corrosion does material damage of \$7 billion annually. Europe has estimated material and fish losses at \$3 billion a year, with damage to crops, forest, and health exceeding \$10 billion a year from air pollution. Clean-up

⁵² *Washington Post Health*, Nov. 29, 1988, p. 7, as quoted in D. Leviton (editor), *Horrendous Death, Health and Well Being*, Hemisphere Publishing Corporation, New York, 1991.

⁵³ D. Leviton (editor), *Horrendous Death, Health and Well Being*, Hemisphere Publishing Corporation, New York, 1991, p. 177.

estimates range upward from \$12 billion a year.”⁵⁴ It is interesting to notice how *costs are socially distributed and benefits are privately appropriated*.

Capitalism seems able to guarantee well-being only as a privilege, and *privileges are not for everybody*. Pushing more on this side of the analysis, we can say that we are not so distant from the situation in which capitalism will not be able to guarantee well-being even of the capitalists. This is a point of rupture that can be an important future consideration.

Some scenarios of death due to environment are described by the *Horrendous Death* authors. The first is related to damage to the immune system and the reduced ability to produce antibodies. The second is related to massive contamination of food, water etc that make the planet uninhabitable. The third is related to alterations of the earth's atmosphere due to greenhouse, nuclear winter or other causes that can destroy both farms and uncultivated grassland and bring about death of animals and humans over large regions of the earth.

Often people hesitate in taking a stand -- also in political terms -- because they perceive that the threat is real but under control. The DASIQGH Project (Death as Stimulus to Improve the Quality of Global Health) has the motivation to “insure our future health and the health of the future.”⁵⁵

How would the DASIQGH be implemented? The original plan conceptualized the bringing together of influential social policy makers from various domains to work cooperatively at the international level to improve the quality of life. Seven domains were identified: government-politics-law; commerce; labor; the military; science and medicine; religion; the media.

Several organizations are already involved in this Project:

⁵⁴ Ibidem, p. 181.

⁵⁵ D. Leviton (editor), *Horrendous Death and Health: Toward Action*, Hemisphere Publishing Corporation, New York, 1991, p. xxvii.

- Consortium on Peace Research, Education and Development (COPRED) that requires grass roots participation;
- The Center for Innovative Diplomacy, a 6,000-member organization of people who believe that horrendous death can be eliminated by participatory democracy;
- the Ground Zero Pairing Project (GZPP), which is one of the largest suppliers of educational materials for promoting friendship among citizens of hostile countries.

Other groups, and organizations are a referent of DASIQGH Project:

- the American Alliance for Health, Physical Education and Recreation (AAHPERD);
- the American School Health Association (ASHA);
- the Adult Health and Development Program (AHDP), which organizes trainings of theory, exercises, intimacy, sexuality, drug interaction.

There are also organizations such as Physician for social Responsibility, Educators for Social Responsibility, International Psychoanalysts Against Nuclear Weapons and many others. These groups are, at the moment, among the most progressive and aware associations of intellectuals in this field.

The models of action proposed by these authors are directed to promote political, social and economic intervention by "ethically aware nation states". They do not address any kind of hypothesis of a change in the modes of production and distribution of the wealth. Paraphrasing Jim O'Connor,⁵⁶ they talk about overcoming the second contradiction of capitalism without overcoming capitalism.

"Communism or barbarism," is more than a simple slogan, and it may be understood as an ambivalence, if what we know is true about the falling rate of surplus value, the increase in capitalistic concentration and exploitation, the expulsion of labor force from the point of production, the "necessity" of aggressive corporate

⁵⁶ J. O'Connor, "Capitalism, Nature, and Socialism: A Theoretical Introduction," *Capitalism, Nature, and Socialism*, N. 1, November, 1988.

imperialism in those areas still to be colonized. Wars seem to give new impulse to capitalist economies, allowing it to re-start the accumulation process.

In a world stuffed with nuclear and chemical plants we know what it can mean. Concerned scientists tell us that a single Titan II detonated in any metropolitan area can kill two to four times as many people as the United States lost in the civil war, the two World Wars, the Korean war and the Vietnam war combined.

The idea of the end can stimulate and develop energies we didn't know. This is true for the women cancer survivors I interviewed, who starts to be involved in activism after being diagnosed with a "non curable illness". This is true also for capitalism that speeds up its processes of exploitation and destruction when its crisis becomes deeper. I think this can become true also for us: knowing that we are here for a certain number of years means working harder and more effectively toward our goals.

My intent was not a final assessment, nor the application of a theory to an empirical field. Rather I consider this effort as a first glance at the intersections of environment, health, and new movements -- and the analytical categories of class, gender, race, and sexual preferences. For this reason I want to reclaim the character of incompleteness and partiality of my work. As Derrida taught us,

totalization no longer has any meaning because the nature of the field excludes totalization.⁵⁷

I hope my work will be of some use for other scholars and for activists. I want to end this chapter with the words of Peter Kulchyski from his *Primitive Subversions* because the resistance of women with cancer and people of color has much in common with the resistance of Native people both at the level of goals and at the

⁵⁷ J. Derrida, "Signature Event Context," in *Glyph*, N. 1, pp. 172-197, 1977, p. 102.

level of practice. And because his concern about the future is also my own.

I have related a story and constructed an interpretation in the hope of illustrating *the degree to which subversion is most frequently a matter of micropolitics, a politics of everyday experience*, of speech and gesture, a politics that leaves few traces, but may be passed on from generation to generation through stories or values and may also disappear into a backwater eddy of history, not even serving to inspire those who bear its spirit of constructive refusal.⁵⁸

⁵⁸ Peter Kulchyski, "Primitive Subversion: Totalization and Resistance in Native Canadian Politics," in *Cultural Critique*, N. 12, pp. 171-96, Spring 1992, p. 190-1. My emphasis

Chapter 2

THEORY AND METHODS

2.1. Introduction

In this section I will make some points about the theory of method and the method of theory. The empirical part of my research has an exploratory character: this is the case when, I believe, quantitative methods need to be re-invented, in order to be applied to new situations -- since less can be taken for granted during exploratory investigations.

Many theories -- among those offered by the fields surrounding (or crossed by) empirical research -- can be used to explain parts of the phenomenon under analysis. An interdisciplinary approach becomes a must when looking at complex phenomena that cannot be explained strictly within the boundaries of one discipline. Complex phenomena can be approached with different combinations of theories and sets of ideas. A merit of this work is its attempt of doing so and its "transversal" character.

I tried to keep my path clear of obstacles when looking for conceptual tools to help me explain different segments of the same social phenomena. I could use ideas and concepts from different theories to comment or critique processes, ideas or passages in the interviews, as they were emerging and connecting to my mind. Sometimes I couldn't recall which author suggested to me an approach, a perspective -- maybe stuffing my writing with quotations wasn't a goal, I was more concerned about producing a chemistry of new ideas.

I believe it is important to achieve intellectual freedom in the reading of the results, i.e., not being bound by loyalty to a specific method or theory. However I feel that without a theoretical frame to start with, any design is prone to failure: it is condemned to travel from the particular to the particular without reaching the general.

A project without a theoretical frame -- at the very least -- takes the risk to describing a piece of the reality without connecting such a piece with other social processes. In metaphorical terms, a "pure" *grounded theory* may collect a body of interesting materials, without providing a "head" that would function as monitor for the very ramified nervous system of theoretical insights.

2.2. Relevance of this Research

This study was conceived as an attempt to theorize about

1. the production of death under capitalism;
2. the ways in which increasing awareness that our societies produce untimely and avoidable deaths can become a stimulus in the development of oppositional consciousness and collective forms of resistance.

From the general hypothesis that the search for profit -- and its location in the top of economic and politic concerns -- produces untimely and avoidable deaths both in direct and indirect forms, I moved toward the realm of social praxis, narrowing down the focus on more specific issues such as occupational hazards and life-threatening diseases related to environmental causes. In the Marxist tradition, I moved from the general to the particular, and then from the particular to the general, with a new theoretical awareness built in the two passages.

A wider study about capitalism-related death in general would need to take into consideration the whole body of different studies on many different causes of death, such as homicide, suicide, job and war casualties, deaths from hunger and from lack of care.

I chose one illness and looked at its causes as my empirical field of analysis. Cancer etiology presents several problems and issues common to other life-threatening illness and other causes of death. Cancer also presents specific features that cannot be understood without a technical background. I had to develop such a

knowledge to the degree necessary in order to interview cancer scientists and activists.

A discourse about illness in general would have implied studying also the technicalities of many, and to assess common trends and denominators. I decided to more deeply analyze just one illness, and I chose an environmental illness because of four socially and politically relevant characteristics, which constitute the reason of my choice.

The first reason is that people do not have much control over most of the causes of environmental illness. Increasingly, groups of citizens in western countries are focusing their attention on the quality of air, water, and food; on toxic waste, chemicals, and radiation.

The second reason is that not even specialists have much control over environmental illness. Some of the scientists I interviewed declared to have met limits in the process of knowing the truth about the production of cancer.⁵⁹

The third reason is that environmental illnesses are "man-made" and mainly produced by the imbalance between human beings and non-human nature. The process of manipulation of nature is intrinsically connected with the development of productive forces. Under capitalism the process of manipulation of nature becomes more destructive and unsustainable.

Most environmental illness could be avoided or at least reduced in a social-economic formation where a balance between human beings and non-human nature is respected, where profit would not be at the highest point as hierarchic value.

⁵⁹ Few of them, like John Gofman, former director of the Livermore, and Samuel Epstein, former key expert of EPA have been ostracized in a way that reminded me the persecution of heretics in other historical ages. What I understood as a central problem is the funding system and the role of some public and private institutions - from corporations to the military sector - which have the relative power of silencing issues representing obstacles for their activities.

The fourth reason of my choice is that when people find out about the causes of environmental illness -- if social conditions allow collective processes of organization -- they struggle for the defence of their health, their lives, and the lives of the people they love.

Sometimes they win, even inside the limits of legal systems which do not seem to allow much expression of social disapproval and opposition, and don't seem to defend people's interests.

The reason why I chose cancer among other environmental illnesses resides in the fact that it is the leading cause of death among adult women in most of the industrialized countries, and the second cause of death for men (after heart disease). Cancer is also increasingly affecting the male population, younger people and children.

As the World Health Organization wrote in 1964, 85% of detected cancer is related to "environmental" causes, which are said to be, by and large, preventable. Even though several interpretations of the WHO statement have been provided, and many definitions of "environment" have been disputed, we can define cancer as the most important among the "environmental illnesses."

2.3. Conceptualizing the Research. The Critique of Western Science

When I started my dissertation work I was pulled by opposed drives and motivations: the political urge of amplifying the voices of the oppressed -- which does not conflict with my scholarly commitment to fairness -- and the desire of enjoying the privileges of theory.

My "European background" was impeding me from understanding what was new, in the same way a background noise prevents one from distinguishing a voice. So I turned it off.

By the time I started my field research I freed myself from the ballast -- a loss of weight. During the research trip I was feeling like Peter Pan, a dragonfly. I wasn't concerned about time -- I was

convinced that inventing takes more time than re-interpreting what others already wrote.

Later, during the writing process, I went back to my background as to a treasure chest, but I wasn't the same person any more. I developed the conviction that most of the academic knowledge I had embodied during my European training as a scholar -- that knowledge I had criticized from a class standpoint only -- had to undergo a process of deep revision.

Not only the theory I absorbed was elitist, "bourgeois," and made women invisible: Western theory started to appear to me as the incarnation of male dominated social relations -- intrinsically patriarchal in structure and goals -- and as a "white" theory.⁶⁰

As Julia Emberly argued in the introduction to an anthology of Native women's writings "traditionally theory has been the preserve of an intellectual vanguard (...) hegemonic representatives in academic institution of power"⁶¹ whose role has been challenged by feminist theory and the heterogeneous production of contemporary philosophies by Black, Brown and Native social theorists.

I became familiar with their literature only in recent years. What I have learned from these authors is a shared common ethos in their methodological and theoretical perspective, and a similar critique of the Western science:⁶² a science that historically represented a tool for the oppression and the genocide of the dark people of the world, of the Jews, the Gypsies, and the homosexuals. A science that openly legitimized control, domination and cruelty

⁶⁰ J.A. Ladner (editor), *The Death of White Sociology*, Random House, New York, 1973.

⁶¹ J.V. Emberley, *Thresholds of Difference. Feminist Critique, Native Women's Writings, Post-colonial Theory*, University of Toronto Press, 1993, p. xvii

⁶² In this dissertation the term Western science refers to the *hic et nunc* of the dominant science. Other terms are often used. Depending on the context, science is defined as "capitalist," "patriarchal," "white," "racists," "heterosexist." However, each one of these terms alone does not account for the interaction of class, race, gender and sexual preferences in the scientific discourse.

over women. An unjust science that serves the dominant classes, not the people.

The critique of science made in Black Studies, Ab/original philosophies and non-Western theories have some points in common: the re-evaluation of the role of intuition; the respect of the unknown; the concept of contemplating and sharing *versus* a science obsessed with controlling and possessing; and the idea of unity *versus* the idea of separation.

This reason is not discursive ... It is not antagonistic but sympathetic. This is another path to knowledge. Negro reason does not impoverish things (...), eliminating the juices and the sap; it flows into the arteries of things, espouses all their contours and comes to rest in the living core of the real. *White reason is analytical through use, Negro reason is intuitive through participation.*⁶³

Asante pointed out how Asian cultural reality affirms the supremacy of spirit over matters. In contrast, he asserts that "Eurocentric perspective of reality holds that the material and the experiential are the only phenomena that are real and that the spiritual is an illusion. In essence, everything that is not scientific and that the senses cannot experience is nonsense."⁶⁴

Both perspectives assume an epistemological separation between material and spiritual, which is not allowed e.g., in the Afro-centric worldview:⁶⁵ "there is no separation between the material and the spiritual, the bonding of and continuity from material to spiritual being the reality of the Afro-centric worldview."⁶⁶

⁶³ L.S. Senghor in 'African Negro Aesthetic,' translated by Elaine P. Halperin, "Diogenes," N. 16, Winter 1956, p. 24, as quoted in the Introduction of *Essays on African Writing. A Re-evaluation*, edited by Abdulrazak Gurnah, Heinemann Educational Books, Oxford, 1993. [My emphasis].

⁶⁴ T. Anderson, *Black Studies. Theory, Method, and Cultural Perspectives*, Washington State University Press, Pullman, 1990.

⁶⁵ This is true also for India - which can be considered at the crossroad of Asian and African inputs for many matters - but I didn't find any mention of it in the literature I reviewed.

⁶⁶ Ibidem p. 9

As Richards stated, the way people look at the world and the accepted scientific representations shape the way people look at nature and at each other, the mode of relating to material and non-material matters. Ultimately, it affects people's social and political needs.

A people's worldview affects and determines behaviors. A universe understood totally in materialistic or rationalistic terms will discourage spirituality. An ethos characterized by a will to power, by the need to control, will derive pleasure from a technical order.⁶⁷

Considering the role of those intellectuals who are organic to the status quo, Chukwuemeka Onwubu argues against the *Mertonian* definition of intellectuals as a social role -- instead of as a total person. His critique gives new legitimacy to avocational choices and ultimately denounces the segmented and taylorized character of western knowledge: a knowledge grounded purely on the logic of intellect, a knowledge that despises the role of intuitions.⁶⁸

To Onwubu, social scientists are often "social technologists of the established order," responsible for conceptualizing and setting the criteria for racial grouping, genetic deterministic theories and ideas, and ultimately racist ideologies.

What is the epistemological meaning of giving voice to the voiceless, oppressed? To find the legitimacy of their resistance, the "other reasons" -- the reasons of the others.⁶⁹ I wanted to be part of this process, as social actor and as an intellectual. I started investigating the struggle on the environmental causes of cancer as a politically and sociologically relevant issue. I started working with

⁶⁷ D. Richards, "The Implications of African-American Spirituality," in M.K. Asante and K.S. Asante (editors), *African Culture: The Rhythms of Unity*, Greenwood Press, Westport, 1985.

⁶⁸ C. Onwubu, "The Intellectual Foundations of Racism," in T. Anderson, *Black Studies. Theory, Method, and Cultural Perspectives*, Washington State University Press, Pullman, 1990, p. 78.

⁶⁹ As Ferruccio Gambino would say.

women who had cancer as a woman who had cancer. When I interviewed them I had the privilege of being an insider in the universe of their meanings.

Turning off my background didn't prevent me from having insights based on my knowledge of classical and contemporary theory. A few interviews were enough to understand that the cancer establishment was perceived as the producer of despotic signifiers among survivors. And the applications of Bourdieu's theory of "control over the field" is still the only one I would use to explain the scientists' polemic around the concepts of threshold and acceptable risks.

I didn't want the consciousness of my conceptual tools to interfere with the process of assimilation I was involved in -- and to prevent me from catching phenomena for which I might have no tools. My point in doing this dissertation wasn't the one of finding pretexts to demonstrate how much theory I know. Rather my attitude was the one of exploring the virgin area, populated by cancer activists and cancer scientists -- mostly unknown by social scientists.

2.4. Feminist Epistemology Suggestions: Beyond Methods

I wasn't thinking in terms of feminist methodology when I wrote my dissertation proposal. I started to look at feminism also as epistemology of difference -- and not just as a practice of struggle.⁷⁰ Only *a posteriori* I understood that parts of my work could be analyzed with the tools of feminist methodology and that some of my concerns and reflections were those of other authors.

The parts of my research that can be inscribed in the recent tradition of feminist methodology have to do with its critical revision of the mainstream postulates upon which much of social inquiry is based.

⁷⁰ This was a suggestion from Nancy Stoller.

As Jutta Berninghausen and Birgit Kerstan argue in *Forcing New Paths*, new postulates need to be conceptualized in social science methodology, by speculating on the following concepts: conscious lack of neutrality; women's solidarity, and partial identification -- based on the premise that "all women are affected by patriarchal structures."⁷¹

Women researchers are conscious of their bias when investigating matters that have much to do with gender oppression and gender based class inequality. Jutta Berninghausen and Birgit Kerstan believe that structures of domination cannot be simply "described" because of the partial identification of the researcher. Male researchers are "biased" too -- but the pretended neutrality of social structures make them less conscious of the way his work is gendered.

Berninghausen and Kerstan point out the necessity of active participation in emancipatory activities and "the necessity of a view from the bottom" which is also a view *toward* the bottom "through communication with those actually positioned on the bottom (...) *in order to achieve something, one must change it.*"⁷²

In feminist epistemology, the research process becomes the source of reflections on the effects the research process had on the researcher and the subjects involved, like an expanded "consciousness-raising experience" for both the researchers and their subjects.

As I mentioned in "Theoretical Locations," one of the main areas of concern in the feminist discourse is the construction of a discourse around the relation between investigated and investigating subjects. This is true especially for those subjects who have been historically objectified by despotic practices of knowledge, those

⁷¹ J. Berninghausen, B. Kerstan, *Forcing New Paths, Feminist Social Methodology and Rural Women in Java*, Zed Books, London, 1992. p. 6.

⁷² Ibidem, p. 8. [My emphasis].

whose bodies and minds had to submit to the intrusive eyes of the power.

In her *Subaltern Studies*, Gayatri Ghakravorty Spivak explains,

this is the greatest gift of deconstruction: to question the authority of the investigating subject without paralyzing, persistently transforming conditions of impossibility into possibility.⁷³

The possibility for the research to affect the directions of change and to open spaces resides to the specific location of the investigator, his/her relationship with the investigated subjects and their values systems.⁷⁴ The contradiction between the subjective and the objective level is not mechanical: on one hand the investigator is "partial," on the other hand his/her location and relationship with the object is a *conditio sine qua* the object cannot be investigated.

Feminism and historical materialism have been struggling in competing and integrating approaches for a couple of decades. With its foundations in the works of Selma James,⁷⁵ Mariarosa Dalla Costa,⁷⁶ Iris Young,⁷⁷ Zillah Eisenstein,⁷⁸ Angela Davis⁷⁹ -- and many others through the Eighties -- a vast international production of theory and empirical analysis has been established.

⁷³ R. Guha, G. C. Spivak (editors), *Selected Subaltern Studies*, Oxford University Press, New York, 1988, p. 201.

⁷⁴ Here I should say that during my research I wasn't always a privileged knower. While "at home" with activists, in the scientific community sometimes I felt more of an "infiltrator" - since I was looking at them as part of a world that wasn't mine.

⁷⁵ S. James, *Sex, Race and Class*, Race Today Publications, London, 1976.

⁷⁶ M. Dalla Costa, S. James, *The Power of Women and the Subversion of the Community*, Falling Wall Press, Bristol, 1975.

⁷⁷ I. Young, "Socialist Feminism and the Limits of Dual Systems Theory," in *Socialist Review*, Vol. 10, N. 2-3, March-June 1980, pp. 169-188.

⁷⁸ Z. Eisenstein (editor), *Capitalist Patriarchy and the Case for Socialist Feminism*, Monthly Review Press, New York, 1978.

⁷⁹ A. Davis, *Women, Race and Class*, Random House, New York, 1981.

Marx himself noticed that "the very first division of labor occurred in sexual intercourse." He also pointed out that "division of labor becomes 'truly such' when the division of mental and manual labor appears."⁸⁰

Marxist-feminist theory discovered the direct and indirect nature of the production of surplus value within the domestic setting; the areas of reproduction of the labor force; and traced a feminist standpoint on the sexual division of labor under capitalism.

A systematic body of studies is emerging as a result of a quantity of works and a process of formalization of a Marxist-feminist epistemology started thirteen years ago by authors of *Discovering Reality: Feminist Perspectives of Epistemology, Metaphysics, Methodology, and Philosophy of Science*.⁸¹

Marxist-feminist epistemology can be considered *a theoretical synthesis*, in which several approaches coexist: at one pole, those that look at how to supplement class analysis just by adding the concept of male domination; at the other pole, the 'radicals' who see capitalism as a product of male dominance, rather than *vice versa*.⁸²

A feminist epistemology is based on the principle of *overcoming duality* -- against the masculine *Hegelian* recognition of the self as structured in opposition to the non-self. Since women through pregnancy experience the "Other" as a continuum -- the female construction of relationship tends toward the appreciation of

⁸⁰ N.C.M. Hartsock, "The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism," in S. Harding, M.B. Hintikka, *Discovering Reality*, Reidel Publishing Company, Dordrecht, Holland, 1983, p. 290.

⁸¹ S. Harding, M.B. Hintikka (editors), *Discovering Reality. Feminist Perspectives on Epistemology, Metaphysics, Methodology, and Philosophy of Science*, Reidel Publishing Company, Boston, 1983.

⁸² N.C.M. Hartsock, "The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism," in S. Harding, M.B. Hintikka, *Discovering Reality*, Reidel Publishing Company, Dordrecht, Holland, 1983, p. 290.

"connectedness and continuities with other persons and with the natural world."⁸³

Such a feature has informed my work as well as the work of women activists -- while I didn't deepen the implications of the following, which here I only mention for completeness.

Hartsock points out that another -- dramatic -- characteristic of the male experience is "the substitution of death for life (...). The self surrounded by rigid ego-boundaries, certain of what is inner and what is outer, the self experienced as walled city (...)." ⁸⁴ She agrees with Bataille that death emerges as the only possible solution because of this discontinuity with the others.

Her analysis ends with a statement on the necessity of exposing the inhumanity of social relations and the ontological basis of new social synthesis "which need not to operate through the denial of the body, the attack on nature, or the death struggle between the self and other, a social synthesis which does not depend on any of the forms taken by abstract masculinity."⁸⁵

Sandra Harding and Merrill Hintikka emphasize the conception of "objective inquiry" as a product of male dominated way of thought. If we look at the ancestors of Western civilization, since Aristotle, in fact, the "natural superiority" of men has been based on measurements of rationality.

Women were not supposed to possess any of this quality -- and the whole political theory has been based on the notion of Aristotle's 'biology of reproduction': women are not rational animals. Definitions of authority, science, and what is *socially accepted as real* are based on male perceptions, negotiations and decisions that systematically have excluded women.

⁸³ Ibidem, p. 298.

⁸⁴ Ibidem, p. 299.

⁸⁵ Ibidem, p. 303-4

2.5. Empirical Goals As Intermediate Level Between Theory and Praxis

This work achieved some empirical goals:

1. Framing the debate around cancer etiology and primary prevention in the scientific community;
2. understanding the roots, components, and perspectives of a new social movement around cancer and the environment;
3. testing the social perception of the idea that profit is an obstacle in the primary prevention of cancer, among scientists and activists.

The scientific community agrees that cancer is largely preventable -- but disagrees on the causes we should try to prevent. I investigated the debate around the causes of cancer, primary prevention and the role of profit.

This debate involves different social actors: scientists, technicians, women survivors, community activists, people of color, environmentalists, governmental agencies, private industries. I interviewed sixty of these actors in several U.S. cities [see section 2.6.].

Even though the empirical field I have chosen -- the cancer arena -- was quite defined, the frame of my research has a wider perspective. How did I decide to connect theory and praxis? The former -- as stated in the Preface -- can be synthesized in three statements:

- late capitalism produces untimely and avoidable deaths, strictly connected with its reproduction as a system;
- keeping the same level of development of the productive forces, many of these deaths could be avoidable -- under a different mode of production and distribution, if profit were not the main concern;

- untimely and avoidable death can become a political terrain for antagonistic movements.

The first and the second have the axiomatic form of a statement that cannot be proved -- not in principle, but because of the different ways in which death data is recorded⁸⁶ -- the third statement represents a pure syllogism. Since it can be tested I would also consider it a sign of likelihood or truthfulness of the other two statements.

In short, what I contend is that a society based on profit making as hierarchical value necessarily produces more death than it would if profit was not the main economic concern.⁸⁷

I started with the described (general) idea -- which emerged as frame and motivation for the research. Then I identified the field for the empirical work. In the Marxian tradition, I went from the general, to the particular, and then back to the general with a new consciousness.⁸⁸

The decision to produce empirical research was based on the necessity to overcome a gap between the theory -- capitalism as production of death -- and any empirical sphere I would have chosen. How you can "empirically prove" that capitalism produces death was a question without an answer.

I found myself willing to work on the development of an idea I found theoretically relevant. But such idea was not, by empirical

⁸⁶ An axiom should be accepted as true or rejected as false. Stating axioms may have a dogmatic flavor - as Donna Haraway pointed out in her comments to my writings. Yet, as Kant pointed out in his *Critique of Pure Reason* - who adopt a *scientific* method, have the choice of proceeding either *dogmatically* or *skeptically*. For once, I will take the risk of dogmatism.

⁸⁷ This is not empirically demonstrable because we are unable to compare the rate of death of different societies taking into account the variables that changed during the development of productive forces and affected people's mortality. E.g., we cannot compare England today with England yesterday; and we cannot compare England yesterday with Nigeria today, even though the same process of primitive accumulation is taking place.

⁸⁸ In the terms of poet T.S. Eliot: "... at the very end of our research we will begin again from where we started recognizing that place as a new one."

standards, "testable." One of the reasons is that capitalism today is a global process and any attempt of building consistent comparisons failed during the first year I struggled with the concept of capitalism as production of death.

I tried to narrow down the whole axiom to different aspects of production of death. The past few years I worked on research projects related to work health hazards, work accidents and occupational illness -- areas in which the relations between production of death and creation of profit are more obvious.

There are no recent studies attempting to connect capitalistic relations with the production of this illness. The recent work by Vincente Navarro, *Dangerous To Your Health. Capitalism in Health Care*,⁸⁹ is based on the omission of care under capitalism and the subsequent production of more illness and untimely deaths.

My work is focused on avoidable causes of illness and death. In other terms, relative to Navarro's work, this one is located *before* the health care system interventions and omissions. Moreover, my approach is to look more at preventing such causes than to the care that needs to be delivered to the already ill, because of my personal and political interest in this area and because I noticed a lack of studies in this thematic area.

I believe that the social scientist always has his/her own general theory about society, social relations, and social change. Then he/she might not have -- or chose not to have -- a theory about a specific aspect, relation, or segment of social reality.

I think such a starting point -- the theoretical frame which the social scientist is moving from -- should be made explicit and stated at the beginning. I made clear what my theoretical background is and the approaches I used in the introductory chapter "Theoretical Locations".

⁸⁹ V. Navarro, *Dangerous to Your Health. Capitalism in Health Care*, Monthly Review Press, New York, 1993.

I overcame the gap between the theoretical statements and the empirical research by building an intermediate level⁹⁰ -- the level of social representations -- between the theoretical statements and the empirical work I have chosen as a dialectical pole.

Since I wanted this work to be a step toward the construction of a theory of capitalism as production of untimely death, in the final part of the interviews I posed questions about the connections between cancer causes and profit making. Most scientists and activists identified profit as an obstacle in cancer primary prevention.⁹¹

The method I chose was to interview cancer scientists and activists in order to achieve an understanding of the underlying representations and ideologies that cancer scientists incorporate in their discourses, in their definitions and their taxonomies. This is the part of my work closer to a sociology of science perspective -- partly influenced by socio-linguistics and deconstructionism.

The area of social representation allowed me more flexibility in the use of non-sociological approaches. It was also a place where I did not have to choose between material processes and subjectivities emerging from such processes.

Since its very beginning I preferred to think of my work as an interface between the body, environment, and socio-political identities. I was sensitive to the call for a plurality of paradigms and epistemological pragmatism. Social representations offered me a vehicle for building the "in-betweenness" I was looking for.

In contrast with Kant, I think no object of consciousness can be a "thing in itself" -- there is an essential difference between the object and our consciousness of it. For this reason, knowledge is not pure. In this dissertation, methods to understand cancer causation

⁹⁰ This advice was given me by Walter Goldfrank.

⁹¹ Some also pointed out that cancer hits one American citizen out of three and kills one out of five and more should be spent in prevention, which absorbs a tiny part of the cancer money, compared to the dollars spent in the etiological research, detection, treatment and rehabilitation.

are not an object of analysis *per se*: they reflect precise standpoints of the scientists. Scientists do have spontaneous theories about society, also when they are not aware of them. Some of their ideas are the product of dominant ideologies, which shape the scientific world, with its class and race composition, its male supremacy. As a matter of fact, some of the scientists' ideas are functional to the maintenance of the capitalist profit order -- others are antagonistic to it and tend to suggest its replacement or radical change.

2.6. Methodology of the Interviews

Prior to interviewing scientists and activists I investigated which theories have been produced to explain cancer and the social representations that have been evoked. I found this territory as sociologically unexplored. I believe further analysis is needed on the ways in which theories produced by natural and social scientists are similar, different, affecting each other; and about the ways in which representations of cancer produced among specialists affect cancer activists' agendas -- and *vice versa*.

For the purpose of this research I interviewed

30 scientists (22 male and 8 female);
 20 activists, (17 female and 3 male);
 4 scientist/activists (2 female and 2 male);
 and 6 specialists (3 male and 3 female).

Scientists have been referred to me because of their work in cancer etiology and/or in cancer primary prevention. The initial group of scientists was chosen by me in the Bay Area. I tried to include as much as possible a wide range of position -- in terms of political and disciplinary location -- in order to obtain a diverse sample. In this work I refer to some scientists by name and others

by interview number. In one case -- since strict confidentiality was requested -- I don't display the gender of the scientist interviewed.

Some of the scientists I interviewed were more oriented toward etiology and others toward prevention. Usually -- but not always -- toxicologists, molecular biologists, and biochemists deal more with etiological issues, while epidemiologists tend to include preventive concerns in their work. Before interviewing each subject I reviewed his/her writings. The first part of the interviews with the scientists related to the interviewee's scientific production.

While activists are a more homogeneous group, scientists belong to different disciplines, such as biochemistry, epidemiology, occupational medicine, industrial hygiene, sociology, and environmental toxicology.

I interviewed scientists and activists in the following cities: Berkeley, San Francisco, Oakland, Seattle, Sacramento Los Angeles, San Diego, Tucson, Miami, Atlanta, Cincinnati, Chicago, Boston, New York, and Washington D.C.

The interview consisted of four parts. The first part was meant to introduce the subject and describe the social context within which the interviewee is located. In the case of the scientists, I asked questions about their *curriculum studiorum*, scientific production, and the kind of involvement and role in his/her work. In the case of the activists, I asked questions about the reasons of their involvement in the cancer movement: for most of them activism followed a cancer diagnosis.

The second part was meant to inquire into the interviewee's opinions and representations on cancer etiology, and to situate both scientists and activists in the current debate on genetics, lifestyle, and environmental factors.

The third part of the interview was focused on primary prevention strategies. I asked scientists and activists where would they allocate prevention resources and efforts -- if they had the power to.

The fourth part of the interview dealt with political and ethical issues in cancer causation and prevention. I started this section by asking scientists which are the main obstacles in primary prevention. This part is connected to the debate around known carcinogens, risk assessment, and threshold of tolerance.

Beyond the technicalities, I wanted to find out where scientists and activists situated themselves in the polarity between two priorities, which also express two different philosophical approaches. Taking the risk of oversimplifying, I would say that scientists can be divided among those whose concerns are more oriented toward protecting "the right businesses have to make profit out of their activity" and those who argue that protecting people's health should be put first. This cannot be said also for activists. I didn't find the same degree of contradiction among them. Even though some expressed concern for "job losses" and for "harming business", activists as a group argued that people's health should be a supreme value.

The interviews were semi-structured around the following questions.

- 1) Introduction. Information on the scientist and his/her work or on the activist involvement. Description of which kind of activity materially connects the interviewee with cancer; how the scientists or the activist got involved into cancer research, activism or both.
- 2) Representations of cancer causes. Can you rank 5 causes of cancer in order of relevance? What is your definition of "environment." Which factors would you consider as "environmental" and why. Which factors would you consider as not being part of the environment and why. What about the definition "lifestyle"? What do you think about the current debate on cancer etiology and the different positions expressed in the scientific community?

3) Primary prevention strategies. If you had the power to decide, which kind of strategies in primary prevention would you implement. Which suggestion or critiques do you have? In which direction do you think more effort is still needed? Which areas do you consider as neglected in primary prevention? Which are the most important obstacles in primary prevention?

4) In which ways do you think cancer causes are related to economy, politics and society? What do you think should change for a decrease in cancer rates? In which ways do you think profit making may be connected with cancer causes? Do you think concerns about profit may affect primary prevention strategies?

Moreover, I had a sub-set of questions to deepen the conversation or cover areas that were omitted by the interviewee. In the etiology part, if the scientist didn't mention some of the causes, I mentioned them and asked him or her to express a position.

In the political and ethical part I asked questions about the banning or overtaxation of cigarettes, if the interviewee didn't talk about it in the part on primary prevention.

I also asked scientists and activists what they would like to see, when there is a substance suspected to be a carcinogen, and I offered them to choose among three different options:

1. to stop the production until the substance is proved to be safe;
2. to lower the exposures until the substance is proved to be safe;
3. no actions: the substance is innocent until proved harmful.

During the interviews I also tried to find answers to specific issues which emerged during the development of the theoretical and empirical research project. As a work in progress, when the scientists were available for a longer session, I tried to understand criteria in distinguishing "genetic" cancer as opposed to "environmental" cancer -- and the linkages discovered between

modifications in the non-human environment and the human environment -- i.e., between external and internal.

During the interviews, I discovered the concept of scientific "evidence" as more relative than I used to think: the amount of evidence necessary seems to change if we talk about exercise, nutrition, radiations, or water poisoning as "causes" of cancer. Sometimes I asked questions concerning this specific and contested thematic area.

Often I asked scientists what they considered to be a risk factor, and why; if they perceived stress as a "cause" or a co-factor of cancer and assessment of class and race issues. When discussing of exposure to carcinogens, bio-behavioral features, and habits/lifestyles I questioned the scientists how those factors could be related to class, race and gender issues. Some of them made the connection without my intervention.

At the end of each interview I asked the scientists how they perceive cancer activism, and the activists what they think about the scientists, because I was curious and wanted to mirror their reciprocal representations.⁹²

Besides the common questions on etiology, prevention, risk and the role of profit, I asked the activists about their roots, and their opinions about what the roots of the cancer movement are. Why was this recent phenomenon started by women? Why are lesbians such a strong component in women's cancer action group? Who is considered an ally by the cancer activists and who the enemy? Which are the division and the contradictions on the horizon of the movement?

I noticed during the interview that activists tend to slip to the final set of questions, quickly connecting causes of cancer with economics and social relations. I decided the interview didn't need

⁹² The results of this part - as well as other minor parts - are not included in the dissertation since they do not fit in the economy of this work. Even though this data present interesting aspects, it is peripheral in respect to the main body of the research.

to strictly follow a sequence, as long as the four topical areas were properly covered and answers were provided to the main research questions.

With scientists I met the opposite problem: at times it was necessary to add a supplement of explanation for the questions relating cancer to "social factors." However, most scientists -- with substantive differences in degrees and motivations -- perceived profit as an obstacle in cancer primary prevention.

The most "conservative"⁹³ scientists -- those oriented toward genetic and behavioral explanations of cancer etiology -- saw the connection between cancer and the profit system as limited to the interests of the tobacco industry. On the other side, the scientists who believe cancer is mostly caused by environmental factors were more likely to critique the whole "cancer industry," and see the profits of the powerful corporate polluters -- such as the chemical industry -- and the pharmaceutical industry.

Some scientists, optimistically, envisioned profit as an incentive for cleaning up the environment and for eliminating several causes of cancer -- in a context of ethical business, socially changed relationship of production, and increased state responsibility over health and environmental surveillance. We are going to discuss these issues in the last chapter.

2.7. A Retrospective Look at Data and Process

During my field trip I collected fliers, books, articles, and tapes with interviews. In trying to coordinate my actions on the materials I knew that the ways in which I was organizing my files would affect the configuration of the dissertation itself.

⁹³ Here I am using the term "conservative" with a high degree of imprecision to characterize those scientists who call for individually oriented prevention policies - smoke quitting, changes in nutrition and other "lifestyle" intervention focussed on behavior modification.

Organizing the material is a creative process in itself, where the researcher decides priorities, connects issues, gets rid of a lot of padding. About the latter: many things that seemed to me of great importance at the beginning of the research became useless by the time I was finished. At first this matter made me think that my early account of priorities in selecting the material I wasn't judicious enough or that I made some mistakes in the choice of criteria. Later on I realized that the field research has been not just a way to collect first hand data, but also a learning process that changed in part my perspective and my representations of the problems I was investigating. If I had chosen to write my dissertation in a library I would have probably felt less ambivalence and contradictions.

During the process of ordering the material, some reflections emerged -- and I felt the urge to write them down. In my previous dissertation -- although I presented the methodology chapter at the beginning -- it was the last one I wrote. In so doing I lost some memories of the passages that take research from one step to another. This time, the freshness of such memories -- besides re-creating some atmosphere -- was kept in my personal journal.

I made a few decisions at the very beginning of the research about the configuration of the research itself. One was that of not doing a purely theoretical work. I wanted my doctoral dissertation *located at the interface of theory and praxis*. Moreover, I wanted my research to have subjects -- social actors to be captured in a specific moment of a transformational process. I chose to approach these subjects using the method *par excellence* of qualitative sociology: the interview.

I travelled across the country, and for the first time since I had been here, I engaged with my host culture as a researcher. I entered a part of the American culture through different sub-cultures and from a dual perspective: the one of American scientists and the one of American activists.

I should mention here that the research trip had a quite anthropological *gusto*. The aesthetics of my research -- travelling

across an unknown country on a Greyhound bus -- was making me feel more like an anthropologist adventuring in the jungle. Looking retrospectively at the iconology of the research trip -- after a few weeks on the road my image was quite distant from the one of some unruffled sociologists.

I prepared my sets of questions on the basis of secondary sources: books and articles on etiology and primary prevention of cancer, with special attention to the scientific literature produced in recent years.⁹⁴ My immediate goal was to "produce" a debate among different and objectively opposed theories of cancer causation and prevention.

When I started to get acquainted with the scientific literature - - which I found at times esoteric -- I didn't have a specific hypothesis about the outcomes, and I was curious to explore some territories that weren't considered yet: the sociologically unknown, the yet-untold of cancer research.

Several studies had been produced on the AIDS arena, its actors, their claims and goals. We do not have corresponding studies when it comes to cancer. Furthermore I should point out that I didn't find much sociological analysis on cancer made by sociologists. Some sociological analysis was provided by health scientists and epidemiologists -- which only partially fill the gap. In our discipline there are no studies on the cancer arena and its actors that can be compared to those produced to analyze the AIDS arena.

⁹⁴ From now on, I am going to refer to primary prevention simply as prevention - not just for brevity, but also because I got to the conclusion that calling early detection and rehabilitation respectively secondary and tertiary "prevention" is misleading. I will discuss this point at the beginning of the chapter on primary prevention.

The sociological studies I reviewed tend to focus on specific aspects, such as women cancer support groups, the emerging breast cancer activism.⁹⁵

I was interested in describing a wider context, in including different social actors and in comparing their perspectives, in an early stage -- what Italian sociologist Alberoni named, in a Latin expression *statu nascenti*, a condition in rapid development, already containing *in nuce* (deeply embodying) all the contradictions and potentiality. Like a sprout, a situation captured in its *statu nascenti* displays its maximum degree of vitality.

I was interested in what activists have to say, their desires and critiques, which kind of knowledge they want. I also wanted to investigate what scientists take for granted and why -- their relative unquestioning the directions of cancer research, the lack of self-reflection about the ways in which cancer research is produced through their job.

During the reading phase I had developed the belief in the necessity of finding a new kind of data: the data I needed didn't exist either in theoretical or in empirical studies. The desire of creating such a set of data was the main motivation to undertake the field research.

I began thinking in terms of symptoms -- as Lacan taught me. Following the constituting principle of grounded theory, I tried to enter the field with few preconceived notions about what would be found later. This is one of the reasons I preferred first to read studies about the etiology of cancer -- and get my own take on them -- and then read the critiques of such studies made by activists and other social actors, and the small amount of non-scientific literature that has been produced on this topic.

In the process I developed my own positions. By reading many studies that have been carried out on cancer etiology I realized, for

⁹⁵ There are practical works made by sociologists devoted to very specific topics, such as the effectiveness of anti-cigarette smoking campaigns and diet/behavior modification.

example, that they were overwhelmingly focused on genetics and behavior, to the detriment of environmental factors. But my positions about the specific weight of each etiological factor changed over time, as well as my perspective on single controversial issues. And changed again during the writing process, in light of re-elaboration of old materials and analysis of new ones: my intention has been consistently the one of letting the theory emerge from the empirical research.

I made the effort to meet interviewees with as little bias as possible. This happened to a large extent, even with persons who were situated far from my ethical values and political beliefs.

During the research I recorded several dilemmas I faced in gaining access -- to the scientists more than to the activists. I also attempted/wanted to look at the interview as a relationship, at its setting, and to record other observations emerging from the interview. I tried to keep a journal, though keeping a journal wasn't always feasible, but I collected some of those post-interview-notes and sometimes I used them in my chapters. Although not systematic, they give the flavor of the environments in which the research took place, the different strategies I used for constructing dialogue and creating contacts.

I recorded and transcribed all the interviews. Listening to the tapes I realized that sometimes the interviews became discussions in which I forced the subject to be consistent with their positions and to push forward the analysis of what they were saying, explaining their reasons and defending their positions. This Socratean *maieutica* process was necessary in order to get beyond what the scientists wrote in their scientific papers (too neutral) and beyond what the activists wrote on their flyers (too agitation-oriented). From my subjects I wanted their *doxa* -- their opinion. And when they didn't seem to have a strong one, I stimulated their reflections on the topic and facilitated the emergence of a position -- of which the subject was often unaware. I have not been a passive listener; at times I

questioned answers (also those I agreed with) in order to get deeper responses.

During the transcription of the interviews I realized they gave me more information than I wanted to gather. I made very few mistakes: in a couple of cases I forgot to ask one of the sub-questions -- but I always covered the 4 thematic areas, even when the order of the questions was changed by the flow of the conversation.

When people -- both scientists and activists -- talk to me, they are aware that I am not a US citizen, and they talk to me as a foreigner, they explain things to me, they are conscious about saying "here in the US" most of the time -- and not just "here in Arizona" when giving me their answers.

They usually contextualized what they said, since they cannot take for granted things that they could have with a local interviewer. Especially scientists tended to adopt a more international view on the issue than I suspect they would have done with a non foreign person. Often they asked me questions about research and facts in Europe or in Italy.

When I asked them to rank the 5 main causes of cancer, most of them didn't ask me "where" -- when they did, I answered they should focus on the US situation and their perception of it. When they left out of the list important factors -- like sun rays, as it happened in most of the cases -- I mentioned them at the end of their answer to get their position.

In transcribing I realized that more unplanned questions emerged from me during the interviews, while the research was progressing. My positions also shifted when I obtained more insights and sharper definitions. At the end I was more focused and careful than at the beginning. Yet I was tired, and in the last few tapes I recognized impatience in my voice -- even though I wasn't aware of it during the interaction.

After I finished the interviews' transcriptions -- with some help from other students -- I started to organize and analyze the enormous amount of material produced. I had to switch perspective

from the inside to the outside, in order to be able to produce a retrospective look on the research as a whole. My first object of methodological analysis was the relations between observer and observed, subjects and objects, insiders and outsiders.

Overall, if I look retrospectively to the whole research project, I see that I collected more data than I needed, often following intuitions and parallel paths. Even though I am not going to use most of the material and information for my analysis, having explored more of the context of my research gave me a better vision of my specific field of study and its connections with other issues.

Conclusion

This research provided the data I needed for my dissertation and much more. It achieved the result to stimulate interest, conversations and concerns about the issues I was raising. In other words, it wasn't a mere process of production of knowledge, it became a factor of change: some of my interviewees connected with each other because of my research, relationships developed. I was aware from the beginning that this might have happened, but I didn't know to what extent. But I was right to suspect that I would not have had much control over the processes that I was priming.

From the perspective of the Sociology of Organization, I should say that I have not been a simple user of what they define "pre-established structures". Un(and)intentionally, I contributed in making more complex the relations among the social actors involved in the cancer arena. Sometimes my work created connections in the scientists' and in the activists' network, new bridges between the two communities. A few of the actors involved reached me after the research was completed to express appreciation.

From this point of view, the project may be qualified as a research-intervention. A posteriori I may say that the old separation between knowledge and action -- lamented by Nietzsche in his "Birth of Tragedy" -- has been small. When I started writing on the cancer

movement as it is today, it was an embryo, little more than an intuition.

The production of the kind of knowledge I was looking for, necessarily implied some qualitative changes in the geography of the debate and in the consciousness of the actors. I realized I forced 60 relevant actors -- thorough the interview process -- to question themselves and their work around my set of issues.

The issues I focused on were chosen on the basis of my assessment of social relevance. Such a choice clearly reflect my professional background as a sociologist and my political interests.

As Goffman suggested, I looked at the cancer arena as a theater, with different actors involved. I looked at their different roles and their performance. I requested from all scientists a curriculum vitae and asked questions about how they got involved in cancer research.

At first I listened to cancer activists as to "voices out of the scene" -- somewhat indistinguishable, like echoes reverberating from the walls surrounding the official "scientific" debate.

During the trip across the country I realized that there were more interactions between activists and scientists than I expected -- both at the material and at the symbolic level. And that scientists and activists were quite conscious of the effects of their actions and words on the other side of the fence.

I became especially aware of the cooperation between some scientists and the cancer movement. Parallel to the disclosure of differences in the scientists' attitudes and expectations toward cancer activists -- the range including those who -- off record -- perceived activists as "hysterical women" and those who welcomed or even requested their involvement and perspectives.

I became more judicious also in discerning differences among the activists, instead of focussing only on the commonalties and at unifying factors. I wanted to include diversity and contradictions as a positive quality, since the arena I was looking at wasn't exactly homogeneous, I made the choice to respect cancer activism's

polymorphous and polyphonous character, by zooming on the activists' diverse backgrounds, their priorities and focus, their complementary and conflicting goals.

Chapter 3

THE GENETIC PARADIGM

3.1. Introduction.

In this chapter I am going to introduce the scientific debate over cancer etiology by looking at different theories of cancer causation competing today. The dominant scientific paradigm has a double focus on genetic predisposition and individual behaviors. In this chapter I will concentrate the reader's attention on the debate over genetics, while I will discuss environmental factors, lifestyle, and risky behaviors in chapter 4.

After some preliminary notations in section 3.2. on cancer definitions and on cancer etiology research, and a brief history of the virology paradigm in section 3.3., I will analyze the current focus of cancer genetic research in the frame of the Human Genome Project,⁹⁶ which constitutes the core of the genetic paradigm -- in section 3.4..

Even though I will write in the context of cancer genetics, I want to acknowledge that the genetic paradigm heavily affects scientific research in general, from cardiovascular diseases to -- increasingly -- issues traditionally under the dominion of social sciences.

In section 3.5. I will analyze the positions expressed by scientists about the role of genetics in cancer etiology. The scientists interviewed can be grouped in three areas. In the first sub-section I will present the perspective of those scientists who believe genetics is a main factor. They focus on individual predisposition. In the second sub-section I will present the arguments of those scientists who are more prone to give genetics a low rank in cancer etiology. They focus on "what triggers the gene."

⁹⁶ B. Katz-Rothman, "Of Maps and Imaginations: Sociology Confronts the Genome," *Social Problems*, Vol. 42, N. 1, February 1995, pp. 1-10.

In this section I will also analyze "hybrid" statements of scientists who tend to locate themselves in between the two paradigms. On the "fence," these scientists seem to express the need of a more dialectical approach between genetics and environment, and they offer materials for epistemological considerations on separation between genetics and the environment.

In section 3.6. I will discuss what activists said about genetics and cancer etiology. Overall, activists tend to disregard the role of genetics in cancer causation, and to connect genetics with environmental causes of cancer. Some of the activists consider the current focus on genetics as part of the "blame the victim" attitude of the scientists -- another expression of individual-oriented scientific practices. Each section contains the framework or context for the current debate.

3.2. Preliminary Notations

Before introducing the debate on cancer etiology some preliminary remarks about the definition of cancer may be useful.

Cancer was a known disease also in the ancient world. What we know in the western world about cancer in the ancient era is mostly related to the discoveries made in Athens, Rome and Alexandria of Egypt. The word cancer -- which means "crab" in Latin -- was invented by Hippocrates (460-370 B.C.) who observed how cancer tends to infiltrate neighboring tissues departing from a center. He believed that not all cancers should be removed.

Few hundreds years later, Galen (130-200 A.C.) produced a theory in which cancer was initiated by an excess of black bile -- and should be removed. His theory dominated for more than 1,000 years. It was only in the eighteenth century that people started talking about environmental carcinogens, thanks to the research produced in London by Percival Pott (1714-1788) on young chimney sweeps and cancer of the scrotum. During the first half of the 1900s research on tobacco as a carcinogen was already produced.

Among scientists, even the definition of cancer has been a subject of disagreement. Among those who think cancer is a group of diseases and we should speak about them separately -- there is the American Cancer Society. By ACS, cancer is defined as

a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. Many cancers can be cured if detected and treated promptly. Many others can be prevented by lifestyle changes especially avoidance of tobacco.⁹⁷

Interestingly enough, in the same paragraph ACS advocates looking at different cancers as if they were different illnesses, and mentions tobacco -- the cause of lung cancer -- as if it were a cause of all cancers. Their definition of cancer is challenged by those scientists who believe cancer is one illness and cannot be prevented just by avoidance of tobacco.

Cancer is a single disease because every malignant cell breaks the same rules of normal cellular behavior and, as we shall see, shares certain other traits with every other malignant cell.⁹⁸

If we analyze the *mare magnum* of recent studies in the field of cancer etiology (causation), we can recognize several approaches referring to different overall theories. Moreover we will notice that causes are conceptualized in different ways among specialists -- and the category "factors associated with cancer" is far more utilized than the the term "causes of cancer." For simplicity, in this work I will refer to causes when proofs of carcinogenicity have been produced -- in animal lab testing or in epidemiological studies *a posteriori*. I will refer to associated factors when evidence of causal relations are controversial or trials are in progress.

⁹⁷ American Cancer Society, *Cancer Facts and Figures - 1992*, Atlanta, p. 1.

⁹⁸ G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994.

While preparing for this research, I constructed a classification of the most recent scientific findings on cancer etiology.⁹⁹ I grouped the studies I was reviewing under the following headings:

- a. diet/nutrition, physical fitness and exercise;
- b. tobacco (smoking, passive smoking, chewing, and snuffing) and alcohol consumption;
- c. exposure to chemical and physical carcinogens (electromagnetic and nuclear);
- d. genetic and para-genetic factors;
- e. viral agents, "precursor" illnesses, premalignant lesions;
- f. transplants, surgeries, and medical therapies (e.g., hormones and the birth control pill);
- g. stress and other psycho-social factors;
- h. mixed etiologies (multifactorial etiology);

The analysis of the studies I reviewed would constitute a dissertation by itself. It would be interesting to work on these studies in order to:

1. juxtapose different studies and different results by cancer site, by carcinogenic factor, by ethnic group etc.
2. translate the scientific jargon and explain the technicalities in simple language.¹⁰⁰

⁹⁹ Most of the bibliographical material is obtained from:

- searches on Medline, conducted with the assistance of University of California Santa Cruz librarians Jacqueline Marie (Women's Studies Librarian) and Michael Fineman (Science Library);
- searches on the Canadian Center for Occupational Health and Safety Database (at the National Institute for Occupational Safety and Health, Berkeley);
- searches at local Divisions of Occupational and Environmental Health, Environmental Protection Agency;
- searches at University of California, San Francisco, Medical Library.

¹⁰⁰ This work does not fit into the economy of the dissertation. I intend to use my notes later on, and write an appendix *in coda* for the specific purpose of making these studies accessible to cancer activists.

Looking at the studies produced in the last 5 years, despite the complexity of cancer etiology, we can recognize a *continuum* among two groups of scientists, having two poles:

- a. those who are oriented to study causes of cancer that can be ascribed to the individual -- his/her behavior, his/her genetic makeup
- b. those who are oriented to study causes of cancer that can be ascribed to factors that elude the individual control -- mainly physical and chemical carcinogens.

While it is largely agreed that cancer begins when one of the 100 trillion cells in our body stops obeying the rules that govern normal cell behavior -- there is little agreement about what triggers this one cell to become "defective," which factors should be prioritized in the research, how much do "transcription errors" account for.

The disagreements among scientists concerns three main areas:

the role of genetics;
 the role of environment;
 the role of behaviors/lifestyle.

As we will analyze, on the basis of different work priorities and etiological orientations, cancer scientists can be grouped to distinguish those who advocate for individual-oriented policies as primary prevention, and those who advocate for social and environmental policies.

3.3. The Genetic Paradigm's ancestor: the Virology Paradigm

Less than a quarter century ago viruses, not genes, were thought to be responsible for cancer.¹⁰¹ Then the viral theory of

¹⁰¹ And before viruses, the "germ theory" was the predominant in the scientific medicine, as explained in H.S. Berliner, J.W. Salmon, "The Holistic

cancer 'evolved' into the oncogene theory of cancer. The oncogene theory of cancer initiation is the dominant one today. The initiating event is seen in the alteration of a gene in a chromosome within the nucleus of a normal cell.

Most molecular biologists today are convinced that cancer occurrence is the result of alterations of DNA, but until the late '1960s the virology paradigm was still the dominant one. Hundreds of millions of dollars were spent on the search for "hidden viruses" in humans with no success. In the late sixties the paradigm was in crisis, but two virologists at NCI proposed a new version, which gave origin to the "oncogene" theory.

Instead of abandoning the viral theory, the theory was dramatically altered. "It is not viruses within the genes that are the cause of cancer, said the experts, it is the genes themselves." The oncogene theory proposes that responsibility for cancer depends not on hidden viruses in genes but on about twenty specific genes called *proto-oncogenes*. (...) Proto-oncogenes are supposed to be normal parent forms of oncogenes. They have functions within cells, as do all genes, and do not cause cancer. However, when mutated, proto-oncogenes are believed to malfunction and become oncogenes that can cause cells to become malignant.¹⁰²

Needless to say, the oncogene theory has been supported by virologists, who still control a large part of cancer research, regardless of the fact that very few cancers have been proved to be related to viruses -- most scientists say less than 5%.

Even in the case of Papilloma Virus "associated with" cervical cancer, recent investigations have put under discussion the believed causality by demonstrating that more then 50% of U.S. women have Papilloma virus, but such 'latency' doesn't seem to produce any cervical cancer.

Health Movement and Scientific Medicine: The Naked and the Dead," in *Socialist Review*, Vol. 9, N. 43, January-February 1979, pp. 31-52.

¹⁰² G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994, p. 19.

If the virus *per se* is not the cause of cervical cancer, we may have two hypotheses. One is that another factor may be triggering the action of the virus -- if the virus is really responsible for causing the cancerous lesion. The other one is that a depression of the immune system might increase its virulence and decrease the body's capacity for defense. These two hypotheses are not competitive. Both take us far from a virological approach and stimulate a question: which factors trigger the virus -- or depress the immune system? The answer is offered by the new paradigm, which looks at personal genetic susceptibility to carcinogens, rather than to carcinogens exposure and its effects on DNA and on the immune system.

3.4. The Genetic Paradigm and the Human Genome Project

Here I will use the term "genetic paradigm" to refer to the dominant scientific mindset in cancer research. It includes much more than genetic priorities. As any scientific paradigm, it produces an ideology to reproduce itself. Its supporters represent a well established bloc, a complex alliance between molecular biologists, virologists, radiologists, and surgeons.

The genetic paradigm in cancer etiology has corollaries in cancer detection, treatment and rehabilitation. Being the "core" of the scientific tendency that looks at the micro, at the infinitesimal, the genetic paradigm condenses many of the issues and problems related to the detachment of scientists from social issues.

As sociologist Patricia Flynn pointed out, molecular geneticists are those who epitomize what is called a "reductionist approach". Their job is to examine a single gene, or a single chemical. What is left out is that a living organism is more than its genetic information. It is the unique consequence of a developmental history resulting

from the interaction of internal and external forces, of heredity and environment.¹⁰³

The dominance of a genetic paradigm in cancer research can be understood in light of the supremacy genetics is gaining in other medical and non-medical fields. From the remotest place in terms of social relationships, genetics -- a scientific practice -- becomes a way to look at society.

The postulates of contemporary genetics-related theories in the social sciences can be found in the socio-biology of J. Watson. He argued that the "ultimate answers" to many "social problems" individual and collective behaviors, are to be found in our DNA.

When finally interpreted, the genetic messages encoded within our DNA molecules will provide the ultimate answers to the chemical underpinnings of human existence.¹⁰⁴

The dangers ascribed to this way of thinking about social issues is criticized by authors such as Abby Lippman, who warned against that "process by which differences between individuals are reduced to their DNA codes"¹⁰⁵ and suggested how -- besides the genetic paradigm -- a process of 'geneticization' of social issues is taking over in the public debate.

Looking for genetic and biological causes of social problems places those problems beyond the reach of collective social and political action. Theoretically, the genetic paradigm tends to locate the source of problems in "human nature," but empirically the research tends to look at these problems as being embedded in the

¹⁰³ P.A. Flynn, "The Human Genome Project," *Society for the Study of Social Problems Newsletter*, Vol. 24, N. 3, Fall 1993, pp. 4-8.

¹⁰⁴ J. Watson, "The Human Genome Project: Past, Present, and Future," *Science* Vol. 4951, N. 248, April 1990, pp. 44-49.

¹⁰⁵ A. Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities," *American Journal of Law and Medicine*, N. 17, 1991, pp. 15-50.

genes of particular social groups, such as Jews, Gipsies, Blacks, and sexual minorities.¹⁰⁶

Today, one of the most significant cultural operations in terms of legitimation and cohesion -- in and outside of the scientific community -- is the Human Genome Project.

In the past few years, scientists launched a fifteen- year biological investigation to map, sequence, and determine the functions of the distinct genes found in the cells of each of us and which comprise the human genome. The purpose of the genome project is to map a territory discovered in 1865, when Gregor Mendel first described hereditary 'elements.' Many claims are made about this effort. It is said that the information from the project will change the ways medicine is practiced, the ways science is performed, and will even change the ways we think about ourselves. The concept of the project developed from then chancellor of UCSC, Robert Sinsheimer's wish to put Santa Cruz on the map with a big science project -- 'biology's moon shot.' (...) From an initial reluctance on the part of scientists to endorse such a move, to the point where most scientists jumped on the bandwagon was a swift course.¹⁰⁷

Up to the present time, the Human Genome Project has been in the midst of several controversies, one of which led to the resignation of the head of the project, the Nobel laureate James Watson in April, 1993.

Reports of his leaving revolved around patent disputes with then head of NIH Bernardine Healy and conflict of interest questions about his owning genetic corporation stocks.¹⁰⁸

Others disputes concerning the Human Genome Project were more focused on issues that involve the shift in direction of scientific

¹⁰⁶ S.J. Rosenthal, "Biological Determinism, Public Policy, and the Rise of Fascism" paper presented at the Annual Meeting of Society for the Study of Social Problems, Los Angeles, August 1994; R. Hubbard, E. Wald, *Exploding the Gene Myth*, Boston, 1993; R. Lewontin, R. Steven, L. Kamin, *Not In Our Genes, Biology, Ideology and Human Nature*, Pantheon Books, New York, 1984.

¹⁰⁷ P.A. Flynn, "The Human Genome Project," *Society for the Study of Social Problems Newsletter*, Vol. 24, N. 3, Fall 1993, pp. 4-8.

¹⁰⁸ *Ibidem*.

research -- from scientists to politicians -- and many were concerned that

... in mapping and sequencing the 50,000 or 100,000 genes in the 3 billion base pairs in the genome, perhaps 95% of this material is nongenic, and some object to spending time analyzing this 'junk.'¹⁰⁹

The costs/benefits evaluation and the problems produced by a huge investment in genetic research is often mentioned by activists and scientist/activists. One of my interviewees -- who offers an insider perspective in terms of genetic research is the molecular biologist Prof. Richard Strohman at the Department of Molecular and Cell Biology at U.C. Berkeley. He stated that, up to the present, genetics accounts only for the 2% of cancer and cardiovascular diseases [see Appendix 3].

If genetic research doesn't explain the causes of cancer, why is most of the cancer money devoted to basic genetic research? What does cancer research specifically have to do with an effort such as the Human Genome Project?¹¹⁰

Genetic research is advertised through mass-media as the big hope for cancer cure -- and even for prevention. The Human Genome Project represents the theoretical and empirical frame affecting the methods and the aims of etiological research for the most important illnesses -- ranging from heart diseases to reproductive problems.

The result of the Human Genome Project would be the generation of a systematic body of scientific knowledge through a complete "genetic mapping." What is a genetic mapping? It is

¹⁰⁹ Ibidem.

¹¹⁰ The public legitimization of genetic cancer research will be analyzed with other areas of legitimization and social control. Interestingly, the Human Genome Project has recently co-sponsored a conference on genetic factors in crime, focussed on addressing a plan for youth violence prevention. From the 'violence prone individual' to the 'hyper-aggressive and hyper-sexual' inner city children.

the process of assigning genes to specific chromosomes. Genetic linkage maps determine where one genetic locus is relative to another on the basis of how often they are inherited together. A genetic locus is an identifiable marker on a chromosome, the presence of which indicates that a specific trait -- eye color or blood type -- will be expressed by the gene. (...) A map of the genomes tells you where genes are located, but does not disclose their function.¹¹¹

Despite this explicit limit in the aims of the Human Genome Project, recently genetic research has obtained mass-media coverage as a possible solution for a number of diseases -- such as cancer. In a panorama of a general enthusiasm, *The Washington Post Health Supplement* published April 19, 1994, takes a relatively critical stand toward genetic research. In the opening article, Rick Weiss explains in plain terms what it means that all cancers have a genetic component, and how this doesn't mean that most cancers are inherited.

Indeed most cancers are caused by genetic mutations that occur after birth. In breast cancer, for example, the vast majority of tumors are caused by an accumulation of genetic glitches acquired throughout a woman's life -- perhaps from damaging compounds in the environment or the diet. Only 5 to 10 percent of all cases are the result of a mutant gene passed from parent to child at conception.¹¹²

The author recognizes that "despite their proportionately small numbers, these hereditary breast cancers have attracted immense attention from both researchers and patients" the goal is being able to "identify which one of the 50,000 to 100,000 human genes causes hereditary breast cancer when mutated" and to test children or even fetuses.

¹¹¹ P.A. Flynn, "The Human Genome Project," *Society for the Study of Social Problems Newsletter*, Vol. 24, N. 3, Fall 1993, pp. 4-8.

¹¹² R. Weiss, "Scientists Track a Familial Gene for Breast Cancer," *The Washington Post Health Supplement*, April 19, 1994, p. 3.

Once the scientists have found the gene -- and the discovery has been said to be just weeks away for a while, Weiss argues -- they would have to prove that the cancer gene has something to do with the rest of 90-95% of cancers, which are not explained by hereditary causes.

Then -- if the goal is screening the population for the gene -- which sounds like a great business -- there will be serious ethical dilemmas: "Will some women choose to abort their BRCA1-positive fetuses even though breast cancer might never arise in the child -- or might arise and be treated successfully? Will adults who harbor the gene be denied health insurance or be otherwise discriminated against?" The list of possible undesired outcomes could be longer -- including prophylactic mastectomy. In the global context of environmental crisis and limited resources, will poor people who carry the "wrong" genetic makeup be allowed to reproduce -- if the cost-benefit analysts will find out that "it is not worth it"?

The whole project is based on the assumption the the HGP is "morally justified and that the medical applications resulting from this research will constitute social goods. [As the report on *The First Five Years*, p.20 posits] 'The plan to map and sequence the entire human genome is *predicated* on the belief that mankind will benefit immensely from attendant advances in medicine, biological research, and biotechnology. The ability to screen for diseases, but not to treat them raises interesting issues for sociologists. Troy Duster recounts how identifying the sickle cell gene placed undue burdens upon the African American children so identified and stigmatized. Would identifying those with any number of aberrant genes also stigmatize without helping?¹¹³

Besides these ethical issues, many scientists consider the prospect of re-manipulating the onco-gene as very far off -- if not impossible. Despite the unlikelihood of any useful scientific discovery, enormous costs involved in basic genetic research are sustained.

¹¹³ Ibidem.

Even NIH director, molecular biologist Harold Varmus, denounced these experiments are going too far.

It's not an¹ accessible problem, and it is not the sort of thing scientists can afford to do.¹¹⁴

The Institute of Medicine, at the Academy of Sciences, issued a report on "Assessing Genetic Risks: Implications for Health and Social Policy" in 1993. As the report points out, the more genes are identified, the more "there is a growing pressure to broaden the existing screening programs and otherwise increase both the number of available genetic tests and the volume of genetic information they generate."

The report also notes that only one in 200 women inherits a defective gene. Yet, Don Hadley, genetic counselor at the HGP in Bethesda predicts that a genetic test will be identified within 1995 and announced that it might be commercially available within two years.¹¹⁵ This operation-testing will probably be very profitable for those who will be able to market it. Hopefully it will open the debate on the social utility of "large scale testing, when genetic susceptibility accounts for such a small proportion of common diseases."¹¹⁶

3.5. "Technical Problems" in Oncogene Research. Dermer's Critique.

Some scientists consider the oncogene theory -- after the bankruptcy of the virology theory -- as another failure. One strong argument is that human oncogenes do not transform true normal cells, which have a normal set of chromosomes:

¹¹⁴ N. Angier, *Natural Obsessions: The Search for Oncogenes*, Houghton Mifflin, Boston, 1988.

¹¹⁵ A. Hott, "Can Genetic Testing Help Prevent Illness?" *American Medical News*, August, Vol. 37, N. 22-29, August, 1994.

¹¹⁶ Ibidem.

... there is absolutely no evidence from observations of human tumors to indicate that the mutation of any proto-oncogene is essential for cancer initiation. In fact, in many tumors, all supposed proto-oncogenes are normal; there are no oncogenes present.¹¹⁷

In his critical work, cancer scientist geneticist and a cell biologist Gerald B. Dermer showed how many predictions based on the oncogene theory of cancer initiation failed to be upheld by empirical evidence. He pointed out that there are some mutations in the so-called proto-oncogenes and increases in the amount of their proteins within cells that *might be true in the lab but are not required in the human disease*.

Dermer explained that oncogene theory of cancer initiation began by proposing that twenty normal genes, the proto-oncogenes, were responsible for cancer. One mutation of one proto-oncogene within one cell was believed to be enough to cause the cell to become malignant. Since mutated proto-oncogenes couldn't be found in real tumors, a new concept called "anti-oncogene" was promptly invented and introduced in the scientific labor process -- in order to correct the oncogene theory. In other words, instead of questioning the theory in light of empirical evidence, an additional theory is created to support a theory that failed its testing. It was so stated that

if mutated proto-oncogenes cannot be found in tumors, then perhaps there are mutated anti-oncogenes that act in a manner opposite to oncogenes.¹¹⁸

How was this second theory tested? It wasn't tested by inserting the suppressor genes on a real tumor and watching for changes. Instead of using real tumor cells the scientists used manipulated models of cancers called "cell lines," which have the features of being unstable and undifferentiated.

¹¹⁷ Ibidem, p. 71.

¹¹⁸ Ibidem, p. 74.

As I am going to present, there are many doubts that artificially reproduced cell lines are scientifically reliable. This reason led Dermer to introduce an alternative theory, based on the 'revolutionary' concept that -- if mutations are actually irrelevant to cancer initiation (as the research on real tumors suggests) -- it might even be that mutations are *the results* of cancer rather than its cause. This would change the whole perspective on cancer initiation and on the role of physical and chemical elements.

Dermer's hypothesis might be right or wrong. What is relevant to us is his critique of the procedures implemented in the search for oncogenes -- and the explicitness he is using in disclosing important matters, which get hidden or mentioned with embarrassment in professional meetings.

I have identified theoretical knots surrounding the technical ways in which hypotheses are tested as important in the debate and in the development of a critique of cancer genetic research. I will be devoting to this issue a large part of the following sub-section, which necessarily contains some technical elements. Parts of the sources are organized in appendices.

Molecular biologists seem to avoid discussing that the procedures for transferring genetic materials produce mutations of genes. In fact,

researchers can never be sure if the gene with which they began an experiment is the same once it gets inside the recipient cells.¹¹⁹

F.M. Burnet, in his account of genetic cancer research at the beginning of the seventies was already posing most of the problematics that the critics of genetic research are embracing today. In *Genes, Dreams and Reality*, Burnet wonders:

¹¹⁹ Ibidem, pp. 70-71.

Why has the outcome of sixty years of work by many first rate scientists and at a cost of hundreds of millions of dollars had so insignificant an influence on the prevention or treatment of cancer?¹²⁰

His question remained unanswered. More hundreds of millions of dollars have been poured into genetic research, with almost no results except for rare forms of childhood hereditary cancers. In the following fifteen years, the field of genetic cancer research -- despite its glamour -- has accumulated many critics. J.C. Bailar and E.M. Smith, in their critical essay "Progress Against Cancer?" ask an important question:

Why is cancer the only major cause of death for which age-adjusted mortality rates are still increasing?¹²¹

Some of reason why genetic research on cancer is criticized as being unsatisfactory if not inconclusive may be seen in important 'technical' aspects of the lab research process, which are almost unknown among the non-specialists.

Why is genetic cancer research based on "cell lines" -- manipulated models that are very different from real tumor cells? The reason has to be ascribed to the taylorization of the scientific division of labor, which systematically produces a deficiency of communal knowledge between the field of pathology and cancer research -- instead of increasing the mutual understanding.

The separation between cancer pathologists and cancer researchers -- between praxis and theory -- has determined the precondition for the creation and use of specific kinds of technology -- which are proved unable to provide reliable tools to investigate genetic factors in cancer etiology.

¹²⁰ F.M. Burnet, *Genes, Dreams and Reality*, New York, Basic Books, 1971, p. 132.

¹²¹ J.C. Bailar, E.M. Smith, "Progress Against Cancer?" in *New England Journal of Medicine*, N. 314, 1986, pp. 1226-1232.

There is little communication between surgical pathologists (who know a great deal about human cancer) and cancer researchers (who do not). The two groups undergo different training, use different technical jargon, usually work in different buildings, attend different meetings, and read different journals. The two sides of the cancer coin -- clinical and research -- exist in almost complete isolation from each other.¹²²

Pathologists and oncologists refer to the journal *Cancer*, where ACS publishes the results of observations on real tumors. Cancer researchers refer to the journal *Cancer Research*, which publishes mostly results of experiments on cell lines:

Given the widely divergent models of cancer that are studied in the research papers featured in *Cancer* and *Cancer Research*, it is not surprising that the pictures they present of cancer are equally divergent.¹²³

Cancer researchers who work on models do not have any familiarity with the 'real thing': "we have rarely seen a real human tumor"¹²⁴ one of them admitted during a President's Cancer Panel Meeting.

Many scientists who support the genetic paradigm are radiologists and virologists -- the latter still holding positions of power in the cancer research establishment by the law of inertia. The core of genetic research is represented by molecular biologists -- who study the molecules within cells -- but most of them focus only on one kind of molecule, the nucleic acids, which form the genes.¹²⁵

¹²² G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994, pp. 43-44.

¹²³ Ibidem p. 44.

¹²⁴ Cited in *Transcript of Proceedings of President's Cancer Panel Meeting*, December 7, 1990, NCI Silver Spring, MD, p. 90.

¹²⁵ In other words, molecular biology is becoming *de facto* a branch of genetics - specifically, molecular genetics - instead of being branch of biology.

By working on artificial cell lines -- instead of using cells from real tumors -- molecular biologists are able to obtain a larger amount of data in a shorter time. Cell lines are "convenient" because they allow the cell to reproduce rapidly -- and they can be duplicated endlessly. The use of cell lines enable cancer researchers to keep up with the pressures in the scientific work about lab productivity and academic competition.

Before considering the critique advanced by Dermer, I am going to answer a few questions. What exactly are cell lines? How are they created? Why are they criticized for being so different from real tumors? Cell lines are cultures of cells derived from animal or human tumors and normal tissues. They can grow forever in small plastic Petri dishes¹²⁶ as long as a fluid called a "culture medium" is provided to nourish the multiplying cells.

Dremer's critique starts with the consideration that cell lines never die -- and no one knows why. This factor changes the nature of cells themselves, which become "immortal" -- they never degenerate nor die, in *vitro* environments.

It therefore follows that cells that will thrive forever under such unnatural conditions must themselves be artificial, an artifact (...) When a cell adapts to permanent life on the bottom of a culture dish, it takes an evolutionary step that enables it to survive and thrive in its new environment. The cell line that results is neither human nor animal. It might just as well be from outer space.¹²⁷

While the scientists of the American Association for Cancer Research believe that the behavior of the cells in their petri dishes is analogous to the behavior of cancer cells in the human body, Dremer argued that this model is not reliable for several reasons.

There are four important issues that make the cell-lines model not appropriate for human tumors: stability, differentiation, initiation

¹²⁶ The name honors Dr. Julius Petri, German bacteriologist.

¹²⁷ G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994, pp. 38-39-41.

and metastasis. I have summarized these four arguments in Appendix 4. Here, in extreme synthesis, I will say that Dermer proves that cell lines are artificial models, since they are -- as opposed to real tumor cells -- unstable, underdeveloped, ageless, and undifferentiated. Cell lines, in the process of their creation, also lose their gender specificity and could belong indifferently to a liver as well as to a breast, while real tumor cells present the important feature of being site-specific.

I want to conclude this section on Dermer's critique of cancer genetic research based on cell line by reporting a significant episode in the context of a national symposium on cancer and genetics I attended in San Francisco in September 1994.

Breast cancer "guru" Dr. Susan Love -- a passionate supporter of genetic research addressed several issues and, in passing wondered about the problematicity of the cancer genetics knowledge being based on research mostly done with artificial models. Scientists in the audience were visibly embarrassed, the few activists were positively surprised, nobody among other panelists nor the public addressed her point.

3.6. What the Scientists Say About the Role of Genetics in Cancer Etiology

In this section am going to analyze the positions expressed by scientists about the role of genetics in cancer etiology. The scientists interviewed can be grouped in three areas. In the first part of this section I will offer the perspective of those scientists who believe genetics is a main factor, and their focus on individual predisposition. In the second part I will present the arguments of those scientists who are more prone to give genetics a low rank in cancer etiology, and their focus on the exogenous elements that trigger the gene.

In the third part I will analyze statements that express the necessity of looking at both factors -- exogenous and endogenous -- with a more dialectical approach between genetics and environment,

since the separation between genetics and the environment is only a disciplinary one.

3.6.1. The Focus on Personal Genetic Susceptibility

Several scientists I interviewed demonstrated a sharp interest in genetic issues and satisfaction about recent findings. These scientists tend to look at the individual factors more than at social and environmental ones. The focus of their discourse is on personal susceptibility to carcinogens, rather than on carcinogens as causes of cancer. Even among epidemiologists -- for whom "personal susceptibility" should not be a concern -- there are several enthusiasts of cancer genetics research who focus their answer on personal variations.

Among them, a high ranking epidemiologist at the American Cancer Society headquarters in Atlanta.

Not everybody's response to a particular level of carcinogens is the same. [Interview N. 50]

This kind of statement is not infrequent and indicates how in much of the scientific community the problem is the individual level of tolerance (of proven carcinogens and other toxic substances suspected to be carcinogens), more than the exposure *per se*.

In a way, it is taken for granted that exposure is "normal" -- just one of the risks we take in our everyday life -- and that nothing can be done about it. The whole thing becomes a matter of adaptation strategies for the communities and genetic screening in the hazardous workplaces to select those who can be exposed more than others.¹²⁸

When such scientists do deal with environmental causes of cancer, often they are prone to think more in terms of *personal*

¹²⁸ E. Draper, *Risky Business. Genetic Testing and Exclusionary Practices in the Hazardous Workplace*, Cambridge University Press, 1991.

susceptibility than in terms of the general impact of a certain substance on a determined population.

A Professor of Toxicology at the University of California at Berkeley, School of Public Health, focussed his discourse on the *individual response* to the exposure; he believes such a response is related to personal genetic characteristics.

I'm particularly interested in why such and such a person is susceptible to getting cancer -- while another person seems not to be. You seem to have this thing where ... you know some people who smoke and drink all their lives, don't get cancer, live to be 100. And other people who smoke and drink very little, but get lung cancer and die at the age of 33. So ... why? What makes people susceptible or ... why are people different. How do people react in their environment to chemicals -- and how chemicals react with people. That's what I'm interested in. [Interview N. 38]

It is precisely the innocent question "why are people different?" under the attack of some critics -- who argue that looking at individual and racial differences produce theories of genetic supremacy -- and the division between those who are "predisposed" and those who are not.¹²⁹

For some scientists, genetic makeup is a pre-condition for cancer to develop. In other terms, if an individual is not "predisposed," he/she can be exposed without (or with less) danger. If the issue is predisposition rather than exposure to dangerous substances, the problem is the person, instead of the chemical. A scientist at the National Cancer Institute in Bethesda -- who asked for strict confidentiality -- took this position:

You have to die of something: some people are just more likely to die of heart diseases, and so forth. For *the others who are genetically predisposed* to have a susceptibility if they were not exposed to the carcinogens they would not develop cancer. Since they are [exposed] , those who are [susceptible], do develop the cancers. There are some subsets that might develop it anyway. But I think there is actually a very small proportion that

¹²⁹ See also T. Duster, *Backdoor to Eugenics*, Routledge, New York, 1990.

would develop the cancer anyway, a very small proportion.
[Interview N. 49]

Often scientists state that the impact of a carcinogen will affect "a small proportion" of the population, in the attempt to minimize the problem. By "small proportion" they are referring to the producers of the goods we all consume: industrial and agricultural workers are those more directly exposed to carcinogens.¹³⁰

Nicholas Petrakis -- Professor Emeritus of Preventive Medicine and Epidemiology at the Dept. of Epidemiology and Biostatistics, University of California San Francisco -- looks at genetic research from an insider's point of view and with pride. He had worked on genetic issues and believes genetics are a first cause of cancer [see Appendix 5]. Still, the reader can note ambivalence and perplexities are emerging.

You can inherit a gene, two maybe, but why doesn't it start right away? Why does it happen, you know, twenty years later? Thirty years later? Forty? So we then have to assume there are other factors.

I would like to include another "ambivalent" scientist, Director of a cancer institute in Los Angeles. He believes that genetic predisposition is "the first and most important category of causation" [see Appendix 6] but also admits the unlikelihood of the oncogenetic enterprise to "remanipulate the genes."

How one can *introduce* a gene or *change* a defective gene throughout the body billions and billions of cells ... *but obviously those genes are doing something* and we might be able to do something about what they do. [Interview N. 37]

¹³⁰ As Ferruccio Gambino pointed out, sacrificed people are *always* a small proportion. There is no sacrifice without an ideology of "small proportion" because the ritual of sacrifice are celebrated to strengthen a larger majority of those who cling to a community.

This statement ends with a declaration of faith. The interviewee has faith in cancer genetic research. Since everybody now is enthusiastic and genetics is getting the bulk of research money, there must be good reasons for it. Yet, there are a few things that do not sound quite right and make him display some perplexity.

Scientifically, he is somewhat skeptical about the applications of oncogenetic research. What they say doesn't seem completely plausible or probable to him. But he is not able -- and he is not in the position -- to develop a critique. And why should he do that, in a context where criticism is widely discouraged. He has his own comfortable niche -- and no reasons to make his life harder.

So he ends his long statement with a declaration of trust in the current direction of scientific research and in its dominant paradigm. He sounded almost embarrassed to have doubts, "heretical" questions and hesitations.

The atmospheric conditions around those who believe in environmental causation are just the opposite. Those scientists who are convinced that environmental factors are the main cause of cancer have developed their position *against* the current frame of scientific research and *in spite of* the discouraging lack of attention and funding.

Scientists who believe in environmental causation are *not* in the position to be able to say -- paraphrasing the interviewee's statement: "it is hard for me to understand how environmental factors might develop cancer, but I believe it ... because everybody says that."

They are *not* in the position to say, "it is hard for me to understand how we would decrease the rate of cancers by phasing out known carcinogens" -- even if it sounds a matter of logics. They cannot even say: "I don't know how ... these chemicals produce cancer, but I still believe that we should phase them out since they are proved to produce cancer in animals, and for sure do nothing good to human animals."

In other words, if a scientist like the one I quoted above believes in genetic causation -- without being very convinced about it -- he/she is allowed the comfort of supporting such a position without much effort. While scientists who believe in environmental causation cannot have such position without feeling quite strongly about it.

A scientist who believes in genetic factors doesn't have to prove as much: everybody around them takes for granted the importance of genetics. It is the scientist who believes in environmental causation who has to be defensive -- who has to prove everything and can count on much less resources.

The enthusiasm for the "breast cancer gene" has conquered also one of the most prominent and successful women in the cancer arena -- and a hero among many breast cancer activists: surgeon Susan Love. On the pages of world-wide prestigious *New York Times* she took an open stand in favor of genetic research. She didn't completely disregard environmental connections -- but made clear to her audience how the oncogene effort needs to find their support and patience.

'You see, the gene is like a robber in the neighborhood,' she said. 'We have the neighborhood roped off. Now all we have to do is knock on every single door.'¹³¹

It is almost embarrassing to notice that -- behind the 'police action' metaphor -- such a "neighborhood" has millions of inhabitants. At the National Cancer Institute, a top epidemiologist explains the overwhelming interest around genetics and the focus on personal susceptibility in terms of dominant paradigms.

Let's put it this way: it is difficult to do new things. It is always difficult to do new things. It is difficult for the scientific

¹³¹ M. O'Neill, "A day with Dr. Susan M. Love. A surgeon's war on breast cancer," *The New York Times*, Wednesday June 29, 1994, p. B6. In Appendix 8 the reader can find the whole quotation.

community to accept new ideas, whether it is new methods or new theories, or whatever.... it is difficult for them. In part because there are so many new ideas around and part of the job of the scientist is to invoke a certain part of skepticism about the new ... this is part of it. The other part is that there is only so much money to spend on research and only a relatively small fraction of the research is getting funded and what is getting funded tends to be ideas and study designs that are accepted as normal, or reasonable -- this is a reflection of what Kuhn said on the structure of the scientific process, there is a consensus about what is the way you do it. There is a notion of the best way and we are interested in doing it in the most normal way. [Interview N. 32]

This last statement is of particular interest because it is expressed from the inside of the dominant paradigm and sounds like a self reflection. The statement is not meant at all to be a critique of the status quo -- rather it is a clever legitimation of the "normal way" science works.

3.6.2. "Little To do With Cancer"

Some scientists positioned themselves in the debate by regarding genetics as having "little to do with cancer," with the exception of some "very rare" forms of cancer. These scientists are not necessarily critics of the "cancer establishment." Among them Los Angeles "mainstream" epidemiologist, former Chairman at the National Cancer Institute.

Now ... people commonly ask about genetic factors in cancer and there are certain very rare forms of cancer, for which there is a very strong genetic component. But these are extremely rare forms of cancer and my view is that with respect to other forms of cancer -- more common ones like breast cancer or lung cancer ... if there is a genetic component -- now emphasized -- if there is a genetic component ... then it is really quite moderate compared to the environmental factors. (...) That is very popular now -- but we've had other popular ones. We've had viruses as a cause of cancer (...) if you want to control the disease I do not think you will get to that point by pursuing so exclusively the biological aspects of the problem, and ignoring the social aspects. Because

you must look upon the disease occurrence as a bio-social phenomenon. [Interview N. 54]

This position is shared by a number of scientists. Among them epidemiologist Richard Clapp, Director of the John Snow Institute in Boston, is convinced that genetic factors do not explain the "steady increase" of cancer over the past 50 years -- while detectable carcinogens in the environment, in our food, water, air and soil do account for such an increase.

We certainly don't deny that there are other things contributing to cancer including genetic makeup, probably. But ... when you look to find the reasons for the steady increase in this century over the past 50 years -- although it is "controversial" to say that the environment has something to do with it -- I think there is a heavy weight of evidence to support that it has something to do with it. What we don't know is exactly how that works and exactly which source of environmental factors cause which source of cancers. But to make the general statement that there is a relationship between environmental hazards and environmental toxins and cancer is something that is not disputed anymore.

Clapp concluded stating that the role of environmental carcinogens in producing cancer "is not disputed any more" -- which is a common statement among scientist/activists and concerned scientists. What my research is demonstrating, from this point of view, is that the role of environmental carcinogens is far from being undisputed.

Paul Blanc, Chief of the Division of Occupational and Environmental Medicine at University of California, San Francisco -- and author of an early book on environmental cancer¹³² -- reconnects the debate around genetics and environment to the larger debate about biological determinism among scientists.

It's hard to do the molecular biology of environmental cancer ...
but it's very easy to do the molecular biology of genetic cancer

¹³² P. Blanc, *Stop environmental Cancer: an Epidemic of the Petrochemical Age, a Citizen's Guide to Organizing*, Campaign for Economic Democracy, Santa Monica, 1980.

and oncogenes and so forth. So part of the tension in this area is just a microcosm of what's going on in terms of reductionist and non-reductionist approaches to science in general.

3.6.3. The dialectic between genetics and the environment

What often sounds missing in most of the scientists' statements is a conceptualization around the limits of referring to genetics as immanent and environment as transcendent. Even though scientists know there are studies about how environmental factors affect our genetic makeup, when it comes to their perception of these two entities it is easy to notice how a separation between genetic and environment -- a manichean separation -- often underlies their discourse. In the statement of a woman epidemiologist in the School of Public Health, University of Illinois at Chicago -- the absence of a reflection about interactions between genetics and environment is particularly clear:

The only ones [cancers] non-environmental are really genetic-linked. I consider everything else "environment." [Interview N. 44]

The creation of a duality -- genetic cancers versus environmental cancers -- obscures the dialectic between our bodies and the environment which includes us. It produces an either/or conception which, in the last analysis, denies that part of what is environmental for a generation can become genetic in the following ones. The issue is touched upon by biochemist and epidemiologist Nancy Krieger, at the Division of Research at Kaiser Permanente Medical Care Program, Oakland. She looked to personal susceptibility that may be rooted in prenatal exposures, at issues that are located in between genetics and environment -- and cannot be defined as "strictly genetic."

The susceptibility may be genetic. It may also be because of some other *prenatal exposures* that occur that are not genetic, but end up essentially being with you from when you are born

depending on what your mother was exposed to, what her levels were of certain carcinogens, how they crossed the placental barrier. Now I don't want to say it is strictly genetic, but it is there when you are born.

She addressed the problem of prenatal exposure. Yet, in her discourse, she doesn't consider parental exposures preceding the conception of the fetus. As some studies demonstrated, DNA damages in eggs and sperm -- due to occupational exposures (chemical or radiations) -- can be transmitted to the children: in these cases, what is considered "genetic" today may be regarded as the effect of the previous generation's environmental exposures.

Richard Strohman, Professor Emeritus in the Dept. Molecular and Cell Biology at U.C. Berkeley has the merit of being especially clear and understandable when explaining scientific matters. He made clear some issues that are commonly mistaken such as the idea that "genetic factor" means "hereditary factor." He also introduced some controversial points. His position tends toward the environmental explanation of cancer etiology -- and argues that malignant mutations in cells do not occur just because of routine "errors in the transcription." Physical and chemical agents are the demonstrable cause of an uncontrolled growth -- with which the cell adapts to the new environment. Strohman faces the problem of the interaction between genetics and environment -- while most of scientists have shown a dichotomous view of these two entities [see Appendix 7].

Some scientists feel that the polarization of the debate between genetics and environment diminishes the role of risky behaviors and lifestyle in cancer causation. As an NCI epidemiologist stated

Personal behaviors have not been studied very well. This is one of the problems with separating out genetics and environment. Obviously how somebody behaves and interacts with their environment makes a big difference. [Interview N. 49]

When the interaction between genetics and environment is addressed by the interviewees, environment is seen as the causal factor and the overall vision is synchronic, oriented to the present, and static -- does not account for change.

Even if you smoke, I think it matters about your genetics and it matters about your diet. If you have a protective diet and you have protective genetics for some reason -- then, hum, you can be resistant to smoking. Where as you have a poor diet, low in anti-oxidants, and "bad genetics," for some reason, that makes you susceptible, then you're in trouble. [Interview N. 38]

Often, even among scientists who believe the environment influences our genetic makeup and our choices -- the vision of the two entities is disconnected: genetics and environment are represented as separate items that interact with each other at certain points of the etiology of cancer -- and this determines greater probability for the occurrence of the disease.

A former National Cancer Institute scientist -- who does not express any dissent with the mainstream directions in cancer research -- also believes the attention and the excitement around genetic research is excessive. The other part of the story, she argues, is that it necessarily distracts the researchers and their audience by shifting the focus of the debate far away from preventing the exposure to well known carcinogens.

Even though she states that only "a very, very small" proportion of cancers is related to genetic factors, she displays fascination toward genetic research. As with most of the scientists (even among those who are critical about the oncogene euphoria) she is "in tune" with the general climate of expectations surrounding genetics.

What we do know from most cancers aside from lung cancers is that we don't know what causes them and they're not fully explained by genetic factors although there is really exciting work going on right now in the genetics of cancer. Even so, once

the breast cancer gene gets found it's probably only going to explain a very, very small proportion of all cancers so we still have a lack of explanation for what causes most cancers. And I think because we know that there are a number of agents in our environment which do have carcinogenic properties could be causes of disease, that it's certainly prudent for us to try and *minimize our exposures* to things that are known to cause harm in laboratory animals and even in humans. [Interview N. 40]

The interviewee is also among the few scientists who mentioned the relationship between genetic and environment. She believes that genetic predisposition accounts for very little in cancer causation yet she finds difficult not to be transported in the wave of enthusiasm surrounding cancer genetic research in recent years. When I got deeper into my interviewing about what I perceived as being a contradiction in epistemological terms, I obtained from her the following statement:

I think it's hard to know exactly what they are [the genetic factors] because it's very hard to disentangle genetics from the environment. But I think that ... *because right now it's just a very exciting time in terms of the genetics of cancer ... I think that there's some really good evidence* to suggest that there may be genetic predispositions that are very important to consider. [Interview N. 40]

The reader is left with the understanding that the scientific phase we are living now represents the "peak" of the genetic paradigm. Even if scientists have doubts, the cohesion created around the dominant hypothesis is powerful enough to sweep away questions and hesitations even among some of those who consider genetics as a minor factor.

3.6.3. What the Activists Say About Genetic Causes of Cancer.

If I were allowed to make a generalization with the small numbers in this qualitative research project -- I would say that scientists tend to rank genetics higher than activists do. The first group usually mentions it among the first three factors, the second

group tends to give a lower rank to genetics. Yet, as we are going to see, there are exceptions.

In the answers of the activists, issues of control are frequent: genetics is perceived as being the least accessible field -- to non-specialists -- the most abstruse, and far away from the social issues the activists can act upon. Basic genetic research is often accused of absorbing most of the cancer research money -- some say up to 80%.

Many cancer activists perceive that the scientists' knowledge fever about genetics hides how little effort is being given to preventable environmental causes of cancer. I also found concern about how knowledge about our genes will be used. Given that so-called "pure" research can be used in any direction -- but happen to be used by dominant classes -- genetic engineering may have dangerous and unexpected outcomes.

Even though genetic factors account for very little cancer, genetic research plays a main role in the mass-media. The perception of genetic factors being important is reinforced by everyday medical praxis. When women go to the doctor for a lump in their breast, what they are asked is about "family history," risk behavior, nutrition; they are not asked where they live and work.

Information about the workplace is recorded without attention to important variables: whether you are a carpenter in a nuclear plant or at University of California, Santa Cruz, is somehow different -- but no epidemiologist will ever know it. Epidemiological studies *a posteriori* often cannot be made because data and information about the workplace and the sites where the person lived are not gathered at the primary care level.¹³³

Among the activists I interviewed, the first reaction associated to the genetic factor in cancer causation I want to analyze is about fear, when they read in the newspaper about cancer being "in the

¹³³ As the epidemiologist June Fisher pointed out during an informal conversation we had in 1992.

genes.” Cancer activist and writer Midge Stocker¹³⁴ explained the feeling of confusion women often experience while being the target of different explanations on the causes of cancer.

I think that women are afraid that it [cancer] is genetic -- particularly women who had it in the family. They tend to believe that it is environmentally caused -- but they are unsure how.

In the answers of some cancer activists I also found hope in genetic research and expectations -- sometimes mixed with skepticism. Genetics becomes a place for scrutiny and ambivalence: is my cancer “genetic”? How many of my relatives got the disease? Did I pass the “cancer gene” to my daughters?

Genetics becomes the possible explanation for the unexplainable -- the black box where all problems can find the hope for a solution. Journalist and activist Paul Brodeur believes the importance of genetics is overestimated and warns about the use of ‘genetic factors’ as a formula that both disregards environmental factors and, once again, puts the responsibility on the subject.

[The] medical profession in this country likes to blame people when they don't have the answer. (...) New studies say that there is a genetic factor but it is not as big as the medical profession wants us to believe.

New York breast cancer activist Betsy Lambert had always been very healthy. She didn't have a history of breast cancer in her family -- like most of the cancer activists I met. Her doctors always reassured her and the mammography she had was one of the many false negatives: “I really believed that a mammogram showed all the tumors, you know—I didn't do much research on it.”

But she had cancer. Now Ms. Lambert is a member of the board of the National Breast Cancer Coalition. Her position is that

¹³⁴ M. Stocker (editor), *Cancer as a Women Issue. Scratching the Surface*, Third Side Press, Chicago, 1991.

genetic research is important and she hopes it will help to "to shut down the malignant cell activity." Yet she believes genetic predisposition does not explain "environmental damage" done to the genetic systems." After referring to cancer research on immigrants - she ends her long monologue with an important question: "when does family history begin?" [see Appendix 8].

The same question is posed by Boston activist Helen Crowley, who scrutinizes this issue from a logical standpoint. She reached a simple epistemological reflection: if cancer is genetic -- a problem of those who "have the genes" -- why is it increasing so much?

My question about the genetic factors is when do they start. Why are scientists talking about that? As I pointed out in my family, that is how a lot of hypotheses came about, from sharing our own personal experience and our own questions. The Irish in Ireland in my family did not have the genes. Something triggers the genes. As more and more people are getting cancer (...) than something is triggering genes.

San Francisco activist and writer Judy Brady goes further, in her assessment of genetics, and links the genes with the environmental and social factors affecting our body:

The genetic factor ... I think is affected by social constructs: we know that the DNA is acted upon by toxic agents. We know that people are born with weaker immune systems. So however the mutations might go, it seems to me that if we want to take the snake by the head rather than by the tail you have to look first at the environmental factors.

San Francisco Breast Cancer Action Director, Nancy Evans believes that genetics will eventually be useful in prevention and therapy -- allowing the scientists to find a way of remanipulation of the onco-gene. Yet she points out how basic cancer research is often isolated from society.

Particularly basic scientists, I think, are very far removed from the real world, in many cases, although I do think that when we find a way to actually prevent or cure cancer it will be at the

basic science level in some kind of genetic manipulation of the immune system.

The common idea that cancer genetic research is not just related to etiology but will eventually offer important breakthroughs in cancer prevention and cure, created a terrain of legitimization among activists. Proposing itself not any more as "pure science" but as a key of the war on cancer, genetic molecular biology has gained the respect of a larger audience as well as political validation.

Nancy Evans expresses an ambivalence toward genetic research quite common among breast cancer activists. On the one hand she expresses the hope that the oncogene effort will land somewhere in terms of prevention and cure. On the other hand she recalls that genetic factors account only for a minuscule percentage of cancers -- and this clashes with the general expectations.

I don't know whether my grandmother died of breast cancer or not because when she died I was a teenager ... 40 years ago ... and back then you hardly said the word cancer, you certainly didn't say the word breast in mixed company. And so nobody really talked about those things, so many women, myself included, don't have a good family history to know. Your family history is certainly important, if there is a genetic link, but that only accounts for 5% of breast cancer ...

It seems to me by looking at the answers on genetic factors, that those cancer activists involved in cooperating with medical and research institutions, tend to be more enthusiastic about genetic expectation than those activists who do their political work on cancer outside institutional contexts.

Susan Claymon, breast cancer activist in San Francisco, represents one of the connecting links between the mainstream part of the movement and public institutions. She didn't have a family history of breast cancer, but she believe genetic predispositions are factor number one. Even though she has a positive orientation toward cancer genetic research and its possible outcomes in terms of prevention and cure, she ends her statement talking about "very

suspicious areas" -- without naming them explicitly -- clearly referring to those factors that are not discussed much in the milieu she is interacting with.

I think we will ultimately find ways to prevent and also ways to predict genetically. There is a lot of evidence of genetic kinds of links and there are, you know, ways of looking at genetic... groups of people with certain kinds of genetic traits who would be at higher susceptibility to the potential of breast cancer. I guess ... I would certainly hope that we would find a way to prevent this disease, and I think it's certainly possible. I can't say what the leading... what should we do first, what should we do second... I'm working very hard on getting more funding legislatively, for instance, to focus on some of the very suspicious areas that we have.

This silencing about the term "environment" gave me a feeling about the non-official ways in which alternative approaches are discouraged within the dominant paradigm. It was the same feeling I had in Atlanta, at the headquarters of the American Cancer Society, when a scientist refused to answer those of my questions related to environmental issues -- and others where embarrassed.

3.8. Conclusion

In this chapter, after some preliminary notations on the illness cancer, I historically framed cancer research by looking at the paradigms preceding genetics. Then, I inscribed the debate over cancer genetic research within the larger debate over the Human Genome Project, which constitutes one of the major embodiments of the genetic paradigm -- its pick, in *Kuhnian* terms.

I analyzed some of the problems related to the fact that most of cancer genetic research is not based on real tumors but on cell lines, artificial models which does not seem to provide reliable information about the ways in which human cancers develop. If the Dermer's critique will conquer more space in the scientific community and become commonly accepted, the foundations of the

oncogene theory -- mostly based on cell lines -- would be seriously jeopardized.

I introduced the debate on genetics and cancer causation among scientists and activists by looking at similarities as well as differences. Scientists seem to rank genetics higher than activists, when it comes to cancer etiology. A group of scientists believe that genetic research will provide the instruments for prevention and cure of cancer. They believe that cancer is mostly a matter of genes; and that once discovered the "cancer gene" more could be done to prevent its development in those individuals who carry it, and one day they hope science will allow them to recode the wrong gene through genetic engineering.

Genetic cancer research is seen by another group of scientists as a great loss of time and money, they believe what happens at the molecular level is triggered by environmental carcinogens; and that we should put efforts in preventing cancer, rather than hoping in the miracles of genetic engineering. Some scientists also raised ethical concerns on the directions and goals of genetic research, since the construction of a category of "predisposed" people *versus* "non-predisposed" would allow the implementation of discriminatory practices.

Chapter 4

THE ENVIRONMENTAL PARADIGM

4.1. Introduction

In this chapter I am going to offer a definition of the term “environmental cancer” and different interpretations and current uses of this term in the scientific community. What is included under the category environmental cancer and what is not included are a subject of debate. I will offer an account of the scientists’ and activists’ perceptions of risky behaviors and an analysis of how they conceptualize causes of cancer that are -- to some degree -- under the control of the individual.

I will also present a selection of quotations to exemplify the range of views on so-called “lifestyle factors.” Some of the scientists conceptualize them as part of the environmental causes and place the stress on social problems at the very roots of “lifestyle factors.” Other scientists conceive individual behaviors as personal choices, and risky behaviors as part of the choices individuals make in their lives.

“Environmental cancer” is neither the name of a disease nor a recognized cause of death in medical diagnosis. I am using this term as a medico-sociological category in order to describe those occurrences of cancer considered to be caused by environmental factors. I will discuss the variety of meanings given by institutions, scientists, and lay persons, to the word “environment” in section 4.2.

Some of the scientists I interviewed tend to inscribe under the category “environmental cause of cancer” any exogenous agent: chemical and physical carcinogens in the workplace and in the general environment, viruses, risky behaviors, lifestyle factors, surgeries and some pharmaceutical products which can cause pre-cancerous lesions. Others make a distinction based on the relative willingness of the subject to be exposed to a substance considered (or

proved to be) a carcinogen. The demarcation line between chosen (or accepted) exposure and uninformed exposure has a wide range. For some of the interviewees working at a hazardous job is an individual choice and the subject is assumed to be

1. fully aware of the risks;
2. able to get access to a different job.

The same discourse is often made for the "choice" of a living place and for diet/nutrition: several scientists consider these as individual options or as choices, rather than as socially determined for those who belong to disempowered ethnic groups -- Blacks, Latinos, Native-Americans -- and those who are White but too poor to escape from toxic "donuts" and to afford an healthy diet.

This lack of awareness sometimes is not explicit -- the scientists I interviewed were not willingly insensitive: nobody ever argued that if some people live on the top of a toxic dump it is "just their fault."

Yet there is something to be deconstructed when the interviewee focuses the answer on issues of *personal responsibility* involved in *knowingly* taking the risk. Or when the interviewee starts off with a positive judgment of the larger options we have today in terms of variety of foods coming from all over the world.

The scientists' representations about personal choices in risky behaviors can be placed on a continuum having as opposite ends the maximum and the minimum of subjective control and personal responsibility that individuals have under given circumstances.

Most scientists draw the line of personal responsibility when it comes to risky behaviors such as tobacco and alcohol consumption. While they admit class -- and race when it means class -- plays a role in affecting the choice about living areas and diet/nutrition, they do not see much the same link in "individual" risky behaviors.

Most scientists recognize there are social pressures about smoking. Some refer to the mythology of the cigarette in the movies, others mention how legally the tobacco industry targets young people and create addictions that can last for their whole life. Yet,

smoking is seen as an *active* way of damaging one's own health: "you can choose to quit."

I would like to introduce a discourse around the "social" environment as the interface between the general environment and the sphere of subjective will.

The term environment would include all physical and chemical carcinogens. Tobacco and alcohol would be incorporated to this category. But it would be a matter of "social environment" how much and why people smoke and drink. Social environment would also include factors such as exercise and the age of pregnancy, which cannot be illustrated by the term "lifestyle" nor can they be called "risky behavior."

Another factor to ascribe to the social environment sometimes named by the scientists interviewed is stress, which undoubtedly plays an important role in lowering the subject's immune system and creating a psycho-physical situation suspected to be a co-factor in the origin of several cancers. Stress alone would probably deserve a whole chapter, given the number of studies and controversies orbiting in this area.¹³⁵

Stress was one of the factors -- as well as genetics -- that made several activists uncomfortable in discussion. With genetics, stress has the common destiny of being emphasized as a "personal predisposition." When asked about this factor, often activists became defensive and mentioned that talking about stress means "blaming the victim." That made me understand that the subject feels somehow responsible for his/her own stress.

In Italy stress was one of the "political" issues in the occupational health movement and in the feminist arena. Among ordinary people stress is commonly perceived as a *social problem*: if you are stressed out, it means that society, your job, and those who are around you are not able to make you happy.

¹³⁵ Here I am only touching upon the subject matter because it is a bearer of sociologically relevant issues. See Appendix 17.

In the U.S.A. I soon realized that stress -- at least in common terms -- was more of an individual issue, and being "stressed out" is perceived as a personal inadequacy to cope with everyday life tasks: if you can't make it, this is *your problem*.

Section 4.2. and 4.3. on the concepts of threshold, multiple exposure, and risk assessment are going to be much smaller than I had planned for this work. I decided not to include a great deal of technical debate around different levels of tolerance and acceptable risks.¹³⁶ Yet I consider it important to mention that there is a deep separation between those scientists who accept a tolerance level in exposure to established carcinogenic agents -- and those who don't, between those who use risk assessment techniques and those who think any use of these instruments is counterproductive.¹³⁷

Such a division is present also among those scientists who are convinced environmental factors play a main role in cancer etiology. In other words, not all those who rank carcinogens high in the list of causes think they should be abolished. Such a division among scientists tends to be cross-cutting. In fact some of the scientists who think tobacco -- and not environmental carcinogens -- is what accounts for most cancers, would ban cigarettes. In other words, the degree of radicality is not mechanically related to the scientist's position on environmental carcinogens.

Section 4.5. presents the scientific debate on human-produced carcinogens in our environment -- in air, water, food. Some scientists believe the danger from environmental carcinogens is negligible while other scientists argue these carcinogens are more harmful than

¹³⁶ In July 1994 I went to Seattle for a three days workshop/meeting of experts on threshold and risk assessment, to obtain the sufficient background to analyze the problem. It was very useful, even though for the economy of this work, I decided to not use the materials I selected.

¹³⁷ The latter group support the theory of a "zero tolerance" - popular in the late 1960s Western Europe among working class activists and occupational health specialists.

lifestyle factors, and that individuals have very little information and control on these causes of cancer.

Multiple exposure is not contemplated in the scientists' etiological discourse. The scientific literature that address "combined" exposures mainly regards the association of tobacco smoking with occupational hazards, such as asbestos and other proven carcinogens. These studies tend to demonstrate that -- given a certain occupational exposure -- the real variable in cancer incidence among workers depends upon cigarette smoking. I couldn't find studies framed within the opposite approach, i.e., looking at two groups of smokers -- only one of which is exposed to occupational carcinogens -- who are differently impacted by cancer incidence.

In section 4.4. I will provide a brief account of the concept of environment at the American Cancer Society by analyzing their materials and the interviews I conducted their scientists. In the last section I will introduce the positions on cancer and the environment expressed by cancer activists by presenting comments from the activists I interviewed.

4.2. Environment, Lifestyle and Risky Behaviors

Producing a definition of environmental causes of cancer was one of my goals; it required some preliminary work of conceptualization. In the first phase of my research project I critically reviewed the empirical research that has been done on the environmental factors of cancer in the last ten years -- in the U.S. as well as in other countries. What does "environmental causes" of cancer mean?

1) Sometimes in medical literature the term "environment" excludes all the causes which are related to subjective will, such cigarettes, nutrition, and other "lifestyle factors."

2) Other times, the term "environment" refers to all the causes that are not related to genetic heritage.

Both definitions per se can be arguable: e.g., cigarettes are also part of the environment for at least three reasons:

- a) because the subject "chooses" to smoke in a certain social environment where variables of class and gender play on their decision, where economical and cultural factors can be isolated and analyzed;
- b) because cigarettes affect the environment also for non smokers;
- c) because it is possible that the use of substances like cigarette smoke can also affect the immune system and the genetic heritage of the offspring.

Whereas we have elements of subjective will -- as in the behavior of smoking -- saying that the behavior is "socially constructed" is just a descriptive statement. In fact, we do not have the means for separating the individual's responsibilities from those of the economic and political system.

Following this path, we can reach the point of defining as environmental causes only the "macro" ones, those which are out of the control of the subject. Yet, we have "micro" environmental causes that are not under the individual control -- e.g., second hand smoking -- and we can have some control over "macro" issues.

If we accept a definition of "environment" as any "macro" dimension *versus* the micro of "genetics" -- we legitimize a separation between the two based on a vision of genetics as "immanent" *versus* the assumed "transcendence" of the environment.

The definition of environment seems to change with the context in which it is inscribed. When I first searched on Medline I realized that "environment" was used as a very narrow category when it comes to cancer etiology. It doesn't include, for example, the work environment. A search for "environmental carcinogens" led me to some unexpected results: e.g., there are only 5 studies on neoplasm etiology in the human female related to the "environment".

In one of these studies, the term "environment" is used as synonymous with "air;" in another by "environment" the authors mean nutritional habits, attitudes toward exercise, and smoking. In other words scientists seem to talk about "social environment" when they stress the social component of the behavior, and "lifestyle" when they stress the individual component.

I am going to present quotations I selected from the interviews. Even though each of the 60 people interviewed expressed interesting differences and nuances, I will not offer the whole range of answers. The criteria of my selection is on the basis of "idealtypes" -- in other words those answers that represent a group of answers/opinions -- and those that represent polarities in the debate.

In the Medical Subject Headings, we can find definitions of groups of factors such as "food contamination," "waste products," "hazardous waste," "water pollution," "air pollution," "ultraviolet rays," and also the category "environmental pollution." I was surprised to notice that the latter is not considered to be a larger taxonomy under which other categories can be subsumed.

Such a confusion is clearly predicated on the absence of an agreement about what "environment" is. For this reason, referring to an "environmental etiology," in medical terms, can be quite misleading for the social scientist -- who, on the other hand, is not provided with a conceptually rigorous definition of what is meant by environment and environmental illness.

My in-progress definition of "environmental illness" is: *illness related to the creation, conservation and circulation of commodities and other outputs, during productive processes directed at the extraction of value from human labor.*¹³⁸ These illness are produced at a macro level and, on a large scale, they increasingly affect

¹³⁸ I am referring to all undesired outputs of the production and circulation processes.

different strata of population who do not have much control over it. Often, these illnesses are life-threatening. Cancer seems to emerge as the most relevant environmental illness.

At the National Institute of Occupational Safety and Health (NIOSH) at Berkeley, the term *environmental cancer* is not rare in materials dealing with occupational hazards. Two databases edited by the Canadian Center for Occupational Health and Safety also offered me a large variety of international studies on the topic -- many from Scandinavian countries.¹³⁹

Regardless of their opinions on how much environmental and occupational exposures account for cancer, some scientists consider lifestyle factors as part of the environment -- while others make a distinction between the environment and lifestyle factors.

A prominent cancer epidemiologist at UCLA, offered an articulated analysis of "lifestyle factors" by combining the key words "access" and "selection."

I am inclined to regard lifestyle as consisting of two components. One is: what is actually available to people to eat. If they have enough calories, if they have enough of this or that, or other kinds of food. If they really have *access* to the food, that's one component. If they do not have access then they, of course, cannot eat that food. The second component is the *selection* by the individual (...) within the range of foods that person can select from. [Interview N. 45]

In mentioning that people have different degrees of access to food, the interviewee's statement implies that preventive campaigns based only on "changing lifestyle" are not taking into account important factors.

A top scientist at the National Cancer Institute is among those scientists who point out how class factors might affect people's risky behaviors. The data are indisputable that the further we go down

¹³⁹ I reviewed them and I am going to group them in the classification I constructed for the recent scientific findings on cancer etiology.

the social scale the greater the increase in cigarette smoking. He explains the data in terms of degree of control people have in different socio-economic contexts. He doesn't use the concepts such as class or race -- yet his analysis is grounded on the recognition that class location matters, when it comes to exposure to carcinogens.

There is this trade off between balancing things that you choose to do versus things that happen to you, that you don't have any control over. *People in different levels of society have different amounts of control.* So the ambient air exposure that you get for example ...or lead is a perfect example: the lead burden of a population tends to be concentrated in the poorer segment of society because they really didn't have a choice to get away from that. In areas where there is a lot of automobile exhaust and that's where the lead came from and they are living in buildings where there's lead paints that peel off the walls. If you are wealthier the paint doesn't peel off your walls: when it starts you have it removed and have it painted again. So it's that sort of thing. So our choices are not the same. But all of us do have some choice but they're just not at the same level. [Interview N. 56]

The controversy over how much is choice and what can be considered "environmental causes of cancer" is not new. In 1964, according to the World Health Organization, 85% of cancers derive from "environmental causes." This statement is still at the basis of a large controversy. Such controversy is quite complicated, from an epistemological point of view, since the inclusion (or the exclusion) of behavioral factors under the term "environment" is not an expression of the scientist's position about the degree of importance to be given to those environmental factors that are completely out of the individual control.

Paul Blanc, Chief of the Division of Occupational and Environmental Medicine at UCSF, wrote probably the first book having the term "environmental cancer" in the title.¹⁴⁰ Blanc ranks

¹⁴⁰ P. Blanc, *Stop environmental cancer : an epidemic of the petrochemical age. A citizen's guide to organizing*, Campaign for Economic Democracy, Santa Monica, 1980. I interviewed him as a scientist: even though Blanc's work has been important among activists in the seventies, he doesn't accept to be

environmental exposure as important in his etiological discourse. Yet, he doesn't agree with a broad use of the term "environment" -- and criticizes the World Health Organization's definition of environmental causes of cancer.

I guess I would not consider fat intake environmental, in that sense, but I would have to say that the... for instance, the WHO, when we talked about 85% of cancer being environmental, they included everything that wasn't genetic. So one definition of environmental is all factors which are not genetic, so (...) diet and smoking and occupation and drinking water and pesticide residues. I'm not sure that that's a very useful definition, particularly including diet, dietary factors other than chemical contamination of food as being environmental in that sense. So, my working definition would probably be ... little bit narrower.

A toxicologist at U.C. Berkeley has a different and opposed position from Blanc about the importance of environmental factors. Yet, he considers the common interpretation of WHO's resolution as misleading, when it comes to environmental causes of cancer. He proposes a definition of environment that includes everything that is not genetic -- also stress -- but making clear that environmental factors cannot be reduced to chemical carcinogens *tout court*.

I think that's caused a lot of confusion in the past because people have talked about the environment being the environmental chemicals and therefore have thought that environmental pollution caused a large proportion of cancer. Higginson said, way back, that he thought that 10% of cancers were due to genetic reasons and 90% due to the environment -- which is classic epidemiology. And by that, he means all the environment: he means food, your diet, he means occupation, he means everything. And that was misconstrued by some people, I think, to mean environmental chemicals -- and then to mean environmental pollution. Whereas I think environmental pollution only accounts for a few percent of all cancers -- and maybe *related to a specific area*. [Interview N. 38]

defined as a scientist/activist ["I consider myself a scientist whose work can be applied in the public interest"].

What the interviewee defines as a "misconstruction" around the WHO statement has been corrected fifteen years later in a text that became something of a classic in the mainstream etiological literature.¹⁴¹ Doll and Peto in *The Causes of Cancer* created the foundations of the contemporary dominant discourse on cancer causes. The theory of this study is made explicit by the authors: "our report consists of a review of the evidence that cancer is largely an avoidable disease." Chapter one is devoted to a "Definition of Avoidability of Cancer" which is predicated on the assumption that "environment" is an entity largely under the control of the individual. Often their concept of environment seems to correspond to a broader-than-usual definition of lifestyle. Doll and Peto provide a "guideline" for a re-interpretation of the 1964 WHO report [see Appendix 10]. They focus on personal behaviors and provide a sharp critique of those who interpreted environment as man-made carcinogens.

Unfortunately, the phrase 'extrinsic factors (or the phrase 'environmental factors', which is often substituted for it) has been misinterpreted by many people to mean only 'man-made chemicals,' which was certainly not the intent of the WHO committee.

In their book Doll and Peto also attack Samuel Epstein's hypotheses of environmental carcinogens being an important factor in cancer causation. Doll and Peto support the hypothesis that cancer is not increasing, while other authors are convinced we are facing an "epidemic." According to them, Samuel Epstein's work is

based on the assumption that Americans live in an era of genuinely and rapidly increasing cancer rates over and above the increase due to tobacco, [Epstein] rejects it out of hand without acknowledging or explaining why the trend in U.S. mortality from non-respiratory cancer is actually downward, and

¹⁴¹ R. Doll, R. Peto, *The Causes of Cancer*, Oxford University Press, New York, 1981.

without serious discussion of the potential biases in trends in death certification rates among older people.¹⁴²

Further, Doll and Peto go back to this topic by stating "from 1900 to the present, lung cancer death certification rates among non-smokers have risen, the largest relative increase being between 1900 and 1950" but dismissing such a data as being "largely or wholly an artifact of death certification practice."¹⁴³ It is interesting to notice that Doll and Peto were not critical of the official data in any other part of their work.¹⁴⁴

4.3. Thresholds, Multiple Exposures and Risk Assessment

As anticipated, this sub-chapter will just briefly introduce the debate over tolerance levels and quantitative risk assessments¹⁴⁵ when it comes to proven carcinogens. Part of the debate is grounded on a disagreement about what is a "proven carcinogen." Some scientists consider lab experiments on mammals as a sufficient verification of a substance's carcinogenicity, while other scientists

¹⁴² Ibidem, p. 1211.

¹⁴³ Ibidem, p. 1303.

¹⁴⁴ Samuel Epstein pointed out during the interview that statistics are age-adjusted and the percentage increase is real.

¹⁴⁵ A quantitative risk assessment is "the process by which the risk of disease or death in a population exposed to a toxic agent is related quantitatively to the intensity and duration of exposure to that agent. Quantitative risk assessment is based upon the scientific findings of dose-response relationship in exposed populations. It is to be distinguished from risk-benefit analysis and from other activities such as standard setting or the establishment of threshold limits or "acceptable" or "safe" levels, which often weigh social, political and economic factors against the risk of disease or death. Quantitative assessment of the risk of environmentally provoked disease in man is a difficult task. Many issues complicate the effort. Among them are the long induction-latent period for chronic diseases, typically of many years' duration; the multistage process of disease induction and progression; the paucity of epidemiological data on health effects due to environmental exposures; the mixed nature of most chemical exposures; and the modification of disease expression not only by multiple chemical exposures, but also by a variety of lifestyle factors."

U.S. Department of Health and Human Services, *Human Health and the Environment*, National Institute of Health, Bethesda, Maryland, 1984, pp. 290-1.

tend to consider animal data as inadequate to demonstrate a substance can cause cancer in humans -- at least until epidemiological studies do not "corroborate" the lab results. Which means that a certain number of persons have to die in order to proof a substance is a carcinogen for humans.

Here I will refer as "proven carcinogens" those listed in the International Agency of Research on Cancer (IARC)¹⁴⁶ resolution -- since this is the most authoritative international agency on the subject matter.

Carcinogens are one of the key areas in quantitative health risk assessment. It has been estimated that "every year more than 1000 new chemicals are introduced into industrial production throughout the world."¹⁴⁷ Most of them are not proved to be safe. We will discuss the issues related to the burden of the proof in chapter 7.5..

Dose-response functions and the methods for estimating the necessary measures for the risk assessments are the subject of discussion and polemic among scientists. Since the assessment of "safe" levels of exposure is based on interspecies comparisons, often the processes through which most cancer scientists develop their research are conjectural. Scientists do have intuitions but, when it comes to environmental carcinogens, proofs seem more difficult to gather.

The environment, in particular air and surface waters, must contain some numbers of synthetic organic compounds which are responsible for a considerable part of the incidence of cancer in the populations of industrialized countries. However thus far only a few substances have been identified as environmental

¹⁴⁶ L. Tomatis (editor-in-chief), A. Aitio, N.E. Day, E. Heseltine, J. Kaldor, A.B. Miller, K.M. Parkin, E. Riboli, (co-editors), *Cancer Causes, Occurrence and Control*, International Agency for Research on Cancer, IARC Scientific Publications, N. 100, Lyon, France, 1990.

¹⁴⁷ S. Forssman, "Health Hazards Associated with Introducing New Chemicals in Industry: Prevention and Control," in *Health and the Environment World Health Organization*, Copenhagen, 1977, p. 115.

carcinogenic agents because they have caused actual cases of cancer in people exposed to them.¹⁴⁸

In fact, there is a fundamental difference between determining cancer risk from chemicals and from ionizing radiation: while the epidemiological data from the atomic bomb survivors are available as a human referent point for studies on radiation, for chemical carcinogens animal data from lab experiments are often all the scientists have to estimate the coefficients of dose-response functions.

Even though the National Academy of Sciences established that effects in animals, properly qualified, can be applied to humans, and that exposure of experimental animals to high doses of toxic agents is a necessary, valid method to discover possible carcinogenic hazards there are a often technical problems in "translating" from mice to humans.¹⁴⁹

Yet, one of the reasons why some scientists think we should accept the monitoring of proven carcinogens and the negotiation around tolerance levels is that they feel any battle for banning is unrealistic or unlikely to win in the short term. They also argue that these techniques and instruments have been useful in the past in order to lower the exposure in many workplaces. Often risk assessment is mentioned as the only tool (among those available in public health settings) scientists can use to protect workers, their families and the citizens living in the surroundings.

Concerned scientists and scientist/activists dissent from this practice and argue that it is wrong to participate in risk assessment programs because it legitimates the idea that there is a "safe exposure" level, which is not considered to be true. If a substance is

¹⁴⁸ A. Berlin, A.H. Wolff, Y. Hasegawa, *The Use of Biological Specimens for the Assessment of Human Exposure to Environmental Pollutants*, Commission of the European Communities, Brussels, 1979, p. 123.

¹⁴⁹ K.S. Crump, "Methods for Carcinogenic Risk Assessment," in Paolo F. Ricci (editor), *Principles of Health Risk Assessment*, Prentice-Hall Inc., NJ, 1985, p. 279.

a carcinogen, they argue, it should be phased out. Energies should be put in finding alternatives to that substance, rather than spending money to evaluate the dose administration of deadly poisons. They also point out that many carcinogens do have an alternative, which is not implemented -- sometimes for profit motive, sometimes just for *inertia* i.e., the absence of any good reason to change.

These scientists also warn that:

- a. once one accept the concept of a safe level of exposure, such levels can always be modified -- and citizens have little control over such processes;¹⁵⁰
- b. when a carcinogen is considered safe at a certain level, this doesn't take into account the cumulative effect of many "safe" exposures.

There are virtually thousands of inorganic and organic substances that occur as environmental pollutants and which are known to be toxic at relatively high levels of exposure in man or animals. However we have little if any information on the toxicity of these substances as a result of ambient exposure levels. None the less, most of these toxic agents are suspected of being causal factors for various chronic disease including cancer (...) At the present there are no feasible methods to determine whether there is a threshold or safe level for most carcinogenic agents. consequently standards for suspect carcinogens cannot be established with confidence according to scientific criteria. *From the viewpoint of protecting the public*, it appears reasonable to support the controversial concept that there is 'no safe dose' of a carcinogen and that any level of exposure to a carcinogen should be considered toxicologically significant for man ... In our view, environmental pollutants suspected of a causal association with serious chronic diseases should be judged 'guilty until proven innocent.'¹⁵¹

The debate over risk assessment, acceptable thresholds, and exposure levels also interests socially and economically disadvantaged communities, cancer activists and environmentalists.

¹⁵⁰ W. Chavikin MD, J.M. Stellman (editors), *Women's Work, Women's Health. Myth and Realities*, Pantheon Books, New York, 1977.

¹⁵¹ R.A. Wadden, *Energy Utilization and Environmental Health*, Wiley & Sons, New York, 1978, p. 115-6. [My emphasis]

When risk assessments take place, frequent disagreements between experts and non-experts take place. There are also theories about public perception of risk as a variable of the degrees of available information. One is grounded on the assumption that lack of information leads to a *tendency to overestimate risk* and to be unwilling to tolerate even minimal levels of risk. Yet, events like "the overwhelming public outcry against a saccharin ban, even after extensive public exposure to media coverage stating that saccharin may be a carcinogen"¹⁵² probably constitute valid arguments against this theory.

Since 1980 we have seen a growth in the concern among governments, individuals, regulatory agencies, private industries and other actors, about the risks presented by man-made chemical agents and disagreements about how much risk is presented by a particular agent, or what level is "acceptable." Risk management was meant to include only objective or scientific factors. Both stages -- risk assessment and risk evaluation -- don't acknowledge that

some amount of uncertainty is inherent in the management process during all phases and cultural, social, psychological, and institutional factors play a role at each point along the process. Scientific data are limited in such a way that precludes the resolution of most conflicts solely on the basis of scientific principles. Furthermore, regulatory agencies often must act despite uncertain data and risk decisions are and must be made without the benefit of "perfect" information" (...) fundamental issues about how to define risk and the legitimacy of the decision-making process, itself, have become the frequent and underlying source of conflict. It has become crucial to understand those dimensions and judgment processes that are used to evaluate and assess risk (...) and to understand how risks are defined from a

¹⁵² Ibidem, p. 11. The author supports an alternative approach to analysis of nonexpert risk judgement, based on variables like: familiarity with the problem (and its jargon etc.), accountability, vividness of the exposure, complexity and persistence of the problem, and personal relevance. Through 3 experiments, the author attempt to demonstrate the effects of the mentioned factors on the nonexperts' evaluation of risk associated with environmental carcinogens. See also S.D. Lee, *Biochemical Effects of Environmental Pollutants*, Ann Arbor Science, Michigan, 1977.

perspective broader than that represented by the quantitative model.¹⁵³

Experts tend to measure risk in terms of two dimensions: the probability of negative outcomes and the severity of these consequences. Critics pointed out how experts often operate without conceptualizing how factors act in concert, in different cultural context, and for different types of people. In fact, studies on environmental -- as opposed to occupational -- carcinogens have a less homogeneous target population, that includes children, the elderly, pregnant women, and other subjects besides adult males.

Various environmental chemicals ... are implicated in the etiology of some forms of cancer and heart disease. yet, for many chemicals to which a majority of the population are exposed at certain times, *we do not know the sources, prevalence, levels, and time-course exposure*. Also, for some chemicals, we are uncertain of effects of impurities, contaminants, or environmentally induced alterations in structure. Nor do we know the precise dose of a specific chemical that can produce in each human subject different pollutant related diseases, most notably some forms of cancer and heart disease. *Dose-response curves for toxicity from environmental chemicals have not been established for different cells of the same tissue, different tissues, different individuals, and different populations.*"¹⁵⁴

For brevity, I will conclude this section by mentioning that the problem of the disagreements between experts and nonexperts in risk assessment has been often approached with "the assumption that the problem stems from some deficiency on the part of the public, rather than biases of experts."¹⁵⁵

¹⁵³ E. Vaughan, *Some Factors Influencing the Nonexpert's perception and Evaluation of Environmental Risks*, Garland Publishing Inc., New York, 1990, p. VII.

¹⁵⁴ E.S. Vessel, "Effects of Human physiology and Genetic Variability on the Development and Expression of Pollutant-related Diseases," in S. Draggan, J. Cochrissen, R.E. Morrison (editors), *Environmental Impacts on Human Health*, Praeger, New York, 1987. p. 35-36. [My emphasis]

¹⁵⁵ E. Vaughan, *Some Factors Influencing the Nonexpert's perception and Evaluation of Environmental Risks*, Garland Publishing Inc., New York, 1990,

II.2.4 ACS' account for the environmental factors of cancer

I found ACS's educational materials of great interest in order to understand the dominant discourse on environmental factors in cancer etiology. In one of their brochure "Cancer Facts and Figures"¹⁵⁶ I noticed that, among all causes of cancer "tobacco use" (cigarette smoking, involuntary smoking, and smokeless tobacco) gets most of the space.

It is interesting to observe how little (eight lines) is devoted to the discussion of industrial hazards -- and how in the representation offered by ACS, industrial hazard does not appear as a cause of cancer *per se*, but only when combined with tobacco use.

Industrial workers are especially susceptible to lung diseases due to the combined effects of cigarette smoking and exposure to certain toxic industrial substances, such as fumes from rubber and chlorine, and dust from cotton and coal. Exposure to asbestos in combination with cigarette smoking increases an individual's lung cancer risk nearly 60 times. Smoking also enhances lung cancer risk in underground miners exposed to radon.

By reading this quotation, the reader is left with the impression that mentioned substances would be harmless if industrial workers would quit smoking. Only a third of a page is devoted to nutrition

p. 7. On threshold levels and risk assessment for known carcinogens, see: P. Ricci, A. Henderson, "Fear, Fiat, and Fiasco: Causation in Cancer Risk Assessment," in A. Woodhead, M. Bender, R. Leonard (editors), *Phenotypic Variation in Populations. Relevance to Risk Assessment*, Plenum Press, New York, 1986; L. Gordis, *Epidemiology and Health Risk Assessment*, Oxford University Press, 1988; P. Oftedal, A. Brogger, *Risk and Reason. Risk Assessment in Relation to Environmental Mutagens and Carcinogens*, ARL Publisher, New York, 1986; C.R. Cothorn, M.A. Mehlman, W.L. Marcus (editors), *Risk Assessment and Risk Management of Industrial and Environmental Chemicals*, Princeton Scientific Publishing, NJ, 1988; ATSDR, *Public Health Assessment Guidance Manual*, Lewis Publisher, U.S. Department of Health, 1992; S.M. Rappaport, T.J. Smith, *Exposure Assessment for Epidemiology and Hazard Control*, Lewis Publisher, Boca Raton, FL, 1991.

¹⁵⁶ American Cancer Society, *Cancer Facts and Figures*, Atlanta, 1992.

guidelines in order to reduce cancer risk. The subject seems to play the most important role, while there are no social factors mentioned, and nothing that would induce us to think that eating habits are socially constructed and affected by economic limits. On the contrary, the paragraph ends by stating that "the American food industry has developed new processes to avoid possible cancer-causing byproducts" while "other areas of the world still consume salt-cured, smoked and nitrite-cured foods" here indicated as causes of the more incidence of cancer of esophagus and stomach in those areas. In the whole document pesticides and other carcinogens present in our foods are never mentioned.

Half a page is devoted to the discussion of the relationship between cancer and the environment. It starts off by stating that "most cancer cases in the U.S. are believed to be (my emphasis) environmentally related." But only "some environmental causes are well known. About 30% of all cancer deaths are directly related to the use of tobacco. Most skin cancers result from ultraviolet radiation in sunlight. Other causes are harder to assess."

Here there are two elements that need to be pointed out: on one side there is a precise account of the tobacco's impact on cancer - while other causes seems to be harder to assess. On the other side, the admission that sunlight is one of the two causes of cancer which are not hard to assess. Yet, there are neither guidelines about sunlight exposure nor references about the reasons why the sun has become a cause of cancer. While the presence of carcinogens in the environment is not mentioned, information is provided about the workplace.

Various occupational hazards, especially ionizing radiations and chemicals like asbestos, benzene, and vinyl chloride are known to cause cancer when exposure levels are high.¹⁵⁷

¹⁵⁷ Ibidem. [My emphasis].

An estimated rate of the correlation between mentioned carcinogens and incidence of cancer -- in the same way ACS estimated the percentage of cancers that tobacco accounts for -- is missing. Also, there are no references to guidelines about limits of exposure. The reason for this lack of accuracy sounds peculiar, after reading the highly detailed section on tobacco use. The paragraph ends reassuring the reader that "overall, however, workplace exposures account for only a small percentage of all cancers."¹⁵⁸

It is interesting to notice that the section on "Cancer and the environment," avoids any mention of environmental carcinogens in air, food, water and soil -- and devotes two thirds of the space to the methodology of Cancer Risk Assessment. This is a cryptic narration, and it is difficult to follow, while the tone of the publication is definitely popular. It mentions the methodology used to develop standards, law and procedures -- and provides reassuring statements such as "for cancer safety standards, only increased risks of one case or less per million persons per lifetime are usually accepted."¹⁵⁹

I also noticed a contradiction in the discourse about lung cancer. The ACS estimates that "cigarette smoking is responsible for 90% of lung cancer deaths among men and 79% among women -- 87% overall."¹⁶⁰ They also state that in the U.S. "higher cigarette prices, health concerns, smoking restrictions, and declining social acceptance of smoking have resulted in per capita cigarette consumption falling over 30%" in the period from 1973 to 1990 -- the lowest consumption since 1942.

Yet figures of cancer death rates by site in U.S. during the last six decades show that lung cancer is the only one that have been constantly increasing at the same rate of growth since 1930.¹⁶¹ It seems to me that other factors should be mentioned in relation to

¹⁵⁸ [My emphasis].

¹⁵⁹ Ibidem, p. 20.

¹⁶⁰ Ibidem, p. 18.

¹⁶¹ American Cancer Society, *Cancer Facts and Figures*, Atlanta, 1992, table p. 3.

such a growth, since it is not explainable with the decrease of cigarette smoking.

The American Cancer Society was a place where the scientists I interviewed were uncomfortable talking about causes other than cigarette smoking, diet, and genetic predisposition. It was also a place where the stress over "choice" in lifestyle gave me an image of behaviors as disconnected from social contexts.

A primary prevention expert at the American Cancer Society, when asked about environmental factors in cancer, didn't want to provide any answer. After more questions, she mentioned second hand smoke as a possible environmental agent.

I don't have a good... I don't think probably I'm certainly the best person to talk about that. I would think Dr. ... (...) And I would say that I would let him be in the call in terms of *that definition*. (...) I'm dealing often with *individuals and individual behaviors*. And there's certainly "environmental factors" when the kids choose to smoke. Environmental tobacco smoke ... I think that in this sort of sense smoking is "environmental." [Interview N. 36]

I interviewed the scientist she referred to as the right person, to talk about environmental causes of cancer. He focussed his answer on tobacco, diet, genetics and radiation. His position on occupational exposure was the same one another scientists [Interview N. 43] gave me in Arizona: *it hits just a few people*. In his statement, it is interesting to notice how tobacco used to be considered a cause of a lung cancer¹⁶² -- and now it is represented as a "cause of cancer" in general. Yet, the same generalization seems not to be possible with other proven carcinogens.

Besides cigarette smoking? It is hard to generalize for cancer as a whole. Different cancers have different makeups in terms of what probably causes them. As a whole I suppose I would focus on doctoring the question. We left one part of the picture out of

¹⁶² Smoke also affects lips, buccal cavity, trachea - but doesn't seem to have much to do with colorectal and other cancers.

all of this discussion which is the genetic compound and causation and obviously that plays a big role. Not everybody's response to a particular level of carcinogens is the same. In the case of cigarette smoking, it is quite clear that there has to be a genetic determinant as well. [Interview N. 50]

While the interviewee is confident that tobacco can be generalized as "cause of cancer" he also states that it is difficult to generalize for other carcinogens -- since in that case "genetic plays a big role" in cancer causation.

An epidemiologist at American Cancer Society expressed a clear position about the environmental exposures. I think his statement is important because it gives an idea about how an ACS scientist positions himself when it comes to social risk, and which are the priorities. I am going to end this section with his interview because it contains an answer to the activists' concerns. It is an answer that many activists do not accept, as we are going to analyze.

They [activists] are off track in trying to necessarily link it [environmental exposures] to a cancer epidemic. (...) I don't think it is. I spent 2 years in New Jersey going around and looking at dumps and so on. What you find is that people's whole complex society tends to reduce environmental exposures. They bring their water in from somewhere else, they bring their food in from somewhere else. *People who live right on top of a dump are thousands of times less exposed* to some substance than the small group of workers who climb down in the kettle and chip the monochloride off of the coke oven, workers with the fumes rising up. There are just all of these systems that tend to reduce exposures unless there is a breakdown. The number of occupational carcinogens that are proven, one of the reasons why it is such a small list is because it tends to be *small groups of workers* and they have to be exposed a long time, there have to be records. The reason why it is so hard to prove occupational carcinogens is the same reasons why their probable total contribution is smaller than something which is much more common [sic]. If you give a figure, like cigarettes, where people go out and get addicted to it, they cannot change the amount of smoke. Every day they buy those packs and they suck those things into their lungs. That is really different from what people are trying to do at work. First of all, most of *those places have moved to Taiwan or some place else*. Secondly, *only the most desperate people will willingly work in a place with industrial fumes all day long*. [Interview N. 33]

A top epidemiologist at the Center for Disease Control in Atlanta -- who had been at the National Institute of Occupational Safety and Health doing research on workers exposed to PCBs -- focussed his answer on cigarette smoking.

I would answer that question in terms of preventable causes of cancer because preventable is really the major issue here and I would answer it very simply. *Smoking, smoking, smoking, smoking and smoking.* I would put all 5, if I had limited money, if I had money to go after preventing cancers in the world, I would focus as much attention and money as I could into cigarette smoking. [Interview N. 39]

It is interesting to notice that in his answer, the five main causes of cancer are in tune with American Cancer Society 'party line,' even though it contradicts his own experience of working on occupational carcinogens. Interestingly enough, his position is that smoking is *the only preventable cause of cancer* -- a paradox that may suggest reflections on the authority and the power ACS's definitions have in the field.

4.5. What Scientists Say About Cancer & Environmental Factors: Two Poles in the Debate

During my interviews I asked the scientists to tell me what they consider to be environmental causes of cancer in order to map the debate around the definition of environmental cancer and to locate themselves somewhere -- then I analyzed their classifications.

As Adele Clark and Teresa Montini pointed out in a similar work concerning the debate around RU486, we need to discuss any specific medical/scientific/technological issue as "contentious arenas

composed of heterogeneous actors committed to action on the core issue."¹⁶³

My approach in analyzing how scientists deal with the environment as a controversial category in cancer etiology has been influenced by Goffman's ideas on the theater of everyday life and by Bourdieu's theory of the control over the "field."¹⁶⁴ I also had theoretical insights and stimulations from the reading of diverse sources which allowed me to understand that "science is politics by other means"¹⁶⁵ and "technologies are places where people meet."¹⁶⁶

In the scientific community I often noticed a lack of self-reflection on the work performed, its methodology, and the socio-political context surrounding the directions of the scientific production. As Stephen Jay Gould wrote, most scientists are objectively part of the system that produces and reproduces them as a privileged elite. Some struggle against the *status quo*, but many tend to accept the dominant paradigms -- the given order of the things, as Foucault would call it -- rather than to challenge it.

Science is no inexorable march to truth, mediated by the collection of objective information and the destruction of ancient superstition. Scientists, as ordinary human beings, unconsciously reflect in their theories the social and political constraints of their times. *As privileged members of society,*

¹⁶³ A. Clarke, T. Montini, "The Many Faces of RU486: Tales of Situated Knowledges and Technological Contestation," in *Science, Technology, and Human Values*, Vol. 18, N. 1, Winter 1993, pp. 42-78.

¹⁶⁴ Here I am using the term "field" in the meaning given by Bourdieu - after his systemic fever - in *Ce que parler veut dire* and in *Le sens pratique*. The field does not have a fixed structure and its boundaries are continually redefined. Yet, relativity of actors and situations works only inside certain structured fields. Fields in Bourdieu's theory can be defined as synchronic spaces concerning positions, sets of rules, and rituals of exclusion. Everybody belong to a field: *tout les gens qui sont engages dans un champ*.

¹⁶⁵ B. Latour, *Science in Action: How to Follow Scientists and Engineers Through Society*, Harvard University Press, Cambridge, 1987.

¹⁶⁶ E.C. Hughes, *The Sociological Eye*, Transaction Books, New Brunswick, NJ., 1984.

*more often than not they end up defending existing social arrangements as biologically foreordained.*¹⁶⁷

Here I am going to juxtapose and analyze some of the answers given by scientists concerning the environmental aspects of cancer. The quotations I have chosen do not wholly represent the diversity of scientists' positions about environmental causes of cancer -- yet the reader will be offered a wide range of variance.

The choice of which quotations to use has been also affected by other factors. While each of the interviewees gave me a position on the issues I was raising with my questions, not all of them offered an articulation of their thoughts on the subject matter. Those who did, provided long answers -- probably because the language used by scientists is much different from the language used by sociologists -- and their statements are often very wordy. Part of the answers are provided in appendices.

If we place scientists on a continuum about their opinions on the importance of environmental carcinogens in cancer causation, on one end we would have Bruce Ames, and on the other end Samuel Epstein. The only thing they have in common is being vocal: they both write many articles and make use of the press to popularize their ideas in terms of cancer causation.

Epstein is Professor of Occupational and Environmental Medicine, School of Public Health, University of Illinois at Chicago. In 1974 he was the key expert for EPA in achieving the cancellation or suspension in the agricultural use of chlorine and heptachlor¹⁶⁸. Working with public interest groups, Epstein and his contingent of heretical scientists managed to force it off the market [see Appendix

¹⁶⁷ S.J. Gould, *Ever Since Darwin. Reflections in Natural History*, W.W. Northon & Company, New York, 1979, p. 15. [My emphasis]

¹⁶⁸ Chlorine and heptachlor are still used for termites extermination: the industry maintained that when it is used underground for termites you don't get the same exposure - which is not considered to be true by critics.

11]. Epstein -- as opposed to Ames -- believes that chemical carcinogens in the environment are a main cause of cancer:

I testified before Rep. Henry Waxman [D-CA] in Summer '87 about the problem of chlorine and heptachlor used for termite treatment ... they represent perhaps *the largest single source of avoidable carcinogens*. There is a very high incidence of misapplication and even when it is treated properly the home becomes contaminated ... it will be contaminated for 20-40 years.

Epstein is convinced that cancer is the illness that allows us to better understand the impact of the environmental degradation on human health.

Cancer is the only disease for which we have clear quantitative data. If you want to use *cancer as a paradigm of the public health issues* ... we don't have quantitative data when it comes to birth defects of neuro-toxic effects ... but on cancer we have quantitative data on trends, incidence, mortality, quantitative data on production of synthetic chemicals and carcinogens. So if you want to get a handle, the only way of doing it is on cancer. It is the only quantitative way because if you were to focus on birth defect -- a very important area -- you would get nowhere with it, because we have no quantitative data to back it up. And the other point is that most carcinogens have a wide range of other effects -- neuro-toxic effects, immunologic effects, So it [cancer] is an excellent quantitative index of environmental degradation.¹⁶⁹

Epstein does not criticize the way data is collected. Even by using official quantitative data of incidence and mortality -- going back to the 1930s -- he believes the relationship between cancer and environmental degradation is clearly demonstrable.

[Cancer] is the only disease that really reflects the relationship between cancer and environmental pollutants, clearly linked by toxicological and epidemiological studies.

Bruce Ames, is a Professor of Biochemistry and Molecular Biology, and the Director of the National Institute of Environmental

¹⁶⁹ My emphasis.

Health Sciences. His studies on chemical carcinogens in the seventies have been largely used by environmentalists and cancer activists. Now his main research interest is "natural carcinogens." Ames' shift of position, which dismisses the importance of chemical carcinogens, opened polemics in the scientific community and accusations of betrayal from the activists. His position about cancer etiology is that

There's three huge risk factors out there: one is diet, one is smoking and one is chronic infections. And then of course there are some genetic factors.

Ames does not dismiss completely the impact of environmental carcinogens that are not under individual control. Yet he is convinced that they account for so little in terms of cancer causation that we should put all our efforts in doing research on preventing those factors individuals can control.

In cases like pollution, the individual breathing in dirty air in Los Angeles, you don't have too much control. You can move out of Los Angeles if you like to, but you have less control, or if there's something in the water you can buy bottled water to drink, but you have less control than something to do with your diet or if you smoke.

Even though most of the primary prevention and research is done on tobacco and diet, Ames argues that scientists should do more research on the main factors -- cigarettes and nutrition instead of wasting their time on uncertain or minor causes. [see Appendix 12]. He believes that pollution and pesticides do not have anything to do with cancer causation

I don't think pesticide residues have ever caused a case of cancer.

Between the dichotomous positions expressed by Ames and Epstein -- both top scientists in the U.S. -- there is a "center" that

represents a wide range of intermediate positions. Yet, each one can be recognized as either closer to one or to the other pole.

4.5.1. Environmental Carcinogens As a Negligible Cause of Cancer

I interviewed a high ranking epidemiologist at University of Arizona, Tucson, whose research on cancer began nearly 20 years ago. Since Tucson is the U.S. capital of skin cancer he is involved in cancer prevention studies, looking both as a primary prevention agent as well as secondary prevention in patients who already had cancer.

He considers the exposure to chemical carcinogens in the environment as unimportant. Interestingly, he also dismisses occupational exposure, including asbestos [see Appendix 13]. In his statement there are a few issues that need to be brought to attention. The scientist admits that "there are occupations that have tremendous exposure to carcinogens" -- but he does not consider the major cancers as being affected by such tremendous exposures.

The exposure is "tremendous" but somehow he does not see any impact on human health. In his long discourse, he seems to ignore large amounts of literature produced on lung cancer related to occupational hazards, breast cancer related to pesticides, and other chemical carcinogens.

The scientist is re-assuring himself by saying that *only few people* are affected -- at least in the U.S. by such "tremendous" exposure. In his statement we can notice the minimization of the problem of occupational exposures -- and the awareness that the decrease of occupational exposure happens *here* -- in the U.S. -- and this might not be true somewhere else, e.g., where those hazardous jobs have been exported.

I don't think I would put occupation among the first major causes of cancer because if you look at the major causes of cancer -- lung cancer, breast cancer, prostate cancer, colon cancer I am not convinced that any of them have a major etiology from the

occupation. Clearly there are occupations that have *tremendous exposure to carcinogens -- but those occupations tend to be relatively few in United States now.*

(...) There are exceptions, *certain occupations, certain environments ...* But I think general chemical carcinogens are not the most common cause of cancer. There are toxic chemicals in fertilizers, in agriculture -- it is certainly a concern in Arizona, where, believe it or not, without any water we have a major agriculture industry that use a lot of pesticides. And for the *few people who are applying the pesticides* there is probably a serious concern. In *large numbers of people who live in the region* -- there is not much convincing information that it is a major cause of cancer ... there are some associations with pesticides and leukemia -- but again you are talking about *those who are applying the pesticide, not the person who happens to live in the same city.* [Interview N. 43]

The rhetoric behind the legitimization of the fact that "few" producers -- versus large number of consumers -- can be exposed informs the statement of a toxicologist: "because they are paid for it."

With regard to environment I'd mean involuntary exposures ... things you can't avoid. Things in your drinking water, things in your air, pollution, etc. You can't avoid them. Whereas with occupation, theoretically you should know what you're working with and you should know that it is potentially dangerous. So, with regard to occupation, I think it's different, so it's a voluntary exposure almost. *Because you're being paid to do it.* [Interview N. 38]

The attitude of blaming the victim was less explicit yet not much different at National Cancer Institute, where a scientist -- who asked me strict confidentiality -- admitted that chemical carcinogens are a cause -- even though s/he defined this as a problem mostly for those who are genetically predisposed.

I think, chemicals interacting ... in some susceptible population. I think, chemicals account for a large amount of the risk. I think in other *non susceptible population* that they probably account for less of the risk. It is not too much. Again I would say tobacco and diet, and exercise account for a substantial amount of and *personal susceptibility* accounts for a certain amount. I would not say it is 5%, I would not say it is 50%. Somewhere in between.

The "sacrificed minority" seem to belong conceptually to two categories. If we think in terms of civil society, they are the producers and those who Troy Duster defined as the screened community.

Indeed, one of the significant ironies is that today's technology tells us that socially identifiable groups such as Jews, blacks, Greeks, Italians and women of a certain age can now be cost-effectively screened for genetic disorders. (...)

In the "community" of those screened, louder voices will be heard in the next decade about who screens whom for what purpose. (...) Japan, India, the United Kingdom, and every European nation will join the United States within the next decade, either in deliberately confronting the social policy issues inherent in a pursuit of the new technology, or in back-sliding into unexamined practices with a 'eugenic' outcome. To put it metaphorically, when eugenics reincarnates this time, it will not come through the front door, as with Hitler's *Lebensborn* project. Instead, it will come by the back door of screens, treatments, and therapies.¹⁷⁰

In terms of class and race analysis, the sacrificed minority is composed by those who don't have control over the centers of economic and political power: the employed and unemployed sections of proletariat -- who are mostly people of color. In these categories we can find with a good degree of predictability, those whose lives are considered to be more expendable than others.¹⁷¹

A high ranking scientist at the National Cancer Institute was specifically hired to investigate the "environmental causes of cancer." Most of what he does is administrative. He deals with people on the staff and with people on the outside, finding resources and handling the necessary paper work for the bureaucracy. He complains that he does less and less research on his own as time passes, because it takes more and more effort on the administrative side. On a day to day basis he spends no more than 10% of his time directly on

¹⁷⁰ T. Duster, *Backdoor to Eugenics*, Routledge, New York, 1990, pp. viii-x.

¹⁷¹ P. Shipman, *The Evolution of Racism. Human Differences and the Use and Abuse of Science*, Simon and Schuster, New York, 1994.

research and 90% on administrative activities: chairing meetings, organizing work groups internally (within the government) meeting people from outside the government, handling press calls. *Ten years ago 70% of his activity still consisted in conducting studies,* generating new data, analyzing the data from various studies to look at environmental and occupational causes of cancer. His answer was focussed on cigarette smoking.

I. 56 Smoking is clearly the number one cause of cancer in the United States -- and probably the number one cause of cancer everywhere in the world. It dwarfs everything else. And so its a major

L.C. Africa too?

I. 56 I think so ... probably ... I mean they smoke. And there is such a big risk factor for the major cancers ... it's just the number one cause. Then I guess the next level of -- if cause means both initiating and preventing [here what he probably wanted to say is initiating and promoting] then probably diet is number two. [Interview N. 56]

The interviewee estimates that environmental carcinogens account only for "2% to 15% and sometimes are up around 30%. But *typically* it is around 5%. And that's probably not too far off, if it's 10% or 15% it's still roughly in the same ballpark."¹⁷²

A cancer epidemiologist at UCLA, ranks environmental causes of cancer in the third spot, after tobacco and nutrition. Nevertheless he is convinced environmental factors play a small role if compared with the main two -- and he believes they do not account for more than 5%.

Then there are other environmental causes, some of them from occupational exposure -- as for example asbestos -- which will induce lung cancer by itself and when combined with cigarette smoking will vastly increase the risk of lung cancer.

¹⁷² If the interview was about taxes, 5% or 15% would make an enormous difference - while talking about someone else's lives, and not about his own money, suddenly numbers become somewhat less rigid. See Appendix 14.

There are certain dyes in the chemical industry that induce cancer of the bladder, many forms of occupational exposures ... environmental exposures, chemical exposures, that cause cancer. But in my view the totality of all those forms of environmentally induced cancers -- apart from tobacco -- are something like 5% or less of all cancers, where as cigarette smoking alone causes now 30% or more deaths from lung cancer. (...) These papers and magazines print a lot of stories about the carcinogens in the food. I think that they may play some role ... But it is hardly measurable -- you can hardly measure the precise role that carcinogens that are sprayed on food, for example as pesticides. [Interview N. 54]

In the attempt to disregard environmental carcinogens, the interviewee stated they are "hardly measurable" -- while other scientists, who share the same position he has on the carcinogens role in cancer causation, admit they are measurable.

4.5.2 Environmental Carcinogens As a Main Cause of Cancer

Nicholas Ashford is a Chemist and Professor of Technology and Policy at MIT. His early interest was in occupational cancer, and then environmental cancer -- specifically in linking chemical exposures with cancer in working populations and then later on in populations in the surrounding geographical areas. He calls "contaminated communities" places where people live and chemical industry is concentrated.

Well, you know ... the causes of cancer are "unknown" and the increases of certain types of cancer are going on at fairly rapid rates, and the work of Devra Davis in her book on "age-dependent" cancers In the case that if you look past the age of sixty-five, you find that cancers were increasing, which means that the cancers were initiated earlier ... What could explain this wide geographical and occupational variation if it's not chemicals?

I asked him to rank what he perceives to be the five main causes of cancer. He put radon as second single cause of cancer, after tobacco.

I mean the overwhelming first cause is tobacco, but that's very specific to lung cancer. We're talking now about ... numbers ... probably radon. (...) I think radon is pretty high. It's probably the second most significant cause of lung cancer, which is one of the largest causes. You know, indoor radon.

The concern about radon as a cause of cancer is shared by epidemiologist Richard Clapp at the John Snow Institute in Boston.¹⁷³

Clapp is not an activist -- yet the work of his Institute is very useful to concerned citizens and activists. He offered a detailed assessment of environmental causes of cancer. After ranking cigarettes as first cause of cancer, diet and the carcinogens in food and water as second, and occupational exposure as third factors,

Fourth, probably in my view would be general environmental exposures and I include in that Radon gas that is from deep underground wells where Radon is dissolved in the water and comes up into people's homes, or in their basements gas that seeps from their basements into their household air, as well as sunlight, ultraviolet light. I think that is a general environmental exposure. Then also toxic chemicals that have gotten into people's drinking water or even airborne chemicals that are carcinogenic.

In his assessment of diet also Ashford accounts for the carcinogens people eat with food instead of just focusing on fats and fibers in their nutrition. While not a scientist/activist in strict terms, his work has been useful to those involved in political issues around primary prevention

¹⁷³ During an epidemic of cholera, in London, a famous epidemiologist named John Snow around the year 1720 started doing maps of where people were doing cholera and found that basically the people getting cholera lived in a certain area, and this area happened to be centered around a particular water pump. Snow started talking to the medical community about how this disease could be water-borne, and everyone thought he was a lunatic. The idea of a disease being borne by water was unacceptable to the scientists of his time. Snow became the laughing-stock of the medical community and eventually was kicked out. But he was convinced about this, and one morning he got up early and took an axe and chopped the handle off this pump. In that precise moment of illegal/subversive action, the cholera epidemic was defeated.

Uhh, the third ... I mean, there are multiple causes: the question is dietary fat, in combination with chemicals. Because we're finding out the association between PCBs and breast cancer, and we also know that there's a notorious relationship between fat and a lot of kind of cancers. But you see, fat concentrates those chemicals. (...) So I would not put diet separately and just say "diet", you know, as a third cause. I would say "diet plus chemicals that concentrate in the lipid system, fat system" (...) Diet meaning carcinogens in the diet, as opposed to fat which harbors promoters.

I noticed important knots where scientists displayed disagreement: the amount of carcinogens released in the environment; the percentage of cancers occupationally related; and the assessment of how much occupational carcinogens will eventually extend their action out of the boundaries of the factory. Even data about the increase or decrease in cancer incidence seem to be controversial. While Ashford argued that "the increases of certain types of cancer are going on at fairly rapid rates," a woman epidemiologist in Chicago is convinced of the opposite. While Ashford thinks that a lot has to do with chemical carcinogens intoxicating whole communities, she has a different opinion and believes that today in the United States people are exposed to environmental carcinogens to a lesser extent than in the past.

The contradiction about lung cancer rates emerges clearly in her statement. The interviewee thinks lung cancer is decreasing because people are quitting smoking, while Ashford -- and the data provided by ACS -- suggest that lung cancer is increasing even though people are smoking less. I am presenting her statement in this section to provide a comparison between the two scientists' arguments -- even though the interviewee is among those scientists who believe carcinogens account for much, in cancer causation.

The cancer rates have really not been increasing that much, so that's kind of a difficult question. *If* the level of environmental exposures to carcinogens increases, then there *might* be an increase. Now whether that's really going to happen, it's difficult for me to say. (...) I think it depends on the specific kinds

of cancer you're talking about. Like, we know lung cancer has been declining, because people have stopped smoking more. (...) Yes, here, right. If you're talking about the U.S., *I don't see that there are a lot of new carcinogens being released*, or people are being exposed to more than in the past ... It's a difficult question; I can look at the trends of cancer rates, and I don't see any large increases now. Whether the exposures today are going to lead to increases in cancer rates in the future. [Interview N. 44]

Sandra Steingreber, like other scientist/activists, is convinced that chemical carcinogens rank high in cancer etiology. Her discourse about etiology is both technical and political. On one hand she adopts the epidemiological definition of environment -- on the other hand she does not accept the dominant rhetoric around diet and the other factors upon which people are supposed to have control.

Like other scientist/activists, she states that the importance of chemical carcinogens is indisputable. It seems that on one side we have a majority of scientists -- "the cancer establishment" -- who seem to ignore or actively dismiss the body of evidence produced against chlorine, pesticides, and other such factors in cancer causation. On the other side we have scientist/activists who do not have any doubt about environmental carcinogens, even if they have different positions in terms of primary prevention.

Her position may sound very radical. My intuition is that, since the debate over environmental causes of cancer is becoming a hot issue, less space will be left for moderation and half-way positions. Also those scientists who have doubts make statements that can be inscribed either within the margins of the dominant paradigm or outside, with the "heretical" -- and their supporters.

Steingreber had cancer herself when she was very young, as a college student: the choice of activism was prior to becoming a cancer scientist.

I'm convinced by the arguments that 80 percent of cancers are caused by environmental factors, and I don't think there's any real dispute about that.

Sandra Steingreber also thinks we cannot talk about causes of cancer in general terms: each community, each geographical area has specific problems. The same can be said about gender, age, and ethnic groups. In the following long statement she explained her philosophy of cancer etiology with respect to environmental exposures [see Appendix 15].

One thing, I think, that one could say: If you divided the environment up in another way and just said that everything we're taking into our bodies comes from essentially three sectors: air, food and water ... I would imagine that food would be more important, because since the chemicals have been already run through another organism, either plant or animal, we know that carcinogens concentrate as they go up the food chain, so presumably every time we take a breath we are getting less of whatever is in the air than if we eat an animal or plant that grew in that air, because they have concentrated that, and we are going to concentrate it further.

Steingreber talked about diet as a vehicle by which we take carcinogens into our body -- instead of looking at "choices" of nutrition.

4.6. What Activists Say About Cancer and Environmental Factors.

In this section we are going to listen to some of the activists' answers about the environmental connection in cancer causation. Most of the interviewees are women who have survived cancer. The gap between their language and the scientists' jargon is noticeable. Most of the interviewees do not have a scientific background. I didn't make corrections in their discourse around causes of cancer. In their answers there is sometimes the attempt to understand which factors might have affected them personally, and to historicize their involvement in cancer activism, usually after a few months from their diagnosis.

Elizabeth Kuper-Herr is an ovarian cancer survivor and activist in Hawaii. To her the environmental connection is the most important factor -- at least for the type of cancer she had. For ovarian cancer, only two specific causes have been identified. One is talcum powder, and the other one is atrazine, which is a rather widely-used herbicide. To her the environmental connection is the most important factor.

Ovarian cancer is basically environmental in origin. There's just so much contamination in our environment, and I feel very convinced from the reading I've done, that that's is behind the majority of this cancer and other cancer. (...) [how much is] under individual control? My gut reaction to that is maybe 5 percent, maybe more, maybe not even that much. I really think a tremendous amount of it is beyond our control. And I've heard so many women say, "Oh, I must change the way I eat," and I've changed the way I eat, but they ignore the fact that's a very small part of one's total environment, you know when you eat you're taking in part of your environment. But there's an awful lot that we can't control. We can't control the air we breathe, or the water that we drink or that we bathe in, or our workplaces. So there's very little an individual can do to control those things. Now, in group action we can try to have some impact on those factors.

Betsy Lambert is an activist at the National Breast Cancer Coalition in New York, who works closely with the medical profession. She believes the search for a cure is very important. She is white, middle class, and survived breast cancer. Her mother and aunts never had it. Yet, about cancer causation, she ranks genetics first. After considering the factors she had put in the category "environment" -- during a long monologue I didn't interrupt -- Betsy Lambert concludes that all these factors might have some effects on the genes [see Appendix 16].

Ellen Crowley, white cancer activist works with the Women's Community Cancer Project (WCCP) in Boston. She mentioned the feeling of isolation when she addresses environmental causes of cancer in places other than the activists' meetings. Even though she

doesn't have a "political" background, she told me that, when it comes to the environment,

... there are people who are denying the truth. (...) It is more coming from professional groups that say women are just getting breast cancer because mammograms pick them up earlier. Or they are getting breast cancer because they are growing older. I was on a television show ... I felt like I was a Martian talking about the environment and increases in cancer.

Dianne Williams, Native-American, points out the negative impact of a number of factors in her ethnic group. Her job is one of a committed health promoter in the Native American community. Williams believes more in health promotion than in primary prevention. I am going to discuss the specific position of Native people on this issue in the chapter on primary prevention strategies. What we need to know before reading her statement is that her distrust in preventive practices and her emphasis on behavior control is not in contradiction with the importance she gives to environmental causes of cancer. It is a way of empowering people, focus on strengthening their immune system, instead of relying on prevention programs that are so rarely implemented.

Yes, we have one of the highest rates in gall bladder cancer so we have 7 out of 10 Indian women getting their gall bladder removed ... Nobody seems to have any answer in the medical profession nor do they have a plan ... *they throw around words about heredity* ... and I really don't go for that ... I think a lot more stands for diet, the poor diet we have adopted -- what I called *the white men's food* -- I think our diets are horrendous. I even looked for a comparison with people who are sort of close cousins to us -- the Hispanics. They have an overall more healthy diet ... we really have a poor diet. And we are adding bad habits to that: high rate of smoking and alcoholism ... this put us tremendously at risk. And these are behaviors we do have the ability to change -- this is what I am interested in working in my community: changing those behaviors. I'd like also to stop the uranium mining and some other things like that -- of course this would involve the environmental exposure that might cause cancer but I try to focus more on what I can do on a day to day basis. So I work with my community on behaviors' modification.

Dianne Williams became a liaison between her community and the cancer movement in the Bay Area. In Fall 1994 her organization participated in a demonstration of women survivors and people of color against the "corporate polluters" such as Chevron and Bechtel, and the offices of the American Cancer Society and California EPA, for their silence and complicity [see Appendix 19].

Among the scientists/activists I want to include Paul Brodeur who -- from the New Yorker's columns and several books -- greatly contributed to creating a public consciousness around asbestos in the past. What got him interested in the environmental causes of cancer?

I met in 1968 Irwin Selikof, the great asbestos epidemiologist in NY -- he had organized and directed the first big international conference on the biological effects of asbestos. I read his studies and I went around the country to interview people and realized that there was a big cover-up of the problem by the asbestos industry and by the government and I wrote a piece in the New Yorker called "The Magic Mineral" in October 1968, 25 years ago this month. (...) 20 million American have been heavily exposed to asbestos during the war time years in the shipyards alone. By the time I wrote about it was sprayed on every building in the city. On the average skyscraper 200 tons of asbestos was sprayed -150 tons were lost in the air. People were walking around the city in clouds of it. Everybody (...) shows traces of asbestos in their lungs. (...) The AMA [American Medical Association] would not admit that asbestos was a major cancer producing hazard ... magic.

Paul Brodeur today is conducting a battle to have electromagnetic fields (EMF) recognized as a major cause of cancer. What is he relying on, to make this statement? And why there is so little attention to this possible factor in cancer etiology?

Of the sixty studies that have been done in the last 14 years almost 60% are statistically significant positive association between exposure [electromagnetic fields] and cancer. 85% are positive to some degree or other only 12% are negative -- and of this 12% almost all have been conducted by industries. And these are not my statistics, these are in the EPA report. (...) Selikof and allowed

me to follow him around, like an intern. He taught me about epidemiology, he taught me how to screw it up by screwing around with the control group. Or you submerge the disease in a huge population. (...) There is no money to study the electric power fields except industry money.

Brodeur told me about Dr. Malinowski, a woman epidemiologist who obtained \$350,000 from the Electric Power Institute in Palo Alto in order to study the telephone company workers -- not the electric ones.

They persuaded her to study the telephone workers -- all 52,000 including the women who make sandwich in the cafeterias, the guys who change the trucks tires That's how you submerge any possible disease in a huge sea of people.

During her study, Malinowsky notices that 4,500 cable workers -- average age 40 -- present 700% more leukemia, 200% more brain cancer and 400% more prostate cancer than average the prostate cancer. Brodeur concluded by stating that

... it was the first time a scientist spoke up against the electric utility industry in US. -- and she did it because she is mad at them, they are lying about her research. She will never get another dime from them, but that's how it works.

Eva Dorial, of the United Farmer Workers, showed me a video about the effects of chemical carcinogens on the workers and their children, interviews with women who work in the fields and have early cancers, images of impressive birth defects. Poor houses, barracks.

Eva is 47 -- but looks younger "it is because I am an organizer, and because I work with Dolores [Huerta]" who is 65 and never stops "she is always on the go, and so accessible, she always says yes, physically I don't know how she can keep it up."

Eva has been a volunteer since 1971, when she moved to San Francisco. She became a staff person in 1990. In the last ten years she has been involved in the boycott of table grapes, a boycott

organized by the Union to stop the use of cancer causing pesticides that are sprayed on grapes.

Farmworkers got unionized to gain better wages and conditions from the growers, the powerful agro-business. Among their achievements: water, toilets, and other basic things that other workers already had, were given not without struggle. The philosophical principles of the United Farmworkers: non-violence, voluntarism and public action -- have been able to keep the Union together, at those times in which the growers were coming to the picket lines backed by the police.

Eva tells me that those working full time for the Union are given enough money just for their expenses and food -- and that their beloved leader Cesar Chavez never earned more than 5,000 dollars a year. Eva has four children and is supported economically by her husband. She cannot speak about causes of cancer without talking about prevention. And the first step toward prevention for the United Farmer Workers means grape boycott.

The first grape boycott resulted in the first grape contract in the field, the second boycott resulted in the passage of the Agriculture Labor Relations Act in the Commission in California, that gave the workers the right to be organized, and to belong to a Union. In 1984 the third grapes boycott started, and it was to eliminate the use of pesticides that are known or suspected to cause cancer and birth defects. The boycott went on for 10 years and still now, against all table grapes."

The boycott is part of the public action strategy and it consists of convincing the consumer not to buy grapes, for their health (most of the pesticides are oil based and cannot be washed off) and to help the farmworkers in their struggle. Grapes are the number two crop in terms of use of the pesticides -- after cotton.

"The result of farmworkers putting pressure on this issue is that some pesticides have been eliminated," says Dorial, but this is not enough, to face a situation where clusters of cancer in the sites where grapes are grown, are quite impressive:

In the central valley the rate of cancer is from 8 hundred to 14 hundred times higher than the norm -- in those small towns. But the only thing the government does is keep doing more studies: the growers are so powerful in politics, they get politicians elected.

As I am going to discuss in chapter 7, economic and political power are often mentioned among cancer activists.

4.7. Conclusion

What the scientists interviewed said about environmental factors in cancer etiology can be classified as follows:

- those who give high rank to genetics and lifestyle factors tend to disregard other environmental exposures. These scientists also tend to speak about behaviors as a personal responsibility.
- those scientists who give high rank to environmental and occupational carcinogens tend to explain genetics as a predisposition that can be triggered by exogenous factors. They also tend to speak about behaviors as socially constructed -- to different degrees.

Often, what the scientists said about cancer causation was inconsistent with the primary prevention strategies they were advocating. In general, I would say that scientists displayed more freedom when talking about causes than while strategizing about prevention.

In their etiological discourse they cite occupational exposure more frequently than in their preventive planning. They probably feel, as many activists, not much can be done if it goes against the interests of large corporations. Some scientists mentioned they want to be "socially responsible" toward the companies and don't want to harm business. Others expressed more concern toward the workers and the communities located around the sites where potentially hazardous productions take place.

Some scientists mentioned low frequency waves and electromagnetic fields as possible causes or as factors we need to know more about. The contradiction in terms of primary prevention was even sharper in this matter -- as well as the feeling of helplessness. The common idea that many carcinogens are *necessary* and *unreplaceable*, that we cannot live without this electricity and these computers, creates a mind set which is conjugated with the absence of funding for scientific research in those fields and *de facto* prevents most scientists from developing knowledge of these subjects.

Activists tend to be more homogeneous in their accounts of environmental causes of cancer. They tend to give relevance to those cancer factors that are not under the subject's control. When it comes to behaviors, they think smoking and diet can be considered a personal responsibility only to some extent.

Even those activists who are convinced about the main role played by genetic predisposition also think that cancer institutions and scientists are not putting enough effort in preventing known environmental causes. They mention frequently pesticides, herbicides, fertilizers, and organo-chlorine. Activists also would like to see more efforts in researching unknown or controversial factors that might be related to cancer, such as low frequency waves and electromagnetic fields.

Chapter 5

RACE, CLASS AND GENDER
IN CANCER CAUSATION AND PREVENTION5.1. Introduction

The Department of Energy has systematically bribed indigenous people in the US (...) to accept the radioactive waste on their reservations -- for a price, of course. Native American women and children are experiencing reproductive organ cancer at 17 times the national average.¹⁷⁴

In the first part of this chapter I am going to analyze how class race and gender factors are accounted for in two main cancer institutions. I will also offer critical remarks about the data. In the second part of the chapter I will present a Native-American perspective on cancer causation and prevention, and an interview on the connection between cancer activism and the environmental justice movement on issues of cancer causation and prevention.

In the last few years several studies have been done to demonstrate that environmental problems do not affect everyone equally. A new conceptual term "environmental racism" has been forged to explain the different ways in which people of color are impacted by pollution, toxic dumping, pesticides and other poisons.

¹⁷⁴ K.J. Warren, "The Earth Summit and Women," San Francisco Examiner, June 19, 1992, p. A20., quoted by J. Brady, "Environmental Pollution and Breast Cancer Among American Women: Problems of a New Political Movement," International Conference on Women's Health, Beijing, China, March 27-April 8, 1993.

Charles Lee in *Toxic Waste and Race in the U.S.* ¹⁷⁵ demonstrates that 50% of all Native Americans and Asian families live

- a. in areas with uncontrolled toxic sites;
- b. in houses built before 1950, which exposes them to toxic lead paint; and
- c. in neighborhoods with heavy automobile traffic.

Dana Alston and Nicole Brown studied the linkage between local forms of environmental racism and global environmental issues where race and poverty play an important role. They see the capitalistic dispossession of third world people and resources as connected with the structures of inequity and injustice that people of color experience in United States today.

If we examine environmental issues internationally, the same domestic pattern of disproportionate exposure to environmental hazards and degradation exists worldwide among those who are nonwhite, poor, less educated, and politically less powerful.¹⁷⁶

Even though I am not going to discuss here the contribution of the Environmental Justice Movement in depth, I want to mention the struggle of this new movement against pesticides, nuclear waste and other carcinogens, since their main targets are the targets of the cancer movement. The connection between cancer activism and the environmental justice movement are discussed in the last section of this chapter.

In 1991 the First National People of Color Environmental Leadership Summit was attended by African-Americans, Latin-Americans, Asian-Americans and Native-Americans. It is very meaningful that the fourth gathering of Environmental and Economic Justice Movement in July 1994, Las Vegas, saw the participation of

¹⁷⁵ As mentioned in P.T. Lee, "Misleading Assumption. The Case of Asians and Pacific Islanders," in *Unity*, Vol. 16, N. 1, 1993, p. 6.

¹⁷⁶ D. Alston, N. Brown, "Global Threats to People of Color," in R. Bullard, *Confronting Environmental Racism*, South End Press, Boston, 1993, p. 179.

cancer activists, people of color from all communities -- including Korean-Americans and Chinese-Americans -- and representatives of indigenous populations from Chiapas, Mexico. At the meeting the necessity of a national and international movement of all peoples of color was reaffirmed.

Robert Bullard, a highly respected social scientist in the U.S. academia, and an activist, is one of the most prominent intellectual leaders of the Environmental Justice Movement. In his books¹⁷⁷ Bullard collected a body of studies that constitute evidence no longer to be ignored. He also provides a picture of environmental racism that ranges from the lead poisoning of millions of inner-city children -- mostly African Americans and Latinos -- to the "Cancer Alley" in Louisiana, where 85 miles of Black communities (the area between Baton Rouge and New Orleans) have their lives put at risk by corporate polluters.¹⁷⁸

5.2. ACS's Account for Class, Race and Gender in Cancer Incidence

Because of the differences between institutional actors in the cancer arena and because of the relative complexity and history of cancer institutions -- which will not be discussed in the present work -- I have chosen to analyze only the two main institutions, the American Cancer Society (ACS) and the National Cancer Institute (NCI).

In both institutions there is a noticeable lack of discourse and analysis of race, class and gender in cancer causation and prevention. In the ACS publication "Cancer Facts and Figures" only one half page is devoted to "cancer in minorities." In that half page, the reader can find some reference to stratification and differences existent in the

¹⁷⁷ R. Bullard, *Dumping in Dixie: Race, Class and Environmental Quality*, Westview Press, Boulder CO, 1990; R. Bullard, *Confronting Environmental Racism*, South End Press, Boston, 1993.

¹⁷⁸ I have interviewed Robert Bullard on cancer causes, primary prevention, and cancer activism among people of color in the United States in section 6.5.

population. However their sociological analysis is very timid and fails to address social inequalities. ACS ascribes cancer risk to cultural differences, rather than economic and racial inequalities.

From the ACS point of view, stratification in cancer risk does not occur because of class and race -- in terms of the physical and social environment's impact on different communities and categories of citizens. According to ACS, differences in cancer distribution happen because of different attitudes -- such as nutrition habits, sexual behaviors, age of first pregnancy. These factors are not seen as a social constructs -- they are seen as affected by ethnic cultural differences rather than by class factors. Nutritional habits, sexual behaviors, and age of first pregnancy are represented as primary causes, instead of being understood as secondary to -- and products of -- social and economic problems.

Because cancer risk is strongly associated with lifestyle and behavior, *differences in ethnic and cultural groups can provide clues* [sic] to factors involved in the development of cancer such as dietary patterns, alcohol use, and sexual and reproductive behaviors.¹⁷⁹

The specific culture subjects bear is seen as an obstacle to access to medical care -- while class factors are not analyzed. "Socioeconomic factors" are accounted for *en passant* in the paragraph on cancer mortality -- while they are not even mentioned in the paragraph on cancer incidence.

Cultural values and belief system can affect attitudes about seeking medical care [sic] or following screening guidelines. Socioeconomic factors such as lack of health insurance or means of transportation can impede access to care, leading to late diagnosis and poorer survival.¹⁸⁰

¹⁷⁹ American Cancer Society, *Cancer Facts and Figures*, Atlanta, 1992, p. 16. My emphasis.

¹⁸⁰Ibidem.

The statement is inaccurate, and in addition no clue is offered about how these differences play out for site-specific cancers and their causes. For example, throughout the publication *Cancer Facts and Figures* you can find statements like "rates for esophageal cancer are over three times higher among blacks than whites," but no explanation follows this description.

Some explanations are offered in the publication *Cancer Facts And Figures For Minority Americans*, where all the data per ethnic group and some analysis are located. The data provided by ACS is organized by site (specific cancers) per 100,000 population.¹⁸¹

The first table shows that Blacks have the highest incidence rate for all cancers combined, followed by Native Hawaiians. Breast cancer is the main one in terms of impact for Native Hawaiian, White, Chinese and Japanese people, while it is prostate cancer for Blacks, Filipinos, American Indians and Mexican-Americans. No explanations are offered for such differences -- nor working hypotheses.

The "explanations" offered by ACS on ethnic variation in cancer incidence are mainly descriptive. Differences in the cancer incidence are said to be "due to cultural, environmental, or hereditary differences in various groups."

Even though it is not stated with clarity, environmental factors emerge as predominant where ACS acknowledges the existence of

studies of migrant populations all over the world [which] have generally indicated that second and third generation offspring of immigrant families develop cancer at rates similar to the host country population rather than the country of their ancestors.

¹⁸¹ American Cancer Society, *Cancer Facts & Figures for Minority Americans*, Atlanta, 1991 presents data from 1977 to 1983. Unfortunately, an updated publication *Cancer Facts And Figures For Minority Americans*, has not been issued yet by the American Cancer Society. A recent *Cancer Facts and Figure* has been issued this year by ACS, but it doesn't show any account of cancer incidence by ethnicity - even though a table at p. 18 it presents cancer deaths by ethnicity.

5.3. ACS's Account of Gender Variation

The common idea among cancer activists that cancer is a women's issue doesn't find support in the estimates provided by ACS. According to their statistics, lung cancer is at the top in terms of both estimated new cases per year and estimated deaths (looking at the new cases per year, it affects 168,000 men every 102,000 women) Breast cancer is second with 180,000 new cases per year; prostate cancer is third with 132,000 new cases per year. Moreover, males seem to be affected by cancer to a greater extent in all other sites of the body.

If we look at the trends in cancer death rates by site and sex, from 1956/58 to 1986/88, we can see that in the last 30 years, lung cancer increased 121% among men and 425% among women, larynx cancer increased 114% among women, while there is no variation in the men's rate. But in almost all other kinds of cancer men display a greater percent change. Breast cancer deaths diminish 20%, cervical cancer decrease 69%, uterus cancer 52%, and ovarian 10%, annuals women's variation, while men have an overall increase of 20%.

This perception of cancer as a "women's issue" has been recently questioned in a San Francisco newspaper.

For American men the prognosis is pretty grim: 50 percent more men than women die of cancer every year. And since 1960, while women's cancer death rates have stabilized, men's have increased by 21%. This is one of the causes that explains why today the average woman will outlive her male contemporary by seven years -- up from only one year in 1920.¹⁸²

According to the author of the article, what makes cancer appear to be a women's issue is not incidence -- rather it is men's

¹⁸² A. Brott, "Getting to the heart of men's health crisis. Genetics ignorance and fear are prescription for early death," *San Francisco Examiner*, May 24, 1994.

lack of awareness about their own bodies. A recent survey found that about half of men don't know the warning signs of prostate or colorectal cancers -- the second and third most common fatal cancers among men -- after lung cancer.

A "macho attitude" toward health care emerged in a national survey conducted by the AMA: twice as many men as women did not visit a doctor in the last year (29% compared to only 15% of women).¹⁸³ Men's denials seem to be higher specifically around prostate cancer and its prevention: the fear of DRE (digital rectal exam) seems to be at the source of problems and denials.

Critical Remarks on Definition and Incidence of Cancer in the U.S.

On the front cover of a publication, the American Cancer Society displays the estimated number of "new cancer cases" in 1992 by state: the total is 1,130,000 (excluding Puerto Rico). Numbers presented in the ACS publication do not include some kinds of cancers, controversially believed to be non-lethal, like non-melanoma skin cancer and the carcinoma *in situ*.¹⁸⁴

About the incidence of cancer, ACS states that "Since there is no nationwide cancer registry, there is no way of knowing exactly how many new cases of cancer are diagnosed each year. The ACS estimates cancer incidence for the upcoming year using the best available data sources at the time." Why in the United States is there no way to know how many cases of cancer there are every year?

In 1973, the NCI began the Surveillance, Epidemiology and End Results (SEER) Program to collect ongoing data on cancer incidence and patient survival. The SEER Program includes data from nine population-based cancer registries, covering only ten percent of the U.S. population. In this way, the estimate of cancer incidence is

¹⁸³ Ibidem.

¹⁸⁴ American Cancer Society, *Cancer Facts & Figures*, American Cancer Society, Atlanta, 1992.

obtained through the numbers recorded by the SEER Program applied to the U.S. Census estimates of the population for the current year.

Brazil -- which is a "third world country," and not a small one - had a National Registry of Tumor Pathology (NRTP) since 1975. The Brazilian Ministry of Health in 1978 signed an Agreement with the Pan American Health Organization (part of the World Health Organization) and other institutions in Latin America for the development of a computerized registry and the latter made possible to store and rapidly analyze large amounts of data.¹⁸⁵

Other countries such as Great Britain have produced studies which make it easy to visualize the geographical distribution of cancer per site and gender.¹⁸⁶ This type of publication is extremely useful because it consists of tables, graphs and maps that show very clear patterns in the distribution of cancer that can be compared to concentration of industries or the presence of a nuclear plant or a toxic dump.

ACS also warns that "It is not appropriate or accurate to evaluate cancer incidence and mortality trends using only ACS estimates of cases and deaths, since these numbers are projected before the year begins, using incidence rates that are several years old."

¹⁸⁵ Ministerio da Saude, *Cancer No Brazil*, Rio De Janeiro, 1982.

¹⁸⁶ M.J. Gardner, P.D. Winter, C.P. Taylor, E.D. Acheson, *Atlas of Cancer Mortality in England and Wales*, John Wiley Publisher, U.K., 1983. Only half a page is devoted to the interpretation of the findings. The factors mentioned as having a possible role in the causation of cancer are:

"a) general external factors such as climate, soil and the quality of air and water;

b) personal factors of individual behavior, such as diet, smoking and reproductive/sexual behavior;

c) occupational and industrial environment of the individual and of the area, and

d) genetic factors"

No specific hypothesis relating geographical pattern with causes of cancer seems to emerge from this study, which has a mere descriptive value.

About mortality, the source of ACS data for the U.S. is the Division of Vital Statistics, National Center for Health Statistics, Department of Health and Human Services. The 1992 estimates of cancer deaths are based on cancer mortality data from 1982 through 1988. International cancer mortality rate is calculated from data made available by the WHO.

The absence of a National Cancer Registry in this country is probably at the basis of the lack of official studies about the geographical distribution of different kinds of cancer in the United States. I found case studies often by "popular epidemiologists" who tried to explain the connections between local productions of carcinogens and higher rates of cancer. Even though such a correlation is so logical that may appear banal, a national systematic study to prove the above correlation is not feasible given the lack of data collection. The "official data" are only estimates based on one tenth of the United States population.

The absence of a national registry in this country makes more difficult the analysis of class, race, and gender variations. A national cancer mapping of the United States -- which would help to verify the claims of many activists around environmental racism -- is an arduous enterprise, not yet engaged by scholars.

5.4. National Cancer Institute's Account for Race and Class in Cancer Incidence

In the National Cancer Institute's sources,¹⁸⁷ statistics and methods do not differ substantially from the ACS's. The overlapping of results raises important questions about the existence of two institutions whose function is the same. In fact, besides the contrasting positions ACS and NCI have concerning the dangers of

¹⁸⁷ National Cancer Institute, *Cancer Statistics Review*, Bethesda, Maryland, 1992.

mammography in pre-menopausal women, these two institutions also express an identical point of view.

The NCI publications are more technical and their language is less accessible to the general public. Cancer prevention and control is mentioned only in relation to NCI's programs for "breast, prostate and lung cancers" and for "population groups with disproportionately high incidence or mortality rates." Yet, no preventive practices are discussed -- causes of cancer are not even mentioned.

In the whole text there is only one reference to the need for more research to investigate "causal factors." Examples of such research don't include toxicological investigations, rather

epidemiologic studies designed to test dietary or hormonal hypotheses suggested or supported by observed racial or sex difference.

NCI seems to be more oriented toward *a posteriori* studies rather than toward preventive research. The reader is left with the impression that

- a. racial and sex difference are to be considered the focus of the problem (instead of the carcinogens and their impact on women, children and economically disadvantaged communities);
- b. the major causes of cancer are diet and hormones -- no mention of carcinogens, not even of cigarettes.

About differences in areas of the United States where more causes of cancer are shown -- these differences are called "geographic patterns of cancer." NCI refers the reader to two volumes: the *Atlas of U.S. Cancer Mortality Among Whites 1950-1980* published in 1987 and the *Atlas of U.S. Cancer Mortality Among Nonwhites*, implicitly meaning that "geographic variations" are to be explained in terms of white-nonwhite groups, rather than looking at how class and race affect the likelihood of living in

geographical areas surrounded by hazardous productions or waste.¹⁸⁸

In the publication on *Cancer Among Blacks and Other Minorities*, issued by the National Cancer Institute and the Department of Health and Human Services, the criteria for measuring cancer incidence are similar to those we discussed above: the estimate of new cases are collected by the Surveillance, Epidemiology and End Results (SEER) program for eleven population-based areas in the U.S., which covers 12% of the U.S. population. The racial account of NCI is collected on eight ethnic/racial groups.¹⁸⁹

The character of this publication is purely descriptive. There is no analysis of the fact that among the major racial/ethnic groups, blacks have the highest incidence rate for all cancers combined. Blacks also experience the highest overall cancer mortality rates.

Native-Americans display the lowest incidence of cancer. Yet, since Native-Americans have the highest incidence of some cancers - - due to occupational hazards in mining -- these data do not seem to reflect that reality. Neither is it therefore mentioned that the statistically low incidence of cancer among Native-Americans (or "American-Indians" in the official data) could be due to inadequate detection practices.

Japanese Americans have the highest overall survival rates, while whites are second. Both blacks and whites experience increasing overall cancer incidence rates. However, whites experience higher cancer survival rates than blacks, and the increase in incidence rates is less for whites than for blacks.¹⁹⁰

Blacks experience disproportionate cancer incidence rates in the following sites: breast (women under 40) esophagus, lung (males), multiple myeloma, pancreas, prostate, stomach. Black

¹⁸⁸ R. Bullard, *Dumping in Dixie: Race, Class and Environmental Quality*, Westview Press, Boulder CO, 1990.

¹⁸⁹ National Cancer Institute, *Cancer Among Blacks and Other Minorities*, U.S. Dept. of Health and Human Services, Bethesda, Maryland, 1986.

¹⁹⁰ Ibidem, p. 5-6.

women also experience a disproportionate mortality -- mainly due to cervical cancer.¹⁹¹

For all these issues no explanations or hypotheses are offered to the reader. In ACS and NCI materials, since no explanation is provided to account for the causes of racial and ethnic differences in cancer incidence and mortality, race itself appears to be as a self-explanatory "factor" in cancer incidence and mortality. The social construction of race and its economic implications remain hidden, as well as social class and gender inequalities. Behind these numbers and the way they are presented there are conservative views of the world -- and an implicit legitimation for looking at endogenous factors -- rather than to exogenous social and economic relations -- in cancer rates.

5.5. Cancer Causes and Prevention in the Native-American Community

I wanted to include the Native-American perspective in my discourse on cancer because I felt the need to refine my thinking around the Native-American culture as it produces a form of situated knowledge which may become of extreme importance in re-defining primary prevention strategies. Looking at the etiology of cancer for Native-American people is not possible without addressing the genocidal attacks several Native American groups has suffered. The question I started from was "why did some Native-American groups perceive the endangerment of our species?" As well as indigenous populations in the Rain Forests, who are resisting the pressure of primitive accumulation, as well as women -- for different reasons -- some Native-American people still claim a closeness to non-human nature as primary source of their survival, both material and

¹⁹¹ Ibidem, p. 7.

cultural.¹⁹² With women they share a social location in the place of reproduction.

Both -- women and Native populations -- are situated in a more vulnerable position than others, when it comes to the scarcity of resources, power based relationships. They developed a capacity for dealing with hardship, a particular flexibility and adaptiveness, and they both trust intuition. Natives of the whole world -- Natives of the Americas and Japan, indigenous populations of Africa, and India, Eskimos and Mediterranean Gypsies -- seem to have in common a relationship with their own reproduction and share the dangers of extinction both at the physical and at the cultural level. When capitalism produces death, indigenous populations are the first to feel it: from primitive accumulation to the most advanced forms of surplus-value extraction, the very existence of Native people is threatened. They are the "keepers of the land"¹⁹³ and the users of those resources capitalistic accumulation never paid for.

Natives have been killed, deported, segregated on reservations where toxic dumping routinely occurs, and nuclear waste gets stored. Given the strategies of survival they had to develop from generation to generation in their history, I wasn't surprised to find community organization around the primary prevention of cancer -- and culturally specific techniques, which are not individually oriented.

As Helen Vozenilek wrote, Native Americans' philosophy includes the principle that the medium and the message are inseparable. This is one of the reasons why the American Indian Cancer Control Project (AICCP) is coming up with new ways to educate Native peoples about cancer. Preliminary results from a 5-year smoking cessation study run by the AICCP suggest that culturally sensitive training brings positive results.

¹⁹² K. Talaugon, "Our Native-American Survival," in *Unity*, Vol. 16, N. 1, 1993, p. 11.

¹⁹³ *Ibidem*.

NCI gave them the resource to open an office in 1990: 1.69 million dollars to focus on a smoking cessation program in 18 urban and rural northern California Indian communities; and 1.05 million dollars for a 4-year study to increase pap smear [testing] among the women of those communities. The staff is composed by seven people. What does it mean "culturally sensitive"? To begin with, few Native Women, as well as women of other minorities -- can identify with ACS standard preventive messages: brochures with thin, white, blond women self-examining their breasts. Moreover Native women think to themselves in the context of their family -- and the *individual oriented kind of message is not effective on them*. Instead to call the attention to the person, the center is trying to get people attention by "talking to them about what's good for their family, their community, or their tribe" So that smoke is not just bad for them, but for their children and for the people around them and so on. In a Native [home] is better to walk a guest outside -- or to put ashtrays only on the porch -- instead of asking not to smoke.¹⁹⁴

According to Vozenilek, cervical cancer 5-years survival rates among Native women are among the poorest of any ethnic group studied. The cervical cancer study will make use of a Native tradition, known as a Talking Circle.

In this traditional setting, issues concerning cervical cancer, breast cancer, sexually transmitted diseases, nutrition pregnancy etc, will be brought up through storytelling and myth weaving. In a Talking Circle, typically a feather or an arrow is passed from speaker to speaker so that each is given the floor and full attention from the group. According to DR. Hodge, talking Circles fully involve all group participants and tend to generate their own leadership and support groups.¹⁹⁵

Yet, the American Indian Cancer Control Project is an institution criticized by other groups of Native American people -- who feel that Native scientists are divorcing themselves from their community and its needs. The Project is funded to look at smoking and other behaviors. It does not address environmental exposure Native peoples suffer. In so doing, as Dianne Williams pointed out,

¹⁹⁴ H. Vozenilek, "American-Indian Cancer Control Project," in *Women's Cancer Resource Center News*, Spring 1994, Vol. 4, N. 2. My emphasis.

¹⁹⁵ Ibidem.

the project fails to address important causes of cancer and betrays the traditional holistic approach by only looking at problems separately.

The activities of the Project are questioned by those who are more involved in grassroot organization of primary prevention, in finding out strategies that can work in their community on risky behaviors, the avoidance of carcinogens, and to develop strategies for strengthening the immune system of the Native people. As Dianne Williams explained, often

the vehicle to translate knowledge doesn't get from the researcher to the patient. (...) The group's ability to affect behaviors is really strong with us and it used to work in a good way -- but now it also work in the bad way, like the drinking behavior (...) And we could just take that pressure from the group and turn it around, that's my focus, there, to use that pressure -- and pressure people into good habits. I try to implement that here (...)

We have an Indian [Cancer Control] Center, but what we miss is looking at the issue in an holistic way ... and I don't see it happening, this is why I am turning to be anti-research, because they are just researching to get their pocketbook fat ... and it doesn't translate to the level of the people. There are Indians in this country who have been researched back and forth, up and down, every little thing that we do ... and where is the benefit of it? Has our condition changed considerably in the last 10-20-30 years? I don't think so.

Dianne Williams points out how cancer prevention can be organized in her own community, without relying on EPA (lack of) action to protect them, and without having to wait for scientists to come up with long term discoveries. She argues that most of carcinogens are already proved to be such -- and does not believe in regulation or in banning them: since the economic system needs those substances, "they" are going to find a way around the law.

Williams trusts her intuitive process of thinking: what we already know can be used, and logical connections can be made in order to maximize our knowledge on carcinogens and hazardous substances. She makes the example of aluminum -- and how exposure can be prevented.

The sad thing is that most of the things they [scientists] already know that (...) And they are going to burn in hell with their DDT - - you ban one and they come back with another, they just change the initials -- and a huge amount of pesticides and fertilizer is down to South America, far away from our concern ... (...) I give you an example about how behavior change can be effective even if the environmental exposure isn't changed. As far as we know aluminum is toxic, is a poison metal. I learned twenty years ago that aluminum had been studied by the FDA in the 1920s and 1930s and ... [they] declared that it cannot be proven harmless to humans, as used in cookware. And we still use aluminum to cook, we cook in a toxic metal that is water soluble -- and this might be related to the gall bladder cancer

Following her intuition, she also makes a connection between the breast cancer increase in this country "women's deodorants in the supermarket: they have aluminum in it. If it is toxic for cooking it seems to me that if you keep rubbing it in your body something it is going to happen -- and how the lymphatic glands under our arms would not pick that up?" The logic of applying what we already know on carcinogens -- at least those we can avoid -- instead to wait for regulations, is part of her preventive philosophy.

I would not be able to stop Kaiser or Alcoa or Reynolds from producing this aluminum that gets into our cookware, our deodorants, aluminum baking powder that we are using in fry bread, and a host of other things -- but we can educate the population to not use those pans, and those deodorants ... there is one small degree that we can have control over the environmental exposure ...

The control over environmental carcinogens starts from defending the community, changing risky habits, reinforcing the legitimacy of traditional medicine and going back to a healthy diet. At the end of the interview, Dianne Williams showed me a book that critiques "the white man's food" from a nutritional point of view. But sometimes, the community can choose within a certain frame.

As Anne Watanabe, member of the Columbia River Inter-Tribal Fish Commission told me in Seattle,¹⁹⁶ if most of your diet comes from the river -- and the river is polluted -- the community has not much choice. Their survival is endangered.

5.6. Conclusion

If it is true that cancer is socially produced -- as an undesired output of the accumulation process -- it is also true that cancer is socially distributed following lines of class, race, gender, and sexual preferences. This is not acknowledged in most literature on cancer, to an adequate extent. Some of the subjects interviewed expressed the necessity to analyze the distribution of cancer by looking at different forms of environmental racism, occupational hazards, and those social factors -- such as stress -- that have been linked to cancer in laboratory experiments.

More studies to explain the social distribution of cancer and the reasons underlying the differences in incidence among various groups, having different locations in terms of socio-economic status, cultural capital, racial and geographical locations in terms of residency and workplace. While we do not have statistics on the distribution of cancer by sexual preferences, the claim that lesbians might be more at risks -- because of not having children, and because of the stress society produce among unmarried women -- should be kept into account.

¹⁹⁶ During a private conversation.

Chapter 6

THE CANCER MOVEMENT.

WOMEN SURVIVORS, SCIENTIST/ACTIVISTS, AND PEOPLE OF COLOR

6.1. Introduction

This section is going to answer some questions about the rise of cancer activism, its protagonists, its reasons, and its often conflicting goals, through the voice of the actors involved: women survivors, minority leaders, scientist-activists, and environmentalists.

The recent rise of cancer activism can be analyzed as an interface between the women's and the environmental movement. The roots of cancer activism are to be found in the feminist experience of this country, in the practice of consciousness raising groups, in their theory that what is personal is political, in the critique of capitalistic relations, patriarchal science and its control over women's bodies. Analyzing the roots of cancer activism will help us to understand the women's hegemony in the cancer movement and why this movement at the very beginning was composed almost exclusively of white women.

Environmental justice represents the near future arena of the cancer movement -- in terms of common goals and strategies -- and we can already notice some signs of this process in the recent cooperation between women cancer survivors and the people of color who are building an environmental justice movement across the country [see section 6.5. and Appendix 20]. Also, some segments of the mainstream environmental movement are starting to give thought to human health and to reconceptualize the body as part of the environment.

Since the beginning of the nineties -- and increasingly starting with the Clinton administration -- we have been witnessing in the U.S. a progressive shift of attention from AIDS to cancer. Here I will not compare AIDS activism and cancer activism -- even though AIDS

activism is the closest model we have when considering cancer activism; AIDS activism is the health movement immediately preceding cancer activism. In contemporary history AIDS activism represents the only situation where a physical disease became a political issue on a large scale in this country.¹⁹⁷

Yet, I must say that the differences probably outweigh the commonalities: AIDS is a contagious disease, and it is new, while cancer has been around for very long time¹⁹⁸ -- which also means that cancer activists had to face a much more powerful and stable *milieu* than AIDS activists. Moreover, most of AIDS activists have been gay men -- many of them affluent and well educated -- while cancer activists are women, often housewives who in many cases felt themselves to be unprepared to carry on the battles they waged. Last but not least, I should mention that strategizing about AIDS prevention is a quite different problem compared to strategizing about cancer prevention.

After introducing the discourse on the emerging cancer movement and its features, I will deal with important divisions among cancer activists. These divisions, though complex, are closely connected to the debate on biological and genetic determinism I discussed in chapter 3. The division among activists about cancer causation reflects the existence of two paradigms in the scientific community. As we saw, scientists can be divided in two main groups: on one side, those who think of cancer etiology in terms of genetics and refer to risky behaviors as a "personal choice," on the opposite side those who think cancer causes are to be found in environmental factors and see risky behaviors as socially constructed.

One of the points of this chapter is that we are not facing a situation of conflict between the scientific community and the

¹⁹⁷ In the past similar health emergencies were produced by syphilis, tuberculosis, and other contagious diseases.

¹⁹⁸ Yet, as Stoller pointed out, cancer as an epidemic is a new phenomenon.

activists, as some press reports would have us believe. We are faced with a situation of double conflict within both the scientific community and the cancer movement, and this is resulting in the emergence of bridges and cross-sectional alliances.

6.2. Roots of Cancer Activism: Feminism and the Occupational Health Scientist/Activists

How did the contemporary activism on cancer begin? What are its goals? And why are the participants in this social movement principally women? In all existing societies we can see categories of individuals whose needs, both materially and symbolically, are not met. As Hirschman theorized, when people are unsatisfied, they tend to adopt either a modality of "voice" or a modality of "exit." In the first modality the subjects tend to change their situation by some combination of complaining, protesting, coalescing, building alliances, and forming coalitions. In the second subjects tend to find a way out (as in the case of emigration, voluntary exile, and divorce) in order to create situations where their needs are met.

Hirschman's schema can be used also as a two-stage model going both ways: the *exit* modality can either follow or precede attempts to express *voice*. In the first case the modality of exit is the symptom of a lack of opportunity to voice discomfort and dissent. More than an option, it is the result of failures in the process of negotiation. In the second case, the modality of exit precedes the possibility of voice. The exit of some may or may not be part of the process of opening social space for others to express voice. It was the case of some people with AIDS in Italy who left to find social environments where their illness wasn't a source of stigma and alternative therapies were available (E.g., in India). While during the Eighties leaving the country was one of the options considered among those who felt less compatible with the political system, in the last few years the attitude toward HIV+ people progressively changed and AIDS activism is finding room for expression.

Cancer activism is a clear cut example of voice. From the beginning of its existence -- whenever we want to date it -- cancer activism had the feature of trying to change public perceptions, media attitudes, medical and research institutions, and health policies. From the beginning, cancer activists -- mostly women -- have used the usual methods to voice their claims, anger, ideas, and requests. Many of them have learned such methods in participating in the civil rights movement, in the agitation against the Vietnam war, in the feminist movement. So cancer activists -- as all activists do -- have distributed fliers, held press-conferences, and organized rallies, demonstrations, and even picket lines. In search of attention, they have orchestrated campaigns, inundating public institutions -- including the White House -- with tons of letters, telegrams, and signatures. They have published newsletters, pamphlets, periodicals, articles on alternative and mainstream press, and books. They have talked on radio and television shows, created videos, art exhibits, and public performances.

Cancer activists have also tried from the beginning to fill the gaps in the system by providing support and information to the diagnosed. Often with little assistance and financial capacities, they have formed resource centers, built small libraries and archives, created a network of specialists to whom to refer the visitors, with lists of good and bad doctors, and lists of persons who are willing to support emotionally or help the just diagnosed as well as the terminally ill.

Helen Crowley at the Women's Community Cancer Project in Boston offered me her story -- the one of an activist who does not have a "political history" -- and who had to find a place for her own rage.

I was diagnosed in 1987 and the diagnosis followed a misdiagnosis where a radiologist read my mammograms, said they were fine. I went for another opinion about three months later. They did not tell me anything was wrong with the pictures. The next day the original radiologist wrote a report to my referring gynecologist with a completely different report on the same set of

mammograms saying that there was a suspicious area. My own gynecologist ... she did not notify me, misread her letter and did not do anything. The long and short of it was another two months before I had another set of mammograms and the cancer had changed dramatically and had the spikes that indicate the metastases. My sister had also been diagnosed a year before I was. She had a mammogram that showed nothing and five months later she had a 5 cm. tumor. Then the two of us were offered the same treatments that my mother was offered when my mother was diagnosed in 1951 or so. *I knew that I didn't want a support group.* I knew that I was angry and I didn't want anybody patting me on the head to get me to work through my anger. One day I was driving to work and I heard an ad that the Cancer Project was holding a political action meeting. So I pulled the car over and I wrote down the time. It was the next day and I cancelled all the appointments I had at work that night. And I haven't missed a meeting since.

When I started to interview cancer activists I realized that two factors can be seen as important pre-conditions of both the rise of cancer activism and the predominance of women:

- the inadequacy of public institutions to cope with people's health in general and with the cancer epidemic in particular;
- the feminist movement and its political history of defining the personal as political, specifically about women's health.

According to San Francisco cancer survivor and activist Judy Brady, the reason why the cancer movement consists mostly of women may be traced to the 25-year history of the women's movement in this country. This movement began with small consciousness-raising groups which were held in semi-private settings, i.e., in women's living rooms. Similarly, the cancer movement started with small groups getting together on issues of support. The famous statement --attributed to C.W. Mills -- that private troubles are indicators of hot public issues became a social praxis among activists. As Brady pointed out,

The process we started 25 years ago was a process of putting together individual experiences and taking a look at the pile of information that we put in the center of the room. Having removed our individual selves from that pile of information, we

could begin to extrapolate what was happening on the social level. In some ways the cancer movement has followed a similar path. Like the women's movement, [the cancer movement] is a social response to a problem that no existing institution is able to handle.

This lack of institutional attention is underlined also by other cancer activists, like breast cancer activist and survivor Marilyn McGregor:

"Y-me" started organizing support groups nationwide because there was nothing for women who were facing a life-threatening illness ... in 1990 in SF I was told that I didn't need a support group ...

This kind of statement was made by several of the women I interviewed and it reflects the deep misperception among medical personnel of what it means for a woman to be diagnosed with cancer and not to have the option of any kind of collective setting in which to compare and socialize her own experience.

Another reason the cancer movement started in the United States is that this country has a long history of voluntary health organizations. Since in Europe people have a legal right to health care the issue of health has been important but probably not as dramatic as in US. Thus, volunteer organizations are not as developed in this sector in Europe as they are in the US. As cancer activist Marilyn McGregor pointed out:

they [the volunteer organizations] do a tremendous work, very traditional, very standard but I don't think they exist as well in Europe... [In the US] they fill the gaps between the health system.

Specifically, cancer activism has had to fill the gaps left by organizations such as the National Cancer Institute and the American Cancer Society. Many activists believe ACS should be a watchdog of the NCI, while in reality it is just "a copy" of it. Some cancer activists identify the cancer movement with breast cancer activism, dating its

beginning when Breast Cancer Action started, in 1990 in San Francisco, or in 1989, in New York and so on. On the one hand, it is true that breast cancer activism didn't start until the end of the 1980s. On the other hand, some cancer activists refer to the existence of women's cancer support group as early as the late 1970s and beginning of the 1980s. To quote Judy Brady:

Movements don't ever have a starting date that one can identify. I was part of a support group in 1980 and it was unusual because it was the only one around [S.F.] that wasn't part of the medical apparatus, led by an old left woman and there was space for the kind of anger I had ... There were leaflets linking cancer with the whole issue of disarmament, shortly after 1981/82. Movements start in a messy way, little jump here, little jump there, and they don't seem connected -- but I think there was no "movement" before the 1980s.

Women who have a past of militancy in social movements such as feminism and the anti Vietnam war, often represent the "thinking mind" of the group they are in -- in terms of defining political strategies when it comes to alliances with other groups, organizing propaganda actions, and dealing with media. In this context, lesbians are those most experienced with issues of body, power, and the critique of the medical establishment. Lesbians represent -- also metaphorically -- the heart of the cancer movement within the women's community. They bring emotions and feelings of cohesion in the movement. By setting up support groups, building informal networks and informing the militant work with issues of caring and service assistance.

As a white straight breast cancer activist pointed out, an explanation of the high concentration of lesbians in cancer activism and in organizing roles can be found in the history of lesbian practice in the U.S. women's community. The supplement of attention lesbians provide is also seen by this activist as a product of their politic of priority: since they have to spend less time on men, lesbians can focus better on women's needs.

While most of the women cancer activists I interviewed during my research viewed the beginning of the cancer movement as a recent phenomenon starting in the last decade if not in the last few years, it is interesting to note that scientist-activist Samuel Epstein dates the starting point much earlier, with the occupational health movement and the emergence of concerned citizens' groups in the late 1960s and 1970s.

Epstein links it to the growth of a public interest movement which had its origins with Ralph Nader and Rachel Carson in the 1960s. As Epstein points out, Carson's book 'Silent Spring'¹⁹⁹ had an enormous impact on President Kennedy, which led to the creation in 1969 of a special Commission, "the first that ever looked into pesticides and their relations to health."²⁰⁰

In this section I have noted important roots of the present cancer movement in the early environmental and occupational health forms of activism -- as well as in the women's movement . However, we must notice that before the beginning of the 1980s there were *no groups in the U.S. dealing only and specifically with cancer*, and defining themselves as part of a larger cancer activism, which spread across the nation at about the same time.

6.3. The Cancer Movement: Features, Goals and Contradictions

How do we define the cancer movement and who is part of it? If we look at the recent phenomenon of cancer activism, especially focused on breast cancer, most of the movement consists of white middle-class and professional women working in about 30 local groups (without counting support groups) around the country.

The main groups are located in San Francisco, Berkeley, Boston, Chicago, Atlanta, New York, Washington, Los Angeles, and near toxic

¹⁹⁹ R. Carson, *Silent Spring*, Riverside Press, Cambridge MA, 1962.

²⁰⁰ See: R. Proctor, *Cancer Wars: How Politics Shapes What We Know and Don't Know About Cancer*, Basic Books, New York, 1995.

waste sites, such as "Cancer Alley" -- the area between Baton Rouge and New Orleans. Moreover we can count about ten national groups, ranging from the National Breast Cancer Coalition (NBCC) -- a "moderate" organization sometimes defined by former member as a group of "nice ladies with pink ribbons," to the National Cancer Prevention Coalition, the latter representing the politically most "radical" national formation.

During my field research across the country I met another definition -- a broader one -- of what the cancer movement is today, with different roots in the past, different membership composition, different goals, and different strategies to achieve them.

I met another cancer movement, 'other' than the one mass-mediated by newspapers and on television talk-shows, 'other' than the one welcomed by policy makers and presidential panels. It is a cancer movement that doesn't wear pink ribbons and is not composed predominantly of white middle-class women. As Judy Brady pointed out,

There is a lot of real work, real analysis and real organizing done by a sector of the population in this country ... that most of the white women in the Y-me and in the NBCC don't even know exist. *In the long run I consider them the cancer movement.* These are groups like the South West Organizing Project, the West County Toxic Coalition, groups of the Environmental Justice Movement, not to mention the radicalization of groups like Greenpeace, who are starting to deal with human health issues instead of just with whales. Most of the cancer activism today -- in a narrow sense -- does not have an idea of how to put things together to promote social change -- and they are just a very small and not so relevant part of it.

In a broader definition of the cancer movement, we should as well include:

- the leaders of geographically disadvantaged communities like those located at the border with Mexico or near Superfund waste sites;

- union militants like the United Farm Workers of America who have been fighting for years against the use of pesticides, herbicides, and fertilizers widely proved to be carcinogens;
- activist groups of citizens especially in economically disadvantaged minorities, organized on issues of environmental health in the inner cities, near incinerators and in industrial areas presenting clusters of cancer related to hazardous productions and byproducts;
- women's health organizations and grassroot health groups which deal with cancer among other issues, such as the National Latina Health Project, the National Black Women Health Project, the National Reproductive Rights Project, "White Lungs" Associations, and the Native American Health Centers and various local groups of concerned citizens and consumers who focus on specific campaigns (clean air, "the right to know," etc.).

For analytic purposes, here I will refer to the cancer movement as the heterogeneous assemblage of groups and individuals who are socially active on political issues related to cancer. They may or may not be cancer survivors. Cancer is their main interest or one of their top priorities. The name of group they belong to may or may not include the word cancer.

Among the groups I studied that mention the word "cancer" are the National Cancer Prevention Coalition; the Women's Cancer Resource Center in Berkeley, the National Breast Cancer Coalition Breast Cancer Action in San Francisco, and the Lesbian Community Cancer Project in Chicago. Among the groups that do not mention the word cancer -- but have cancer at the top of their agenda -- are the Washington Toxic Coalition, the Environmental Research Foundation (which publishes the *Rachel's Hazardous Waste News*), the Committee for Nuclear Responsibility, the Mautner Project in Washington, Y-me, and several women's health clinics and centers that are prioritizing a discourse on women and cancer. The diverse parts of this composite body have in common the idea that prevention is the strategic area in the struggle against cancer.

I will refer to "breast cancer activism" as those individuals and groups that are especially focused on breast cancer issues. Breast cancer activism is composed mostly by breast cancer survivors. This formation is less heterogeneous than the one described above. Here I am not going to analyze their internal differences. In the distinction I am introducing between "the cancer movement" and "breast cancer activism," what does count is that activists belonging to different groups of breast cancer activists have a common focus on early detection, cure and rehabilitation. Their political priority is promoting access, alternative therapies, and research.

The analytical division between breast cancer activism and the cancer movement doesn't deny that there are breast cancer activists involved in the cancer movement: as a matter of fact, several women who had breast cancer among those who I interviewed politically identify with the larger cancer movement, even if their main activity is in a breast cancer group.

The analytical division I made between breast cancer activism and the wider cancer movement is meant to clarify and distinguish political positions and goals that are conflicting in the cancer arena and to understand their complex systems of alliances. Given the kind of mass media coverage and institutional attention, if we ask ordinary people what they think the cancer movement is they would probably tend to identify it with breast cancer activism.

On the one hand, it is true that breast cancer activism has had the very important role of calling attention to cancer, to make it possible for people -- women in particular -- to talk about cancer. On the other hand, it is also true that, as Judy Brady said,

while breast cancer is only *one* manifestation of the cancer epidemic in the US and not even the fastest growing of cancers, the sensitivity of the female breast makes it an excellent indicator of what is happening to human health in general. The breast is an organ particularly vulnerable to cancer as it is largely composed of adipose tissue and goes through rapid cyclic changes during most of a woman's lifetime.

On the other hand, while it creates an immediate public emotional reaction, the interviewee argues that organizing a movement just around breast cancer is too limited a perspective.

Look at the definition of '*breast cancer movement*': isn't it insane ... to become political only about the cancer of *one* organ? (...) When the movement will be grown enough to understand that cancer is only one expression of much larger and deeply serious problems that are affecting the health of people, then perhaps there will be a larger political context in which we could operate.

The reality is that the two areas of cancer activism I described reflect different discourses about cancer causation and prevention, as well as about social change. Even if breast cancer activism could be considered part of a more general cancer movement, the two phenomena still need to undergo separate analysis because of:

- a. differences in roots and composition;
- b. race and class differences;
- b. differences in strategies and political perspectives;
- c. differences in practical goals.

6.3.2. Differences in roots and composition

Breast cancer activism and the cancer movement also represent two different expressions of the social tensions around cancer in the U.S., in terms of *degree of radicality* expressed until now. Some cancer movement activists have stated that breast cancer activism started and was widely sponsored to control, monitor, and dilute a more radical perspective on cancer. As Marilyn McGregor pointed out,

Very early the NBCC had as first goal to control indigenous local grassroot groups and it was successful because members of Congress were terrified: this was a disease any woman could get and they [the women] were very pissed at it -- and their husbands, children, families ... and they [the Congress] had no answer ... and they were feeling assaulted.

Even though "blame the victim" strategies have been tried, it was much more difficult to blame the cancer activists, the way it was done for the AIDS movement. This is probably one of the factors that resulted in Congress having to gain credibility and political control over the whole breast cancer issue.

So the NBCC came along and said that they were the only organization to pay attention at least at the federal level -- they got a lot of money because of the fear of the government of alienating thousands of women.

Breast cancer activism is somewhat more easy to define than the larger cancer movement: it consist of an aggregation of groups throughout the country, of which National Breast Cancer Coalition (NBCC) is the main national expression. NBCC is a federation of nearly 200 support and advocacy groups that "helped to raise the national budget for breast cancer research and prevention from \$90 million to \$420 million."²⁰¹

One of the most prominent spokespersons for NBCC is surgeon and writer Susan Love, who stated that the rise of national budget for breast cancer research happened mostly "... thanks to Anita Hill. After that debacle, congressmen were all looking for a nice, noncontroversial *women's* issue."²⁰²

Judy Brady offered a long and articulate answer about the differences between breast cancer activism and the cancer movement in roots and compositions:

There is a tremendous difference between the two movements ... We came from the civil rights movements, the anti-war movement, the women's movement, Marxist concepts, so we brought to this movement our experience and our difference: women who have been in the unions, in the Communist Party, who have always been organizing around something ... But in the

²⁰¹ M. O'Neill, "A day with Dr. Susan M. Love. A Surgeon's War on Breast Cancer," *The New York Times*, Wednesday June 29, p. B6, 1994.

²⁰² Ibidem.

women's cancer movement you have some people who don't have this kind of intellectual background or acumen or capacity of analysis; many women are just scared, they are facing a life threatening illness and want to find help on many levels ... And the movement has been coopted so soon ... If you look at the chronology: there were individual groups organizing in the late 1980s -- and breast cancer action started in 1990 -- (...) like the Long Island group who did the research on women getting breast cancer and *the CDC said that they were old Jewish women -- and old Jewish women get breast cancer*. But they persisted over time and then the NBCC started coordinating groups that were organized by their own people, and getting national press. Susan Love and others organized NBCC -- and we have an internal document which says that a national organization was needed because "otherwise these radical groups would begin speaking for everybody."²⁰³ From the very earliest days there was a consciousness that these groups -- the indigenous local grassroots groups -- had to be controlled. And suddenly there was an avalanche of media coverage ... unlike what happened with the women's movement when, in the early days, they were said to be man-haters and bra-burners. It took a long time for the women's movement to achieve respectability in the media (...) And, from the very beginning, health was always a main issue.

The main concern of the interviewee seems to be how to get public attention without being coopted -- and how to develop equal partnership -- instead of becoming "yes sayers" in medical meetings. The relationship of the movement with institutions is discussed further in next section.

6.3.3 Differences in Strategies and Political Perspectives

The strategies of breast cancer activism have a quite clear institutional character. From this point of view breast cancer activism can be equated with other pressure groups, since, all along, it displayed most of the features of this type of political aggregation in its emergence -- and its destiny is probably to disappear the same way pressure groups do -- or to evolve into something else, to

²⁰³ I asked the interviewee for a copy of the document, but to this date it has not been provided. However, other activists referred to such a document during informal conversations.

become a new social phenomenon or part of one. The reference points of breast cancer activism are the government, NCI, the scientific community, the pharmaceutical industry, and the media.

Strategies and reference points of the cancer movement are less easy to outline. First, because this movement is less defined than breast cancer activism, it is more polymorphous and it has diverse social components, including groups that do not work specifically on cancer. In fact, groups like the West County Toxic Coalition (and others in the Environmental Justice Movement) work on cancer, but they include cancer among other top priorities, along with sterility, birth defects, and multiple chemical sensitivities.

In the future, as some activists have pointed out, the non-mainstream cancer movement will have to make strong alliances with those sectors of the environmental movement that are becoming increasingly concerned with human health, such as the environmental justice groups that are spreading across this country.

The broader cancer movement's roots are to be found in the interface between feminism, environmentalism, and anti-racism. Its perspective and evolution define it as a potentially anti-capitalistic movement and not just because of its political composition. We can analyze the 'other' (non-breast-focussed) cancer movement as an expression of the irreducibility of the contradiction between profit and health.

6.3.5. Differences in Goals

The primary goal of breast cancer activism is "finding a cure, now." Obtaining more money for research and more attention have been the key words. The National Breast Cancer Coalition has focused its strategy on the request for better means of detection and treatment, including permission from FDA to approve some drugs that now are not legal in the United States. In general, breast cancer activism is requesting a less chemotherapeutic approach and more

concern about the alternatives, even though there is no health plan in this country that will be likely to pay for such alternatives.

Another important issue that has emerged with breast cancer activism is the request that women be given access to scientific panels at different stages of the research.²⁰⁴ This is a more controversial terrain, since it involves the power to affect the direction of the research itself. Up to this moment, as Marilyn McGregor pointed out:

When this inclusion actually happens, the women sitting in a research council become 'yes-sayers' ... they get to play the same role as if they were 'doctor's wives' in many cases -- as opposed to what happened in the AIDS community advisory boards, where the guys are quite well prepared and knowledgeable about research. The problem is how to educate the movement, otherwise our people just get subsumed and coopted in a 'feels good' kind of research -- used by the institutions to legitimize their operation toward the public sphere.

The complain raised by McGregor is not typical; yet radical activists seemed to share a common feeling of inadequacy and discomfort around issues of cooptation. Probably the reasons breast cancer activists happen to be -- or perceive themselves to be -- less armed with knowledge than AIDS activists, are that the movement around cancer is younger and women have been historically kept out of medical professions and scientific research. Moreover, as I mentioned elsewhere, the cancer establishment is older than the AIDS establishment -- and has more experience in keeping over public perceptions and enclosures around decision making processes.

Another issue that can be listed among those that divide cancer activists is the definition of those who constitute their allies and those who are perceived as being the opposition. Marilyn McGregor

²⁰⁴ As Stoller pointed out, the requests for "a cure now" and for participation in scientific panels are common goals among cancer activists and AIDS activists.

mentioned among their allies the pharmaceutical industry, the medical establishment or part of it, research institutions, and congresspersons:

Especially [congress] women who are trying to find the viable issue that they can push ... but they for example are pushing the mammography, which is somewhat controversial, but they need to find some visible issue. Then [on our side] there are some of the doctors -- who have been in prison too -- and, as for AIDS activism, the pharmaceutical industry.

Other cancer activists have a different view of the problem of identifying those who are perceived as allies and those who are seen or experienced as enemies. As with the other divisions among activists we looked at so far, this one depends upon the more general priorities and political perspectives that divide cancer activists. As Brady pointed out,

the pharmaceutical industries are well served by the current system ... they are the wealthiest industries: they have invested a great deal to insure that the current system does not change -- this is why they are buying out the women's cancer movement. The question of allies depends on how you define the goals of the movement -- if you define it the way the ACS [American Cancer Society] does, which is to find a cure, then the allies are indeed the pharmaceutical industry, the AMA [American Medical Association], the cancer research institutes. If we define the goals of the movement as preventing the disease, we have a different picture -- and those who become allies in the first instance become, in fact, the enemies.

6.3.4. Race and Class Differences

Another difference between breast cancer activism and the cancer movement is related to race/ethnicity and class.²⁰⁵ Breast cancer activism is formed mostly by white middle class women. What we define as the cancer movement includes community

²⁰⁵ See also interview with cancer activist Bonnie Withley in section 6.4. and with social scientist and activist Bob Bullard in section 6.5..

leaders, groups of people of color, environmental justice activists, poor whites who live in toxic areas. Women are still the large component and often have the leadership, and men are present too. These groups tend to focus more on issues of class, race/ethnicity, and environmental racism, then on issues of gender.

As Brady explained with extreme clarity, there are important race and class divisions in the cancer movement, which reflect divisions in the environmental movement.

... the environmental movement at this point is in two camps: First, there is the white movement which hugs trees and worries about dolphins. They are not wrong but in a sense they stay at the periphery of other issues. And then there is a movement that is still 'underground' in the sense that it doesn't get coverage in any of the press: the environmental justice movement that is fighting against lead poisoning in their kids and toxic waste dumps, and against Chevron ... Most of these groups are made up of people of color because in this country those people are usually poor -- and we are a fucking racist culture ... and I don't see these white women making any kind of alliances with those people of color. They may have representatives of people of color in their movement, but when it comes to the political agenda, a real alliance is not going to happen in any near future for sure.

In several interviews -- including those with women of color cancer activists, the contemporary breast cancer activism has been referred to as a white woman's movement. As Luz Martinez pointed out, this perception of breast cancer activists has to be understood within in light of what happened in the feminist movement:

it was very white, I was not involved at all and neither were the other women. The women's movement had its own perspective, and it was a white, middle class, educated one. I didn't even consider being a part of that. Other things were going on in the sixties. And we Latina women were invisible to them, as to history books.

Breast cancer activism, because of its roots in the women's movement, has inherited these features of insensitivity toward uneducated women -- who ask for mammography instead of

criticizing it; toward poor women who have backward attitudes; toward minority women who have less time for meetings and too many children to take care of.

At times the word 'racist' has been used to define the agenda of breast cancer activists. My personal take on it is that breast cancer activism is not racist because of excluding somebody a priori, but because of failing to address issues that are important among non-whites.²⁰⁶

The main issues of race/ethnicity/class concern *access* -- whether it refers to prevention, detection, cure, or rehabilitation. Besides alienating women of color from breast cancer activism, the dismissal and exclusion of a discourse about access has kept breast cancer activism far from entering the core of the decision making processes. As a breast cancer activist has explained me, their politics -- still considered to be "right" -- has put them in a difficult position:

breast cancer activism didn't focus on the access issue. And this was right because it would have been only a "cooptation process" as well. But this is [the reason] why the women [in the group] now don't know what is going on, at that level, what the issues are, what they could be

6.3.7. Conclusion

It is possible to say that the main differences among those analyzed mentioned are about priorities: some activists who think that finding a cure is the goal, whereas other activists think the goal should be prevention. As Marilyn McGregor explained, the reason why: " ... at the moment the narrowly defined movement is not dealing with prevention and environment, [is] because it is a movement of *women who already have a life threatening disease*. So they might be worried for their daughters, but what they really want

²⁰⁶ As Patricia Hill Collins pointed out, a view from the bottom to power relations is important, since oppression is difficult to be understood from a comfortable position.

is a cure, now." Prevention is a strategic area, which is going to become increasingly the subject of controversies.

Focussing on the present contradiction between two wings of the movement can have the unfortunate effect of worsening the existent divisions.²⁰⁷ Yet, I believe that shedding light on these processes and differences can help -- in the long run -- to identify obstacles and eventually to remove them, or to build alliances that take internal conflicts into account.

The mainstream part of the cancer movement -- namely the large majority of what we know as breast cancer activism -- is pressuring the scientific community and the government to support cure-oriented research. For them, the ideology of genetics has a greater influence. The promise of a cure that would be able to manipulate the "wrong gene" and reverse the degenerative process is the succulent carrot public institutions offer to this threatening army of single breasted women. Even critics who stand inside the genetic paradigm have warned that finding the 'cancer gene' -- a finding announced as imminent for years -- doesn't imply any certainty of the ability to operate on such a gene. Yet, most of the resources -- some say up to 80% -- of the cancer money goes to basic genetic research.

In the opposite field we have cancer activists who are trying to get attention around issues of primary prevention. In fact, what is called prevention by ACS and NCI is usually 'secondary prevention' i.e., early detection. Here it is interesting to note how naming early detection as 'secondary prevention' obscures the very fact of the minuscule attention paid to primary prevention, the elimination of the causes. If we consider what the major cancer institutions do when it comes to primary prevention, we realize that the focus is on individual-related strategies of intervention, such as "don't smoke," accompanied by dietary tips and the advice to drink moderately and

²⁰⁷ This advice was given me by David Sonnenfeld.

exercise.²⁰⁸ This focus on individual-related strategies of intervention has been described by many cancer activists as produced by a very common attitude in the medical establishment: that of "blaming the victim."

In addition, it is interesting to observe how, beside the omission of environmental factors in general, primary prevention experts in cancer establishment give nutritional advice considered to be important in cancer prevention without mentioning the dangers caused by the presence of pesticides and other carcinogens in our foods and waters.

For those activists who think primary prevention is possible and necessary, environmental issues represent the core of the problem -- and also the area where they encounter the highest level of resistance from private and public institutions.

6.5. Black Women Cancer Activists

Black women and other women of color are still a small group among cancer activists. I want to outline some of the issues and concerns they express. Here I am going to present segments of interviews with two black cancer activists. The first woman, Sylvia Mitchel, doesn't address the issue of color -- and her statements could indifferently be those of a white activist. This may be one of the symptoms of an absence of a discourse around racial issues in some breast cancer groups, absence that was mentioned also by white women cancer activists.

Mitchel is an older black woman, with silver in her braided hair. She was born in Central America and a naturalized U.S. citizen. She is a breast cancer survivor who live in Sacramento; she didn't find her needs were met after the diagnosis: "ACS wasn't enough." So she started working with the Women's Community Resource Center, and later on with "Common Will." Mitchel today participates in

²⁰⁸ Recently some attention has been put on preventing sun exposure.

national meetings with cancer scientists. During the interview she pointed out the danger of being coopted

University, doctors, pharmaceutical industry ... work together and use the activists (...) last year they were intolerant toward activists, this year they only want us!

Mitchel also thinks that while some doctors are allies, some activists can be enemies as much as the pharmaceutical industry. She concluded by mentioning the collusions between the polluters and scientists today, the same way it happened with tobacco in the past.

Bonnie Withley defines herself as "the cancer activist" in the African-American community in Oakland -- and this is true. Even though the San Francisco Cancer Walk in 1994 helped the Bay area cancer groups to recruit activists of color, Bonnie Withley is still the one everybody calls, when it comes to black women and cancer.

She is a community activist and a women's advocate. What got her more involved in the cancer movement was the death of her father. One day his mouth started bleeding; and for the doctors there was not much left to do. And her brother has asbestos poisoning at the age of only 26.

Bonnie Withley believes genetics do not play an important role in cancer causation -- but the genetic research plays an important role in racism -- and she mentions the Nazi experiments. She also argues that racial differences are not a cause of cancer, while economic and social discriminations are connected with factors that cause cancer.

I am "the" activist around cancers, I got involved long before white women got involved—with the underserved.(...) There is nothing to associate cancer with genetics. Especially if you talk about upper-middle class African-American women. If they have insurance and access to health care it's the same; there's no difference. It has to do with economics, basically ... that's all. Research gets so bizarre that we can reproduce the scientists that did all the nasty things to the Jews during the holocaust. But we don't want to believe that. But I think it's happening in this

country. It's really really happening in this country. And they're doing it on poor and underserved people and people of color.

Bonnie Withley advocates for culturally sensitive cancer prevention messages. She argues that one of the reasons that health programs are not successful is because they are not created from the inside of the different ethnic communities [see Appendix 18 A]. She works for African-American women, but she includes in her work all underserved women.

I started off being an advocate for — and I still am an advocate for — underserved African-American women. However, if I find a woman who is in need or access to the health care service, I will fight just as hard. So your advocacy begins to open, and begins to include all women. And it's wonderful because it says that we are all out there struggling for something, and that the struggle that we are trying to overcome is very difficult. So that, I can't turn my back on a woman who is in need of health, whether she's white or pink. I just can't do that.

When talking about the profit system, Withley focuses on the government and the research money wasted in "nothing that is tangible" [see Appendix 18 B]. She also address issues of racism both in occupational and environmental settings.

Yeah. Let's take occupational cancer. I wrote a paper on the occupational exposure of coke workers, African-American men were placed closer to the ovens, and whites were placed further from the ovens. And so there was an assembly line such that coal was being passed down to African-Americans or Native Americans or whoever was employed—men of color—and they had more exposure and the men working closer to the coke stoves developed lung cancer. So I think a lot of the diseases, let's say for lung cancer, is *a direct result of cancer among poor people*. (...) And here the researchers are writing the center saying that we have to study *why these people are dying much faster* — "*it must be genetics*," because they're dying much faster than those groups over there. So even in this country, not only are we divided as far as the profit-making on diseases, we're divided racially, we're divided on research issues, and we're divided on what's causing these people to die at a very young age.

I found the second part of this statement of extreme interest. In fact, during informal talks with cancer scientists I had asked the a question similar to the one Bonnie Withley addressed: why among black women cancer incidence is lower and mortality is higher? The direction of scientific research today is not the one of looking at issues such as poverty and lack of access to health care. Researchers are trying to understand what is "different" in the pathology of tumors among black women.

6.6. Cancer and the Environmental Justice Movement

Interview with Bob Bullard

I believe that research should be liberating, education should be liberating ... I believe in liberation research ... research that communities can use -- especially vulnerable populations, at risk populations that can take that information -- written in a form that can be understood -- and implement some kinds of intervention strategies.

Bob Bullard

Robert Bullard: I think cancer is an environmental illness ... and from the standpoint of the way science is constructed and the way industry and technology are interrelated, we can all see that a great portion of the environmental contaminants and pollution result in human health diseases. So if we talk about prevention models that somehow are based on so called acceptable risk and certain level of diseases are tolerated such as cancer -- we won't get anywhere. Cancer, a big part of it, can be considered environmental induced -- and preventable. (...)

Laura Corradi: What would be your position: preventively stop producing suspected carcinogens, lowering the exposure, or wait for the research?

R.B.: I think -- when we talk about suspected carcinogens -- that we have to look at the total environment. For a long time scientists have only looked at one chemical or one suspected agent at a time and have often time regulated it, and in some case they lower the threshold level to what is considered acceptable. In some cases that particular model still does not address the fact that in some communities at risk populations are not only facing the threat of one carcinogenic but also they have other agents out there that might do harm, a mutagen or ... So even when you lower the level you might not be affecting all communities the same because not all communities are equal in societies. So even when you come up with a strategy to address a particular problem, you may only be addressing part of the problem -- than if you put zero tolerance.

L.C. Because there are different starting points in terms of health in different communities ...

R.B. Different starting points and populations that are particularly vulnerable. For example children are extremely vulnerable. They are not little adults. And when you start talking about exposure level and all kinds of problems that may result early on, that may impact a specific area. For example you might have workers who are exposed to dangerous chemicals in the workplace and at the same time their home, their community might be located in an industrial site or adjacent [home]; and you have a double threat of being exposed at work and at home. So when you look at a model for a strategy that only deals with averages or only deals with what is considered a standard that does not take into account some communities that are saturated with all kinds of chemicals, you underprotect those populations ... and that is unacceptable, this is also an ethical issues. And it affects the ways in which you prevent future harm.

L.C.: In the Native-American community I realized there is not much faith in what the public institutions, the state or the rest of society can do for them -- and I think they have very good reasons to feel that way -- they focus the primary prevention of cancer in strategies that strengthen the individual, through healthy body politics in a way I would define as holistic; they work on fortifying the immune system and avoiding harmful substance that are avoidable . I found they consciously act upon behaviors, knowing they are socially constructed, manufacturing messages in a way that is effective in their culture. In other words, they put energy more on health promotion more than prevention [the same way Cubans do] The community leaders play an important role in this process -- but it is mostly focused on the inside the community -- they didn't look interested in banning carcinogens or things like that (...)

If you had the power to decide, where would you focus the primary prevention of cancer?

R.B.: I think a lot has to do with education, with different ways of impacting the community networking system, the economical political social structure that determines the way information is disseminated. If we look at spirituality of Native-American people, their religion and culture, it is "One" ... and humans are only one little piece of the whole circle. And if we talk about changing the way we see ourselves in the environment and the environmentally induced diseases. I think we have to talk about total health. We can learn a lot from indigenous people: total health means total health of the earth and total health in humans.

Diseases that are found in humans are indicative of some diseases that we have inflicted upon the physical environment, the earth. If we talk about healing processes we also have to talk about human health and the health of physical environment.

So I think to a larger extent we have gotten away from the whole spirituality of health and total community. I think that when we are

talking about banning chemicals that is only a symptom of a larger issue.

If we ban one chemical there is another chemical out there and we have to learn to win, take ourselves off of this chemical treadmill. To do that it means that we have to change a whole mindset, how do we learn to live without certain kinds of amenities that we have taken for granted as being the good life and to a larger extent those communities that didn't have access to the "good life" have a lot to do with maybe a mechanism break ... If you never had all this wealth and you never generated all this waste ... you don't miss it. So I think, if we talk about change, I would put confidence in people understanding how powerful they are. You see, we always think in terms of "one person doesn't matter" ... but one person does matter, when you start adding all these people together and the collective in term of changing lifestyle and change the behaviors, what we would accept and what we won't accept, the kind of products that are out there, democratizing what is being produced ... and people can impact what is being produced by not buying it, consumer boycott, selective buying strategies, conscious attitudes to redirect some kinds of production strategies. People are talking about it today, and this comes from grassroots, from a ground swell, from local organizing ... groups who now see themselves under siege in terms of the air, the water, the land ... they can't turn around and they are bombarded with all kinds of environmental problems and they are basically saying "no more... we will not accept some governmental, or some academic institution saying "there is no threat" -- and at the same time a double standard is being used.

L.C.: We need to reconceptualize the relationship between human nature and non human nature as a whole ...

R.B.: I think so because if we put human in the center and we say basically we are more important then the total environment, and that we may somehow race our science to the end of the pipeline ...

and we can fix it ... if we have confidence in technology and we have confidence in science that we can destroy but then we can fix.... as long as we go in that paradigm we are on a total mission of destruction and the same thing is for health care and medicine, -we have a disjuncture between what is being produced out there and the trash that is being pulled up here -- and on the other hand you have the medical professionals who say "we can cure diseases" and government funds both aspect, we fund tobacco growers, and at the same time we fund cancer research.

L.C.: The cancer establishment focuses more on the therapy than on prevention (...)

R.B.: [sunlight as a cause] it is related to what is the concept of beauty here, and the concept of image management -- and again the media, the advertising, would put this brown skinned blond haired golden personality as being beauty, never mind if the sun is producing cancer

L.C.: [New Zealand's primary prevention] As social scientists, who work in the academia, which do you think are the areas of environmental health we should focus on more?

R.B.: I think, if we talk about the environment and we talk about public health, generally the way those issues are dealt with in formal schooling -- colleges and universities -- they are departmentalized in different areas, public health, environmental sciences, medical school. If you talk about training in educating people on the whole issue of primary prevention it is not really addressed in any comprehensive way. If we talk about impacting new doctors that are coming out in the field and trying to get them into correct diagnosis of environmentally induced diseases -- like cancer for example -- They don't get it in medical school, they don't get it in schools of public health in a way that could impact the larger public. And if we talk

about the way most people get information, we must say that most of it comes after school, much of it come from television, radio, newspapers etc. For young people most of their way they get information is visual -- and today television right now is not for education but for entertaining.

So I think we don't have the apparatus to really address the issue the way it should be addressed. It almost like we are in a crisis ... we have to wait until there are major crisis that happen right now, almost waiting for a body count, waiting for a disaster to happen before we can get public policies changing, get curricula changes in the University, and in the high school, changes in order to address the issue..

L.C.: [how epidemiologists collect the data] Cancer is not considered an environmental illness -- the perception among scientists is that it is mostly based on genetic predisposition and triggered by personal behaviors. So when you go to the doctor he asks you about your mother and grandmother, if you smoke and drink, maybe what you eat; but they don't ask you where you live, where you work.

R.B.: That's the problem. The ways our industrial policies, our public health policies, the ways in which research is funded, our methodologies ... contribute to the problem instead of solving the problem. By using an epidemiological model where you have to depend upon cause and effect in the effort of isolating the cause ... no policy is going to be put into place in order to affect the prevention thing. The burden of proof is now on victims, on the communities that have to show to have been harm, not this companies that have been that emit all this kind of stuff from their ... smoketanks. Burden of prof is not on this companies, the burden of proof is on these communities that suspect they have been harmed -- and they have to prove they have been harmed -- and if they cannot show ... there is no remedy.

As long as we use the epidemiological model as opposed to a public health model, prevention is intervention before there is a body count. Right now we are really in the business of regulating poisons versus protecting public health. And as long as we regulate and control the level of suspected carcinogens it means that we accept certain level of disease and death. (...)

L.C.: When I ask natural scientists and health scientists to rank five main causes of cancer, often the first that emerges to their mind is "age" -- And we know that the increase in the rates of cancer is due to neither age nor better technology of detection, since statistics are adjusted keeping into account these variables. In many cases, even when scientists are leftists, I find that there is not a critical attitude toward what they are taught, they are not prone to question the official explanations or to find alternative explanations (...) And other social subjects are not taken into account when it comes to decisions about the directions of the etiological research.

Yesterday I was interviewing a "famous" cancer scientist at UCLA and he was accepting the idea of "using" cancer activists to do prevention (mentioning anti-smoke campaign, of course and the other key-words of the behavioristic school) ... But he was disregarding the possibility of including cancer activists in the decision making processes related to the directions of etiological research "we [scientist] know where we have to do research, we cannot run after everybody's claim, they say pesticide, they say this and that ... we know our job" ...

R.B.: That's totally against creating research that is community-driven, victim-driven that is people-driven. The current paradigms and the current models reinforce themselves. What it does is that it creates an industry around the research -- which is driven and directed by requests of proposals.... that come out of government and academic institutions back and forth, back and forth. And what it ends up is that the scientist create and recreate themselves in their

own research projects, which means that they are very narrow and questions are not even thought of in terms of total community health and total exposure. For example we have communities that are surrounded by all kinds of chemical plants

L.C.: The donuts syndrome ...

Yes, the donut syndrome ... and populations that don't have adequate nutrition, you have populations that work inside of the dirtiest jobs, the most hazardous jobs, with the pressure of being low income. And advertising that is targeted by tobacco companies and alcohol companies ... You add all these things together and you have a profile of communities under siege. And it is not enough just to say "what is the etiology of cancer": these are social conditions that are driving certain threats into certain communities that make them more vulnerable than others and because of institutionalized racism there are very few communities where the residents, the neighbors -- if they happen to be of people of color -- can move to, to get away from this multiple path of exposing them to any kind of risk. Research conducted today doesn't even address that kind of thing. I was in Chicago the other day trying to get funds for research on environmental inequities and public health -- to begin to bring to bear the fact that there should be some control, some direction coming from the community. Not that the research should be done by them ... And who is doing the research? It is the same thing when men were doing all the research on women and women were not involved. As soon as women got involved, they started getting different results. There is no total objective science. We bring our own biases when we look at a problem -- there are social and cultural ... milieu [involved in] the selection and the funding of problems ...

L.C.: They themselves, scientists, know that there is a dominant paradigm -- and that not enough attention is given to "the social."

They know it abstractly but they don't realize how this situation affects what they are doing and how they are doing their job day after day ... The tobacco industry has been able to delay the awareness about tobacco being a cause of cancer, for about twenty years. They [the scientists] are aware about it. But when it comes to environmental carcinogens, most of them say "well, probably it does account for very little 3 or 4% of the cancers ... we don't know enough." They repeat the official data ... but they don't wonder why we know so little about it, and how the interest of big chemical corporation have something to do with this lack of studies -- and they cannot be so innocent: if you know that there is a dominant paradigm, and that there has been in the past some profit in hiding an important the cancer such as tobacco (...) you cannot just play "Marxist" molecular biologist and then pretend that what happens in your little lab doesn't have much to do with what is going on at the macro level (...).

Some of the activists think that the burden of the proof should not be on the corporations because if they pay for the research they will very likely find out that there is no harm in what they produce -- as in the recent case of the cellular phones and brain cancer

R.B.: I am not saying that the industry should produce the data that we rely on, I am saying that there should not be a system that is structured on people being exposed to certain kinds of chemicals ... having to show that they have been harmed and that a particular substance is causing them to die ... Without a doubt, if you look at where the resources are, in those communities there are no resources to pay for the research and do the toxicological profile of those chemicals, or the epidemiological studies ... It's a matter of resources, to document what is going on. People feel that it should not be a responsibility of the community to show that they have been harmed. There is a public health function there, the government is in the business of protecting people health and the environment ... it is a matter of the extent to which you can force -- through some

legislative mandate -- force the polluters to show that they are not [polluting the environment] -- as opposed to the communities having to show that they are. This is not to say that they have to do the study but somebody has to do it ...

L.C.: In Europe it is different probably because many more things fall under the dominion of the State -- and they have to take care of you, if you get sick, which is not true here -- and many industries are owned or in part owned by the state ... So there is probably more control (...)

Some cancer activists -- survivors and scientists/activists -- came out with some ideas about how the research should be paid for by the government and by the corporations -- and that the team should include scientists elected from the different parts (those who represent the corporations' interest, the state, the communities). Others think that no scientists could be involved in a cancer study if they are getting money as consultant, from the suspected corporations or if they are sitting on the board of directors -- which is what happens for several cancer scientists in private as well as public cancer organizations (ACS, NCI, SKMCC) -- and this is not considered corruption. (...)

R.B.: In setting up a model, I think we should be very careful that we bring in the public side, the community side as an equal partner. Many times people are brought in without having a lot of information -- and they are brought in as secondary players -- and they end up being in a project. And even people who are collaborating in a major project, with large agenda settings strategiesoften times are coopted, often times they become another group that ends up validating an agenda that had been already put in place. So I think that citizen advisory boards, have to be very careful and really almost set up to change things ... If not, it won't happen.

L.C.: (...) There is also a problem of technical language, activists don't know most of the scientific terminology, their codes ... So it can be easy to open the doors to activists, just to re-legitimize the directions of the research toward the public, who would feel reassured by the presence of people from the community ... Yet, among some cancer activists I felt there is lot of suspicion about what comes from the scientific community (...)

Do you think cancer activism is part of the environmental movement?

R.B.: I think the area of cancer activism is part of a larger movement for bringing in the public and the communities of impacted areas into the movement. And for a long time science and research have been very disempowering phenomena it has been a way of bringing power and prestige in the universities. At the same time very few benefits have occurred to communities that are inundated with all kinds of environmental problems. So the movement to broaden the scope of what research is done, the policies to address how to prevent present and future risks ... it is part of the whole environmental movement. Public health should re-gain some of the power, some of the prestige that they have lost to other movements. (...) And [the cancer activism] is not a movement in itself but is part of a larger movement. And I think because the public is demanding information, open meetings, open books on certain kinds of research that has been conducted behind closed doors by small group of scientists -- and who knows what they are doing ... Let's open it up! Explain what you are doing and how this is going to be used! Since much of the research comes from tax money people want to know. People are saying "we demand -- since we are paying -- to know what you are doing, why you are doing it, and how it's going to be used"

It is a matter of accountability and making research useful, usable ... moving the agenda away from this room into communities where it can be used or applied. That's the kind of energy generated by these

local groups that are out there trying to pressure inclusion to advisory teams or whatever. They want to be included and make sure that the research is kept honest. And it not bought off by government, industry ... and sometimes these communities cannot really see the difference

L.C.: There is not much How do you consider cancer activism can make a contribution in the environmental movement?

R.B.: I think the cancer activists can bring to the larger environmental movement the visibility of public health ... For a long time, the environmental movement has not focused on the public health agenda. And so that's been to a large extent "the missing piece" -- because you have highly organized, highly trained -- and in many cases very technical -- people out there, included scientists who want to address some of the environmental problems that result in damage to public health. I think it is a good thing because it brings [people] together -- although there is still some resistance by some circles to bring these folks in -- I can think it can only strengthen the movement of total environment of a healthy environment ...

L.C.: Yes, sometimes "the environmentalists" are seen by the workers as those who want to save the trees and the animals -- and the connection is missing. That we are part of the material conditions of life, which allow our existence on the planet. (...) With cancer the connection becomes evident.

R.B.: Cancer activism is particularly important to the environmental justice movement -- and I emphasize justice because when we talk about access to public health ... about "differential impacts of environmental problems" in specific populations and communities ... about "high risk groups" ... the justice question becomes central. Who is affected, who is impacted, who is not part of the decision making

processes, whose communities are considered a "sacrifice zone" ... This is the way you can get a lot of cancer activists involved in local issues, grassroots issues ...

L.C.: Yes, because some areas of cancer activism -- in particular breast cancer activism where you deal also with Republican women - - where the level of consciousness is low ... On the other side, I look at the phenomenon "objectively" -- at the cancer movement in se, instead of per se -- it has a strong anti-capitalistic character

R.B.: Yes: this is an area where you start getting people from different socio-economic conditions, ethnical and political backgrounds. (...) Breast cancer activists can bring in feminist who deal with problems that are unique to their gender, interests groups from people of color, minorities activists, workers who experience particular exposures.

It is raising a kind of issue that has the potential to mobilize and galvanize organizations, groups and communities. And I think that -- to some extent -- becomes a threat to the current power stake holders, people who are in position to maintain the status quo. When you can bring people together, to say that these things can change, it becomes a threat and you get backlash (...).

L.C.: Let's talk about the interface between race and class -- I realized that many kinds of cancer that disproportionately affect minorities -- Blacks, Chicanos, Natives -- are related to their economically disadvantaged conditions ... I found that for those factors such as bad nutrition, alcoholism, cigarette smoking we cannot just talk about "ethnical differences" or "race" per se ... I think those factors are in a place where race becomes class ... And I don't believe that we can find much explanation in genetic differences -- with the exception of skin cancer

R.B.: If you look at the interface between race and class in a racist society it's hard to differentiate ... why are people poor? why are people forced to live in certain areas -- where you get more pollution and risks are elevated? When you start to look at the class phenomenon in this society it is not impossible but it is difficult to determine why people of color are poor -- and are more likely to live in poor neighborhood, in poor quality housing ... It is not just income alone ... you can factor out the income, the class factor, and still have a big part of unexplained variance, that has to be looked at as something else -- and this something else is often times discrimination. For example: access to health care, not having certain types of amenities in one's area, or equipment for early detection, not having insurance ... Looking at all these social phenomena you end up saying that there are some institutional barriers that go beyond income alone. And we find it when we start looking at workplace in public health: greed with racial discrimination impact where people are placed in jobs. If you come across one of the studies that NIOSH did on steel workers, and see whom got to work closer to the oven, they are black workers ...

L.C.: You mean that in first place race determines -- in large extent - the class condition; and in second place class composition determines how "ethnically" the disease is distributed?

R.B.: Yes. Once upon a time there were laws to enforce discrimination. When the laws have been eliminated discrimination still continued ... you had the history of that pattern over the years that kept education level low and income level low for specific ethnic minorities. So people are saying "there is no discrimination" because it is about access to health care and so on. It is not a racial thing now, it is a class thing.

L.C.: But because of race ... so race largely determines the class and then class determines how much cancer you get. I am trying to

separate conceptually how cancer is produced and how it is distributed (...)

R.B.: Let me make an example of the media campaign to discourage cigarette smoking: there is occurring a class and a race phenomenon - the groups that are stopping smoking are college educated, the groups that are starting to smoke or are not stopping are high school [educated] or less. There is a strong racial phenomenon in education, in this country, in terms of drop-out rates, pushed-out rates, access to education, to college and beyond. If you look at media advertisements for cigarette smoking it is targeted toward women, people of color, and [those with] less than high school [education]. And then ... where are cigarettes exported? [They are exported] to countries of the third world. If you look at that in terms of justice -- how cigarettes' contribution to cancer and other public health problems are transferred to other places and seen as economic shift off shore. It is considered a business, not a health problem.

L.C.: It is an ethical problem. The scientists know that the consumption is decreasing in U.S. and tobacco export is multiplying ...

R.B.: It is a matter of filling up markets, and at the same time you fill up hospitals ... growing tobacco within the commerce department here -- or the agricultural department -- is considered a business. The ethical question goes to the core of who is affected ... If those getting sick don't have blond hair and blue eyes, then it doesn't matter. Or if they happen to be in South Korea, or Taiwan it is not considered to be as important ...

L.C.: ... they are "less human"...

R.B.: They are less human, they don't make as much money, they don't live long in terms of life expectancy ...

L.C.: ... and they are used to having a lot of people who die "anyhow"

R.B.: That is a construct that has to change ... because it is the same energy that makes women considered less than men, inner cities less than suburbs, blacks less than whites. And these kinds of concepts drive the medical research in this country (...) How can we change the ways different institutions address the issue of health inequities?

L.C.: I have just been told here at UCLA that most of breast cancers are not due to a "genuine increase" of the illness, but to early detection. This explanation works for white women, but it doesn't work for black women. Because among white women the [new] case finding has been increasing a lot, while among black women it isn't. A famous scientist yesterday was wondering "why breast cancer mortality is increasing among black women? ... if we could understand why breast cancer mortality is increasing among black women, I believe we would have the key to the whole breast cancer problem", he said.

And he is not going to find any key, looking at the data they have. Maybe if they were to ask black women why they are dying more of breast cancer, the answer would be less difficult to find out ... Do you have any hypotheses?

R.B.: There have to be more studies involving people who are at risk. Most of the people who do the research are white men who don't have a clue about it (...) I don't know of any major effort to find out ... who sets the agenda? and the extent to which funds would be allocated or re-allocated -- and with scarce budget today it becomes a political question, besides a science question. Where does the money come from to do a study? Who will be conducting the study? These questions are not in the realm of science but are about politics and economics.

L.C.: This is strategic. And if the social subjectivities are not involved in the process of science making, science is not going anywhere else than where the dominant classes want science to be

R.B.: Exactly.

L.C.: So now, in order to answer to the enigma about black women getting more breast cancer, they will probably write dozens of grant proposals to get the money to kill a few thousands mice ... And they will not come up with anything -- because most of that kind of research is inconclusive by design, most of the research is meant to reproduce the scientists' cast and their privileges ... And if by chance after a few years they find out something about a chemical carcinogen, then such a proof can be considered not enough in a law trial, because "there is not epidemiological data to support the lab findings" and because "humans are not mice" (...)

Sometimes the community wins -- but this is an exception because everything is set up to discourage the people, dismiss their hypotheses, falsify their evidence -- and the adversaries are strong, the institutional context is always in their favor, and most of the scientists go on making a living with experiments on mice -- without ever wondering if talking to people could give them some better idea.

R.B.: We are trying to push to bring in the community side (...) and this is not less objective -- it is more objective, because people can give you information that needs to be put into the study, that needs to be accounted for -- instead of saying "this is unexplained." Bring in the subjects, their lifestyle, their exposure, their environment, workplace ... That for me would be a superior model, but to the current stake holders in terms of scientific community this would be empowering the communities folk -- like in a game where you have X amount of power and nobody wants to give up their part of control. When you start bringing in the public side as equal partner

in the process you are talking about giving up some control and there is where the power struggle takes place. It is not a scientific question -- it is a political question.

L.C. : Yes. It is about control and about profit. At the beginning I mentioned to you the theoretical part of my work -- how capitalism produces death. Where you have profit, it seems like you cannot have health.

R.B.: Exactly. If you look at the system of health care it is all about profit: doctors are entrepreneurs, and when we talk about health care reform we are talking about tinkering with a business. It doesn't have much to do with disease prevention -- it has to do with tinkering with the system so that you will not take away the profit from medical schools, hospitals, clinics, doctors ... There is money in disease, there is profit in disease, and there is profit in research that focuses on examining problems instead of coming up with intervention models.

L.C.: From the production of cancer to its detection, to cure and rehabilitation ... to the burial, profit is all the way ...

R.B.: There are groups advocating how to take the profit out -- and this is a political movement. Because asking to take the profit out is like ...

L.C.: ... asking to overcome capitalism ...

R.B.: Yes. And this is a big question. The wagons have been circled and the whole institution now is under siege. People are demanding action, they want a change, they want to see health -- something that is reality and not a concept up there. Health should be right now (...) And this cuts off the tentacles of capitalism and its production system that feeds on exploitation of the environment, natural

resources, and health. When we talk about total environment we can learn a lot for our Native-American brothers and sisters, who talk about seven generations down the road, the health of seven generations after us. American don't like to think that far in the future because we are more "now oriented" and seven generation are a long time if we talk about taking care of the planet and what is on this planet to make sure that what we leave is in better shape of when we found it. That's a different culture, different from the Eurocentric ideal of nature and environment to be exploited and dominated. There is a connection between the exploitation of land and the exploitation of people's bodies. When you move in that direction you have to challenge the whole infrastructure. People are questioning, even in the academia, what we are doing to our bodies, what we are doing to the environment in a way that embodies everything.

6.7. How Are Cancer Activists Affecting the Scientific Community?

Even though it's early to talk about the long term effects of cancer activism at this stage -- and the situation is changing fast -- I can record a few changes that have already occurred.

1. Cancer activists now participate in academic and scientific meetings about cancer -- they are officially invited to be there and sometimes they are part of the panels. Often the function they have is the one of "window dressing" -- as some radical activists put it. However their presence forces the speakers to keep in mind that women are in the audience for their message, along with colleagues, pharmaceutical industries, governmental agencies, and so forth.

Sometimes a medical symposium on cancer can become an arena where women can disrupt the well established order of things, and issues that are not usually taken into account become questioned. This happens rarely, though, because women survivors usually do not have the necessary background to confront a setting

where the scientists seem to have total control. But the activist eventually find allies among the scientists and begin organic relationships with those who sympathize with their issues. These relationships, as we are going to see, go both ways: the scientist learns a different perspective and feels obliged to more clarity and consistency, while the activist learns the medical jargon and how to do politics.

The other side of the coin is that in admitting *some* activists to the discussion table, the choice is made by looking at those who display more affinity with the scientists' orientations. Those activists who are less likely to create trouble are more likely to get invited. This process of active cooptation produces some frictions between those activists who go to scientific meetings and those who are prone to view the scientific community more as enemy than as ally, except of course for the hereticals, the scientist-activists.

2. Thanks to cancer activism, what is being produced in a particular area of science -- cancer research -- becomes very public, in the same way it happened with AIDS research. Ideas, discoveries, controversies, everything that might be related to the topic gets more media attention than before because activists have made cancer a hot issue. Organizations such as the American Cancer Society and National Cancer Institute get their documents and their actions carefully analyzed, discussed and finally criticized, whereas before they didn't have a public of active interlocutors collectively arguing and bargaining with them.

3. People in general are less afraid to talk about cancer and the illness is not seen by public administrators as an individual problem but as a social one. This change in public perception is going to affect the scientific community indirectly via state administration, since the requests for solutions to be used *hic et nunc* will have consequences in the directions cancer research should take.

4. When it comes to etiological research, the activists' voice is usually not welcome among scientists, who feel that research about cancer causes is their own business, too technical to be understood by activists. Several scientists appeared to be far from accepting a theoretical perspective that takes into account the notion of locatedness of knowledge.

The scientist's epistemology does not recognize the value of non-scientists' perspectives. They tend to believe that what they know can be known only by them. In synthetic terms, while the activist is confronting the scientist by saying: "I know/perceive something you ignore," the scientist is answering: "I do not recognize your capacity to do so" -- before accepting or rejecting the content of the activist's discourse.

5. In practical aspects of prevention, the presence of lay persons is more frequent: even the American Cancer Society has included cancer survivors in prevention programs, aimed to discourage cigarette smoking, and promote healthy diet and exercise. Unfortunately, a large part of the preventive action in this country is designed to improve secondary prevention (i.e., early detection). When it comes to primary prevention, the focus is on those factors related to individual behaviors and personal choices, while environmental factors -- which are not under the individual's control -- are dismissed or ignored.

Nevertheless, in primary prevention, activists have more voice than in the field of etiological research; they also have elaborated some elements of strategy focussed on banning known carcinogens -- and they often mention pesticides and chlorine. In this work their main allies are the Zero Toxic Alliance, the Environmental Justice Movement, and recently some sectors of Greenpeace. Cancer activists have also requested a change in the social messages about smoking and diet: less blame on the individual and more on the economic and ethnic inequalities behind unhealthy and risky behaviors.

6.7. Conclusion

In this work I discovered a new social movement -- the cancer movement. Its roots are to be found in the occupational health movement and in the feminist movement of the sixties and the seventies. We have discovered the cancer movement has three main component:

- a. women survivors activists;
- b. progressive and concerned scientists;
- c. people of color organized in the environmental justice movement.

To read the cancer movement, both Marxism and feminism if taken alone -- are not enough of an explanation. The cancer movement has an "objective" anti-capitalistic character, because the elimination of most causes of cancer is in conflict with the pursuit of profit. Yet, the cancer movement is not a "proletarian" movement in classic terms. It is a "transversal" movement in terms of composition -- but cannot be read with the theories offered by the post-modernists *a la* Touraine -- because the interests of this movement are ultimately the interests of everybody. The cancer movement is not an "interest group" even though its social form now is dominated by the activism of those who are already suffering with the illness.

The cancer movement is based upon three different consciousness-forms:

- the awareness of women biologically and socially responsible of the reproduction of the species;
- the awareness of indigenous populations -- whose conditions of reproduction are strictly connected with the balance between human activity and natural resources;
- the awareness, among different social strata, of racial and economic injustice, and the existence of a specific environmental racism.

Such a complexity cannot be explained with any of the theories we already know. Such a complexity calls for a new theory that can keep into account those movements that resist the global trend toward the disruption of the conditions of human sustainability.

A theory of capitalism as production of death could be represented as a process that proceeds from the margins (third world countries, rainforests etc.) to the center, while progressively legitimating ideologically -- through the science of risk assessment or through a perverted use of the "burden of proof" in the legal system -- the necessity to sacrifice categories of people on the altar of profit.

In this process, capitalist accumulation also produces its antagonists, and various forms of revolutionist accumulation.²⁰⁹ A theory of capitalism as a production of untimely and avoidable deaths needs to keep into account the analysis of specific forms of resistance to random and selective forms of decimation. The cancer movement has, in embryo, the potential for stimulating wider forms of resistance based on body as environment.

²⁰⁹ J. Borrego, "Metanational Capitalist Accumulation and the Emerging Paradigm of Revolutionist Accumulation," in *Review*, Vol. 4, N. 4, Spring 1981, pp. 713-777.

Chapter 7

PROFIT AND PREVENTION

7.1. Introduction

The debate over profit and social responsibility is not new. Yet, the production of articles and books on the topic is scarce compared to other social problems. Most of the articles I found through searches in the sociological literature are not produced in United States but in European countries, and authors are mainly German and Italian. This is probably due to the long tradition of studies in philosophy and ethics, which have a field of application to economy and society.

In the first part of this chapter I am going to review such literature in connection with the results of my research. However, I want to warn the reader about the inadequacy of the literature to attempt explaining scientists' discourses on the role played by profit in cancer prevention.²¹⁰

In section 7.3 and 7.4 of this chapter I am going to present and analyze the scientists' statements around profit and cancer. For the purpose of this dissertation I have chosen to focus on the scientists' answers because they offer a wider range of views, while -- on issues of profit and cancer -- activists seem to have a more homogeneous point of view.

²¹⁰ Presently I am not able to build a theoretical frame that would enhance the comprehension of the phenomenon I am analyzing. Such a construction would require a stronger background in Ethics on my side, since the knowledge I have in this discipline is fragmented and inadequate. An appropriate theoretical framework to analyze the ethical issues raised in this chapter will require me to read philosophers who dealt with ethical issues others than the classics I have studied in my Western intellectual training.

7.2. Different Perspectives on Cancer and Profit

Even though in this work I am not going to analyze the activists' answers on the connections between cancer and profit, it may be useful to consider some structural differences between scientists and activists, related to the specific social location from where they are speaking.

Scientists tend to offer an "insider perspective" that is missing among activists: they receive money from research institutions, grants from the government, and often they work for private industries. Because they are located outside the scientific *milieu* activists have less access to processes and details of the connections between science, government, and industry.

Moreover, since activists look at the cancer establishment as a complex of institutions that systematically alienates them, activists are necessarily suspicious and their views about cancer and profit denote a "critical" standpoint toward the system. On the opposite side, most of the scientists I interviewed lack a critical vision about their work, their relationship with public agencies and private companies.

Chicago epidemiologist Peter Orris constitutes an exception in this matter: during the interview he was able to articulate an auto-critical analysis on his own "dual" experience as a concerned scientist who works in a public agency and as a private consultant for industry. I will present parts of his monologue on roles and contradictions in Appendix 26.

Often cancer activists spontaneously talked about the role played by profit when answering questions on their perception of cancer causes, or when expressing opinions on primary prevention strategies. Several activists mentioned profit before my questions on the subject matter -- which were situated at the end of the interview.

Cancer activists have been exposed to a whole body of literature that relates cancer with the economic and political

structure and with a system of vested interests -- industries, institutions and scientists. Because of their position and their critical readings -- from "The Politics of Cancer"²¹¹ and "The Cancer Industry"²¹² up to the monthly "Cashing In - On Cancer"²¹³ -- they are quite a disenchanted group.

Excluding scientist-activists, the scientists whom I interviewed turned out to be, in a sense, more *naive* on the topic. They offered a great deal of information, stories and analysis, just by speculating aloud on the subject matter. A couple of scientists seemed never to have heard the word "profit" before my question: "Profit? what do you mean by that?" After my explanation, they made the basic connection between the profits made by the tobacco industry and the problems in preventing causes of cancer such as cigarette smoking.

Most of the scientists' statements on this topic are longer than those I quoted in other sections. Their answers on this subject are complicated, sometimes contorted. There are several reasons for this. Scientists' statements on technical matters had a structure that is missing in their talks on economic and political issues. On cancer etiology, scientists could answer by listing causes and how much they account for. On primary prevention they could adopt the same model by listing priorities and neglected areas. But when asked to connect cancer with profit, scientists had to step outside their terrain of competence. Sometimes "profit" was a key word to which they had to struggle to attach a meaning related to their experience as cancer scientists. They found themselves talking about something they don't usually discuss in their work or in their everyday life. With the exception of those scientists who are also involved in cancer activism, they proceeded by offering me examples, sometimes by asking more questions.

²¹¹ S. Epstein, *The Politics of Cancer*, Sierra Club Books, San Francisco, 1978.

²¹² R.W. Moss, *The Cancer Industry: Unraveling the Politics*, Paragon House, New York, 1989.

²¹³ J. Brady, "Cashing In - On Cancer," regular column in *Center News*, Women's Cancer Resource Center Newsletter, Berkeley.

7.3. Anti-Tobacco Scientists and Anti-Carcinogen Scientists

There are several issues cancer scientists mentioned when talking about cancer and profit. Sometimes scientists mentioned the profits made by pharmaceutical and other industries in the context of cancer research and therapy; they also connected economic gains with issues of status and career. Even though this topic is extremely important, I am not going to include the analysis of the statements scientists offered. In the economy of this work I will only focus on *the profit made by private companies -- such as the tobacco and chemical industries -- as an objective obstacle in cancer prevention*. For analytical purposes, I will not address here the personal economic gain cancer scientists make in their profession, in their role of consultant and/or as stockholders of private companies.

Almost every scientist mentioned the profit made by the tobacco industry and some advocated banning cigarettes. Yet, I think the most important distinction that emerged is not between cancer scientists who are for and against the tobacco ban initiative. The most relevant finding of my research in this area is that there are scientists who see profit as an obstacle in primary prevention in general, and scientists who see the connection between cancer and profit only when it comes to tobacco smoking.

Most of the scientists who focused on the tobacco industry and their profits as a main obstacle in primary prevention didn't speak about the profits made by other industries -- by producers of chemical and physical carcinogens, by agricultural companies, by sectors of media connected with these businesses.

This group of scientists -- whose statements are discussed in section 6.3. -- constitutes a "moderate" wing, even when they favor the banning of cigarettes. They can be considered politically moderate because *their critique of the role of profit is partial* these scientists look at the ways in which the tobacco industry deliberately harms people for the sake of profit -- but fail to address that other

industries also knowingly harm people because their profit comes first.

Advocating a radical form of intervention -- like banning tobacco -- in this case is not the expression of a radical content. From the political standpoint of several cancer activists, the banning of cigarettes may be even seen as "smoke in the eyes" of the concerned public -- as another way to distract people from fighting against those environmental carcinogens over which we don't have much control. Another group of scientists -- whose positions I present in section 6.4. -- articulated a discourse around the profit motive as a systematic obstacle both in (a.) obscuring and delaying awareness about unknown environmental causes of cancer and (b.) in the primary prevention of known environmental carcinogens. These scientists often saw profit also as the motive underlying the obliteration of "alternative" research and popular epidemiology. They represent a "radical wing" because they critique profit as a system in different ways and degrees. They are favorable to banning or phasing out proven carcinogens. Several of them, but not all, are involved in cancer activism.

Profit As A Stimulus To Improve Cancer Prevention?

Some scientists argued that the profit motive could be used as leverage to induce industry to clean up the environment. Their statements refer to a "virtual reality" where several social changes would have happened. I am going to briefly summarize their perspective, since it represents an interesting counter-thesis to my theory of capitalism as production of death.

I also decided to include these ideas scientists expressed while talking on the subject of profit -- its role against prevention, and how things should be -- because I think it is interesting to look at social actors' visions and what they imply.

For some of the scientists interviewed, a change in the social role of profit -- from being an obstacle to being a stimulus to cancer

prevention -- would happen in a scenario where the political system becomes able to force the economic system to be accountable for the human and social costs of their profits.

A major state intervention is seen by these scientists as necessary in the primary prevention of cancer, to promote regulations on controversial substance and implement the immediate banning of proven carcinogens. In their vision, a system of taxation and fines would discourage those industries that do not comply with the law. Such intervention from the legal apparatus is seen as an unavoidable measure -- because in their search for profit corporations would do anything but behave in a socially responsible way, unless legally regulated.

Since I consider it relevant that the large majority of the scientists consider the profit motive as an obstacle to cancer prevention, I find very interesting that -- when asked about solutions -- scientists tried to conceptualize how profit should play a different role in our societies. Most of them didn't said that we should eliminate profit. Most of their statements in this area are based on presuppositions, on "ifs" and "shoulds" -- yet they express a desire for change [see Appendix 22].

7.4. Shifting the Burden of Proof to Corporate Polluters

An important element that would allow a change in the role of profit and in cancer prevention is located in the sphere of legal relations and principles. Some of the scientists argued that when a chemical or a physical agent is suspected to be a carcinogen, the burden of proof should be on those who profit from its production, distribution, or disposal. These scientists also advocate a different perspective as one of them pointed out: chemicals should not be considered "innocent until proven guilty," chemicals are not people, they should not be given human rights.

They tend to agree that industry -- or industry and government -- should pay for research on suspected carcinogens, not

those who are exposed. They also argue that scientists should be monitored by the government and/or by agencies that represent the public concern. Everything should be proved safe *before* it is released in the environment -- while the process today is the one of doing epidemiological research *a posteriori*.

I also interviewed two "cancer lawyers" in the Bay Area: Amanda Hawes who has been in community law practice since 1977, and Flora Chu who started in 1983, after a career as a scientist. Both work on occupational disease/toxic tort litigation. The first is Director of Santa Clara Center for Occupational Safety and Health, the second is Director of the Asian Workers Health Project.

They both represent people with cancer, who have worked for a long time while exposed to chemical hazards, or electromagnetic radiations, or ionizing radiations. Besides legally assisting workers who already have cancer, they are involved in prevention and part of their work is to "educate workers about hazards on their job and give them the power and the knowledge to change the conditions on the job and remove the danger or the risk of cancer."

Hawes and Chu see the profit system as being at the basis of the production of cancer, and a main obstacle in preventive actions. In a two-voices dialogue they offer an analysis of how obstacles to cancer prevention are constructed in the terms of the legal system [see Appendices 20 and 21]. They had the necessity to consider the relation between profit and cancer, since such relation is quite clear in the context of their professional life; they also introduced a discourse on the necessity of *shifting the burden of proof from the cancer victims to the corporate polluters* -- in a "virtual" context where nothing is allowed to be produced and circulated in the economic sphere, unless it is proved non-detrimental to human health and the environment.

7.5. Ethics and Profit

Most of the literature I have reviewed takes the standpoint of analyzing specific ethical problems in corporate activities and practical solutions. The terms of the debate are on issues of "moralizing the business world," and setting ethical standards in the competition between corporations or nations.

Business professionals and philosophers of practical ethics are interested in the discussion of ethical dilemmas, and ethical problems such as corruption, bribery, and the scandals that derive from these problems. The literature focuses on the "defects" of the system, on perversions and misconducts -- and how these can be prevented. Problems are analyzed with the mindset that they can be solved within the present mode of production and economic relations, without social changes. Ethical problems are treated as technicalities -- matters of malfunctioning -- which only need some willingness to be fixed.

Legislative power plays a central role in the literature on ethics and profit -- and different governments seems to imply different criteria when it comes to moral choices. The Foreign Corrupt Practices Act signed by Carter in 1977, which considered "a crime for American corporations to offer or provide payments to officials of foreign governments for the purpose of obtaining or retaining business"²¹⁴ and implied severe penalties for the violators -- fines for the companies and prison for the managers.

Philosophers of ethics Pastin and Hooker argue that this law cannot be assessed as morally sound by using either of the two competing ethical approaches. The first -- the utilitarian tradition -- requests that a law promote "well being of those affected by the law to the greatest extent practically achievable"²¹⁵ -- but this law harms

²¹⁴ M. Pastin, M. Hooker, "Ethics and the Foreign Corrupt Practices Act," in P. Werhane, K. D'Andrade (editors), *Profit and Responsibility. Issues in Business and Professional Ethics*, Edwin Mellen Press, New York, 1985, p. 169.

²¹⁵ Ibidem, pp. 174-5.

corporations in their attempts to secure business abroad. The alternative approach -- which I would name as "pragmatic" -- consists of the rule to refer to previous laws, which again invalidates the principle that prohibiting international bribery is a moral action.

During the Reagan administration the Foreign Corrupt Practices Act underwent a revision led by the principle that bribe payments are not unethical. Those experts of ethics who supported the revision argued that corporations have only two obligations: to promote the investments of their share holders and to protect the security of their employees' jobs. While the federal government should protect the welfare of American business and workers.

So corporations promise to promote their investors' financial interests and are morally obligated to them. What difference does this make to the morality of international corporate bribery? My answer is: None.²¹⁶

The literature on ethics and profit presents several paradoxes like the one above: an anti-bribery law that is considered unethical because it harms business. Yet, to my knowledge, there is no recent academic literature addressing the issue of capitalistic profit and ethics as two antithetical entities.

The body of studies on ethics and profit, business and morality, corporations and social responsibility -- both theoretically and empirically -- are concerned with creating terrains of compatibility between the two entities. My starting point in this matter would proceed from establishing that, *since profit is generated because of an unequal exchange between labor and wage, its very nature is anti-ethical*. The studies I reviewed do not look at the incompatibility between ethics and profit because they do not look at their essence -- as I defined it above. The studies I was able to

²¹⁶ K.D. Alpern, "Moral Dimensions of the Foreign Corrupt Practices Act," in P. Werhane, K. D'Andrade (editors), *Profit and Responsibility, Issues in Business and Professional Ethics*, Edwin Mellen Press, New York, 1985, p. 182.

locate on ethics and profit produce a kind of phenomenological knowledge, rather than a substantial analysis of their structure.

Some of the literature looks more at causes and processes, other works try to prescribe what should be done in ethical terms. Among the first group of studies some mention the ethical implications of contemporary socio-economic trends and warns the readers about the limits of growth.²¹⁷

In a recent symposium on utility and morals held in Amalfi, Italy, philosophers focussed on the polarity between individualistic utilitarianism and collective solidarity and on what should be done in order to infuse ethics into our economies and societies. The symposium took for granted such a process would be feasible -- and implicitly admitted a tension between ethics and profit. Significantly, phenomena of genocide, such as the Holocaust, were analyzed by participants as a tribute to modern rationality, technocracy and tendencies toward calculation and instrumentality.

Paul Shapiro focuses on cultural features of modern societies, in contrast to the institutional/structural approach of the Amalfi symposium. He analyzes protestant residues in corporate ethics as the key factor that corrupts moral concerns, ethical behaviors, and religious norms. Bureaucracy is presented as

a decivilizing process that tends to decrease an individual's spontaneous expressiveness. Bureaucratization also acts as a destabilizing force on individual identity and institutions, thus generating a thanatotic ethos.²¹⁸

²¹⁷ K. Raes, "Morele dimensies van het ondernemen. Bedrijfsethiek als socio-culturele stoming" [Moral Dimensions of Management. Business Ethics as Socio-cultural Trend], in *Tijdschrift voor Sociale Wetenschappen*, Vol. 37, N. 2 April-June 1992, p.101-136; see also D.H. Meadows, D.L. Meadows, J. Randers, *Beyond the Limits: Confronting Global Collapse, Envisioning a Sustainable Future*, Chelsea Green, 1992.

²¹⁸ P. Shapiro, "Protestant Residues in Corporate Ethics" in *International Journal of Politics, Culture and society*, Vol. 1, N. 4, summer 1988, p. 615-623, as quoted by C. Grindle in Sociological Abstracts (hard copy reproduction not available; document not on microfilm).

In Shapiro's argument, the death instinct would work at both levels, the one of *inertia* and the one of compulsive repetition. Another factor negatively affecting ethics in our societies is the tendency of all bureaucracies to delegate responsibilities and to create settings where authority should be obeyed also when orders contrast with the personal value-system.

Some studies analyze the relationship between private gain and the public good. David Vogel adopted an historical approach where objective movements of capitalism and the subjective will of the businessman can be juxtaposed. In his work the conflict between those explanations that focus on human nature, personal profit and personal ethics, and explanations that focus on the nature of capitalism are considered to be significant. Interestingly, the author does not "choose" between the two approaches, admitting the existing tension as a dialectical factor.²¹⁹

Another historical approach by Bernd Estel²²⁰ investigates the dialectics between moral attitudes and economy. On one side, the author looks at the ways in which the economy shapes social dynamics and determines ethical attitudes. On the other side, he also looks at the ways in which (socially constructed) ethics can affect economy, its priorities and values.

From a gender perspective, Frigga Haug²²¹ argues that ethical norms are set up with no specific attention to women, and without recognizing that men and women have different moral attitudes. She is convinced that, while men's ethics are based on responsibility,

²¹⁹ D. Vogel, "Business Ethics, Past and Present," in *Public Interest*, N. 102, Winter 1991, p. 49-64.

²²⁰ B. Estel, "Ökonomie und Moral: Aspekte ethischen Handelns in Gesellschaft und Wirtschaft" [Economy and Morale: Aspects of Ethical Behavior in Society and the Financial Domain], in *Sociologia Internationalis*, Vol. 26, N. 2, 1988, pp. 209-222.

²²¹ F. Haug, "Die Moral ist zweigeschlechtlich wie der Mensch: Zur Theorie weiblicher Vergesellschaftung" [Morals, Like Human Beings, Have Two Sexes: On the Theory of Feminine Socialization], in *Das Argument*, Vol. 25, N. 141, September-October 1983, pp. 653-673.

women's ethics are based on their body -- and that both should be studied in the perspective of their complementarity.

In the anthology *Profit and Responsibility*²²² the authors present their studies within a conceptual framework that assumes business responsibility as an obligation to respect human rights. Such a minimalist approach finds its main theoretical reference in Milton Friedman's work.

There is one and only one social responsibility of business -- to use its resources and engage in activities designed to increase its profits so long as it stays within the rules of the game, which is to say, engages in open and free competition, without deception or fraud.²²³

Besides not questioning "the rules of the game," Friedman, and those who subscribe to his statement overlook the essence of profit - - what constitutes its very condition of existence. Profit is the primary sign of an uneven exchange between the worker and the owner of the means of production. It is the concrete proof that something more -- a surplus -- is extracted from the worker, something for which he/she is not paid. If the worker would be paid for everything he/she does, such surplus would not exist. If the worker would work only the time necessary to his/her own reproduction, no profit would be made. And capitalist society cannot live without profit.

The last study I want to mention is "The Place of Profit," by Ronald Cordero, a philosopher of ethics who idealistically argues just the opposite of what reality is: he is convinced that profit should not be the primary aim in business. He looks at monks who produce herbal liqueur in their monasteries and heiresses who decide to feed poor towns. They are in business, but profit is not important to them. He argues that the hierarchical location of profit in business is

²²² Werhane, K. D'Andrade (editors), *Profit and Responsibility. Issues in Business and Professional Ethics*, Edwin Mellen Press, New York, 1985.

²²³ M. Friedman, *Capitalism and Freedom*, University of Chicago Press, Chicago, 1962, p. 133.

a matter of "personal choice." His purely philosophical approach does not take into consideration social and economic structures, which do have some role in profit oriented choices.

In conclusion the heterogeneous literature on ethics and profit has the common denominator of not dealing with the essence of the latter and -- to different degrees -- does not address the social construction of the former. Philosophers of ethics who wrote about ethics and profit do not look at the structure of the relationship between ethics and profit -- they either describe aspects of this relationship as a phenomenon or prescribe how reality should be, by ethical standards.

There are studies that deal with ethical issues, profit, and cancer, among those produced by scientist/activists. These works have not been carried out by sociologists or philosophers, but have an important value from a sociological and ethical perspective.

The Politics Of Cancer, written at the beginning of the seventies by scientist/activist Samuel Epstein²²⁴ can be considered the first stone thrown against the economic and political power behind the cancer epidemic. This work was widely read and translated into many languages. In recent years it has become a textbook in the cancer activism *milieu*. A whole chapter could be devoted to the importance of Epstein's book and its implications.²²⁵

More recent works often do not offer the benefit or an overall analysis, since each focus on a specific aspect of profit as an obstacle in doing prevention. Even though these works are pretty specific and deal with partial issues, they represent materials today available to the scholar who is interested in investigating the connection between the production of illness and the profit system.

²²⁴ S. Epstein, *The Politics of Cancer*, Sierra Club Books, San Francisco, 1978.

²²⁵ See also the historical account of the controversies over cancer, recently published: R. Proctor, *Cancer Wars: How Politics Shapes What We Know and Don't Know About Cancer*, Basic Books, New York, 1995.

Scientist/activists Makhijani and Saleska, in *High-Level Dollars, Low Level Sense*, deal specifically with the management of long-lived radioactive wastes and its politics, and discuss viable alternatives.²²⁶ *Inconclusive By Design* deals with the connection between the profit system and the production of life-threatening illnesses due to the disposal of toxic waste. It analyzes frauds and abuses in Federal environmental health research.²²⁷

The Cancer Industry makes a clear connection between the profit system and the production of cancer, by denouncing frauds among cancer scientists, politicians and the business world.²²⁸

7.6. The Tobacco Industry: Profit in the Production of Death

Returning from the literature review to the interviews, I will analyze what scientists' say about profit as an obstacle, when it comes to the prevention of smoking-related forms of cancers. Since several of these scientists work for institutions such as the American Cancer Society, the National Cancer Institute, the Center for Disease Control, and the Environmental Protection Agency, I have chosen to include also the different solutions they propose against tobacco companies.

I will start with the declarations of two cancer scientists at the American Cancer Society, an agency well known for its (recent) commitment in the struggle against the tobacco industry, represented as the number one enemy in primary prevention. The first scientist I interviewed focussed his answer on the profit made by tobacco companies.

²²⁶ A. Makhijani, S. Saleska, *High-Level Dollars, Low Level Sense*, Institute for Energy and Environmental Research, Takoma Park, MD, 1992.

²²⁷ S. Lewis, B. Keating, D. Russel, *Inconclusive By Design*, Environmental Health Network, Harvey LA, & National Toxics Campaign Fund, Boston, May 1992; L. Corradi, "Inconclusive By Design" (bookreview), in *Capitalism, Nature, and Socialism*, Vol. 6, N. 3, September 1995, pp. 135-138.

²²⁸ R.W. Moss, *The Cancer Industry: Unraveling the Politics*, Paragon House, New York, 1989.

I think the cigarette companies are a great example. It is one of the most lucrative businesses there is and the reason why the advertising is everywhere is because they have a lot of money. [Interview N. 33]

The interviewee opposes the banning of cigarettes because it would create an illegal market for tobacco, the way it happened with alcohol. He supports heavy taxation of cigarettes, which he thinks would prevent young people from easy access to tobacco -- unanimously considered by scientists to be an addictive drug.

Banning? It is a great idea in theory, but could you do it? Maybe if you banned tobacco you would just have another Prohibition with the Mafia. (...)

I think raising the taxes is the way to go. I think the opposition the tobacco companies suggested that is the best way to go because *they are very much against raising the taxes on it*. The more expensive it is the less access kids have. I think you don't want to make a martyr out of the tobacco companies and you don't want to create an underworld of tobacco production. [Interview N. 33]

Also the other epidemiologist I interviewed at the American Cancer Society is convinced that the profitability of tobacco -- and the economy it sustains -- is at the basis of the problems they have in cancer prevention.

Just the settling of North America would not have been viable without tobacco. It is what made Jamestown rock. It has a very strong economic base and it is extraordinarily profitable. *It is probably more profitable than any other business you could get into.* [Interview N. 50]

When commenting on profit and prevention, the interviewee advocated more protection for farm workers -- even though he gave a low level of importance to occupational exposure when answering questions on cancer etiology. He also mentioned pesticides and chemicals as carcinogens, which contrasts with ACS's official silence on the subject. Yet, he dismissed the possibility that those carcinogens -- which he admitted constitute a health hazard for the

workers who spray them on our fruit and vegetables -- might affect our health as consumers as well.

There needs to be a lot more work on protecting farm workers. Certainly the profit from using pesticides and chemicals is a very great motivating force ... [However], when it comes in the food supply and the levels in the general population experience, those kind of chemicals, the risk is much more under control.
[Interview N. 50]

The interviewee also dismisses any danger when it comes to nuclear power plants -- which he define as less profitable than tobacco -- since with nuclear plants the risk is only "theoretical." He appeared reassured by cost-benefit analysis.²²⁹ Interestingly enough, he is convinced that nuclear plants in this country are safe, while those located in Russia would constitute a "real danger."

The cost of building nuclear reactors is very high. In this country the profit margin is much less than the tobacco industry. (...) *I think the risk to health from nuclear power plants are negligible ... aside from the rare remote scenario.* In Russia it is almost probable ... in the reality that there is another reactor. One should hope they would shut them down right away. That is a real risk. We should not be taking power from a reactor. In this country, the technology is different. *I am not saying we have been perfect in the safety thing, but I think the risk is very remote.* [Interview N. 50]

At the end of his answer the interviewee attacks those who believe that environmental exposures and chemicals are being understated. He became very defensive and referred to the activists as driven by conspiracy theories against the scientific community.

I am sure "activists" applies to us all ... the folks that believe that environmental exposures, chemicals are being quite understated ... I don't think there is much merit to the case. I don't think there is much scientific evidence at the levels that prove this could be environment ... from chemicals. It is not that it is not there. There is a theoretical risk at least and maybe in some cases it is measurable. Again, you get back to cost benefit considerations. I do think one of the arguments people would see

²²⁹ On cost-benefit and risk assessment see section 4.3.

great hazard in that area ... [is that] there is a conspiracy on the part of the medical establishment to hide these large risks.

In this part of the interview the scientist again used the expression "theoretical risk" to discredit the role of environmental carcinogens. Since he cannot deny that the risk of these carcinogens is measurable he mentions the cost-benefit analysis as a final argument, in order to demonstrate the lack of merit in the activists' concerns. In other words, environmental carcinogens are not dangerous -- and when they are science provides the proofs that the risk is under control.

7.6.1. Representations of Cancer and Profit at CDC and EPA

In the following sub-section I am going to present the statements of two cancer scientists who work for public agencies, the Center for Disease Control and the Environmental Protection Agency. These agencies have been criticized by activists for their lack of action about environmental carcinogens, while on the other side they are probably perceived as an undesirable presence by some industries.

A woman epidemiologist at the Center for Disease Control who has done extensive studies on women's cancers refused to comment about the connections between cancer and profit. Yet, when talking about tobacco, she denounced the complicity of politicians -- whom she said are corrupted by tobacco companies and lobby for them. However, she does not think -- as opposed to other scientists in this group -- that the government's behavior is affected by the tax money coming from tobacco business.

I think that the reason we have government support of tobacco is not because the government gets money from taxes. It's because in our states, our senators and our congressmen ... there's a large block of them that are from states that are large tobacco producers, and those tobacco-producing states give a lot of money, provide a lot of political support to those politicians.
[Interview N. 45]

A top scientist at the Atlanta CDC believes that profit and other vested interests always represent an obstacle in public health issues, even though he focuses his answer on the tobacco industry.

I think that anybody who has a vested interest in what they are doing is going to do whatever they can to see that they are not damaged. I feel that one should expect that and that has to do with people who are epidemiologists and do work in very esoteric research to very practical research to lobbyists and industries as huge as the tobacco industry. Those vested interests increase as one gets involved in more and more profit and more and more income and really their ability to provide for themselves and their families. As one gets into huger and huger amounts of dollars involved, you can expect there to be more and more concern about anything that would be perceived as a threat to their income. [Interview N. 39]

His answer on profit and cancer shows a suggestive insider perspective: the point of view of the scientist who is just doing his job, and could get more income for his family by doing some research for the tobacco companies. The huge amounts of money poured into the system create privileges among scientists and resistance toward those investigations that constitute a threat for the income of some.

I interviewed a woman epidemiologist at the California EPA, who studied the social and psychological factors that influence the development of cancer, cancer incidence, cancer mortality and cancer survival. Her study suggests that while social and psychological factors do not seem to strongly influence the risk of cancer in men, there is a relationship with cancer in women. In particular women who feel *socially isolated* have a higher risk for developing hormonal types of cancer: cancers of the breast, the cervix and the ovaries. Even though her research might suggest several issues related to economic and social problems at the basis of social isolation, she talks mostly about the tobacco industry. But she doesn't fail to address the connection between cancer and profit.

Well, it's hard not to talk about the tobacco industry because that's the most blatant example that we have, in fact, as you may

or may not know, California's legislature is currently considering two bills which would prohibit smoking in the workplace for California, which would effectively protect non-smokers from exposure to environmental tobacco smoke in their place of work. [Interview N. 40]

She is convinced that the preventive effort should be focused on tobacco, and is optimistic about those companies who are fighting against second hand smoke by voluntarily prohibiting smoking in the workplace.

This is something that's been done voluntarily by many big companies already. There are many local ordinances that have been passed. The City of Los Angeles, just last week, passed an ordinance prohibiting smoking in restaurants in Los Angeles. And so we have something, and the tobacco industry is fighting this very vigorously has come out, as you know, probably, has filed a lawsuit against the EPA because the EPA released reports that say that environmental tobacco smoke is harmful to your health. They call environmental tobacco smoke a class A carcinogen. That means it's an agent that's known to cause cancer in humans. [Interview N. 40]

Since tobacco has been defined by EPA as a known class of carcinogens, this includes second hand smoke and chewing or snuffing tobacco. After mentioning that EPA has been attacked by the tobacco industry, which filed a lawsuit against EPA, the interviewee offered her view on profit.

And the tobacco industry is fighting this tremendously because there's a definite implication for the profit motive of the tobacco industry. And they're not fighting it from a public health point of view, they're fighting it from an economic point of view. [Interview N. 40]

She made an interesting historical connection between the denial produced today by the tobacco industry around second hand smoke and the denial produced in the past about active smoking. Yet she failed to address the denial around environmental carcinogens and the role of those industries that profit from producing them. At

the end of her statement the interviewee spontaneously offered an important ethical consideration.

And what we're seeing now with environmental tobacco smoke is what we have seen over the last several decades with respect to active smoking. To this day, the tobacco industry will not admit that smoking is a cause of lung cancer. And yet it's very well established. There have been lawsuits, even. A recent lawsuit won, making the tobacco industry responsible for wrongful death of a man who died of lung cancer ... and I think that the profit motive really complicated things because ... I have a bias because I work for a public agency, I work in public health, *I happen to think that when you look at values that human health is more important than profit.* [Interview N. 40]

Her final statement sounds like the confession of a thought "I happen to think that human health is more important than profit" -- a confession of a bias "I have a bias because I work for a public agency." Her statement gave me the perception of a work -- the environmental protection -- that happens *under siege*, in a cultural context where being on the side of public health is considered to be a source of bias. Her confession has another aspect that should be deconstructed: "when you look at values ... human health is more important than profit" also means that health is not considered to be more important than profit in other contexts. How many times, during the day, is a cancer scientist allowed to think about "values"?

7.6.2. Representations of Cancer and Profit in the University

In this sub-section I will discuss the answers of cancer scientists whose research work occurs mainly in the University. A top UCLA epidemiologist sees the main connections between profit and cancer in the tobacco industry. He would ban cigarettes, if he had the power. Interestingly enough, he would not ban other carcinogens that can be found in our food, water, air. Here I am going to present a brief part of our dialogue because it demonstrates the development of his position and his argument.

L.C. Would you ban tobacco?

I. 54 Would I ban tobacco? Yes.

L.C. You would ban tobacco ...

I. 54 Yes.

L.C. Would you ban other carcinogens?

I. 54 Aaaaa ... I would identify those that can be banned in a *social* way and that ... *realistically* ... from a social standpoint. I would not ban the sun's rays I would not ban radioactivity [as if radioactivity were a natural element] We don't have the capacity to ban that. But we do have the capacity to ban certain exposures in the work place. And *where the chemicals themselves cannot be banned then workers can be protected against the exposure* .

The last part of his statement assumes that if there are chemicals that cannot be banned, workers can be adequately protected. This is considered to be untrue by other scientists. It would be interesting to understand what he means by "the chemicals that cannot be banned" and which social forces make them unbannable.

The interviewee also mentions a possible relation between profit and cancer in occupational settings -- but only where workers are inadequately protected from carcinogens, in industries where controls are not carried out.

Where there are occupational exposures that are not *corrected*, that may be profit making may be a factor: in not proceeding in exposure control ... there are various ways in which the profit aspects of the situation may be important. [Interview N. 54]

His statement implies that some degrees of exposure is not harmful -- and if problems occur this is due to errors that can be fixed. However, his last comment points out that mistakes in the exposure level and the willingness to not proceed in exposure control can be related to profit making.

UCSF cancer epidemiologist Nikolas Petrakis also sees the tobacco industry as the main enemy, when it comes to cancer

prevention. He would support the banning of cigarettes, even if such a measure would hurt important businesses.

There's no good reason to have smoking. (...) Well, too bad about them [tobacco companies]. I mean, you know, they've had plenty of warning. When I first came into cancer research, you know, back in those days the first papers started to come out on smoking, the real scientific papers, although people had talked about it before.

Petrakis recalls that, when he was a child, cigarettes "were called coffin nails." He argues that forty years ago people already knew that smoking was bad for health -- but cigarettes were heavily marketed and publicized, at that point.

Well, by the 1940's it began to be evident that these are not good for you, and then the studies started coming out in the 1950's, the early Fifties ... 1950, 1951 was one of the first. Some of the first really good papers: Richard Doll in England, Winder here in the United States, and you know, these things are clear. Well, *the tobacco industry just denied it all the way through and they're still denying it.* They still don't admit that it causes cancer. So half of the deaths are tobacco-related in this country, cancer deaths, let alone heart disease, you know. So, that would be the number one thing you'd do.

Petrakis also suggested another connection between cancer, politics, and profit. He expressed some concerns about the fact that his and other institutions are obtaining an enormous increase in funding for breast cancer research. He argues that money is raining on them because of the pressure of women's groups. Petrakis is convinced it won't help much either in prevention or in the cure of cancer. He does not provide reasons for it.

And all these women showed up. In fact, three-fourths of the audience were the Action women, and ... you know ... saying "you need more money for breast cancer research." You know, *there's been a hell of a lot of money spent on breast cancer research.* I mean, I ... we spend \$10 million here, per year, this department, on breast cancer, so ... You know, we could always use more, but I don't think. (...) And now they're going to give \$200 million ... is going to come from the Defense Department to breast cancer. Well, you know, that may be fine, but *sometimes*

when you get that much money out of the government, it's not spent very well (...) yeah, much better than in the army, but you know, the NCI is going to also spend money ... I don't know if that's going to cure breast cancer or prevent it any quicker ... I don't know.

Petrakis statement "NCI is also going to spend money" remained uncompleted. His concerns about getting too much money sounded to me very honest, since his institute is going to benefit from it. He seems to suggest that lot of money is already spent in research, but not adequately. However, he doesn't make an explicit critique about how money is spent.

A professor of toxicology at the School of Public Health, University of California, Berkeley, talked about the economic and political power of tobacco companies, which still get subsidized by the government and are able to keep taxes at a low level. He pointed out that they have been able to delay public awareness about cigarettes as a powerful cause of cancer for decades.

Well, the tobacco companies are a very powerful lobby, with powerful politicians on their side, and lots of money. So that's very difficult, when you fight in the political arena you need money and you need political power, and they've had it. And so they've been able to keep tobacco farmers supplemented -- and have been able to keep subsidizing cigarettes, they've been able to keep taxes low, they've been able to block the regulations, so, yeah. (...) They've also been able to give the perception for 20 years that it wasn't so dangerous ... [Interview N. 38]

I asked him if the denial around tobacco constructed and/or supported by the tobacco industry in order to protect their profit could be compared to the denial we are dealing with today when it comes to other physical or chemical carcinogens. In other words I wanted to know if his statements could be applicable also in cases other than tobacco -- if profit might be the main factor that allows other carcinogens to continue to be produced and to not be recognized as causes of cancer.

The interviewee answered by addressing physical carcinogen such as microwaves and electro-magnetic fields. He took the

example of cellular phones, thrown on the market without data about the hazards they may represent in terms of brain cancer. He mentioned the profitability of this new commodity and the capacity of industry to block the awareness of people around controversial issues.

I think that in general, there's tremendous resistance to the idea that such and such may cause cancer and when you look at the microwave, the recent flack with microwaves, and cellular telephones ... They really put out big time that this is not a problem. But there's really actually no data. And before people started holding cellular phones to their heads for eight hours a day with lots of power ... you would've thought that there would have been some sort of investigation on the potential effects. And right now I think it's being buried by the profitability of cellular telephones and the utility of them. [The] power company is probably the same on the EMF link. Anything they can do to block the advancement ... the better. So, I think it's a big problem. One of the interesting things is that society's values, ethical values and also cultural values reflect whether they think cancer is a big risk or not. [Interview N. 38]

The last part of this statement addresses the issue of uninformed consent. Yet, in the scientist's assessment, values are considered as connected to culture, more than to economics. Moreover, while he seems to look at values as entities affecting science -- he does not address the values of science, as well as most of the anti-tobacco scientists.

In this section I have presented the statements of cancer scientists who talked about the profit made by the tobacco industry as an obstacle in cancer prevention. In the following section I am going to analyze the discourses that emerged among those scientists who see profit as an obstacle in more general terms.

7.7. Profit as an Obstacle in Cancer Primary Prevention

The scientists' answers analyzed in the above section focussed on the profits made by the tobacco industry, while ignoring or

underplaying the role played by other industries, by the government, and by the military.

In this section I am presenting the views of scientists who answered my questions about the connections between profit and cancer by articulating a discourse on the profit motive as an obstacle in primary prevention. Sometimes they also represented profit as an obstacle in the discoveries of environmental causes of cancer. In this section -- like in the one on profit and tobacco -- I analyze the differences among scientists by looking at the types of solutions they propose or advocate. As in the anti-tobacco group, the anti-carcinogens scientists are divided between those who would support bans and those who would not.

The scientists who support the banning of all carcinogens is quite homogeneous: they also share common arguments, reasons and the politics underlying their position. On the other side, the group of scientists who oppose banning all carcinogens is heterogeneous, and the reasons why they don't support such a ban are very different and sometime opposed. In this section I offer scientist/activist Sandra Steingreber's view as a rebuttal to the different positions expressed by her colleagues. As the reader will understand, her moral position on profit and prevention are diametrically opposed to those expressed by an "ethics expert" at the National Cancer Institute. What Steingreber stated reflects the point of view of most cancer activists and also corresponds to my ethical viewpoint.

The anti-carcinogens scientists presented in this section are a very heterogeneous group of scientists -- from epidemiology, toxicology, molecular biology and other disciplines. I didn't discover any professional pattern in the answers they provided.

Nancy Krieger introduced herself the topic of economic and political factors in cancer causation in order to give me a better understanding of cancer etiology and to explain the reasons why some avoidable causes are not prevented.

I think if you do not include economic and political factors in trying to understand why these things happen (...) *it is cheaper to pollute than it is to clean up* what you are emitting into the environment.

Again, you are going to have a conflict there. Often again, in a capitalist society you are going to have the conflict play out and then it is a question of *who has political power to alter how the production is done or how waste products are dealt with*. That is in the sense of direct profit. It will fit with etiology. It is not obvious it will be true with all. Then there are other ways which is not quite so obvious.

Why is it that people who are more impoverished have higher rates of lots of kinds of cancers? (...) Why we have poorer communities and wealthier communities in this country?

Nancy Krieger sees the relation between cancer and profit as a structural one. Health and profit, in her statement, are two conflictual instances -- whose respective interests are represented by the Occupational Safety and Health Agency on one side and the world of business and corporations on the opposite side.

Basically industries have found it ... *less costly ... not to protect their workers from carcinogenic substances* than it is to protect them. There is a clear conflict of interest there often between occupational safety and health and the profit line of various corporations. This has been shown *ad nauseam*.

The history of asbestos and the cover up by Johns Manville Corporation for decades. The cover up by the tobacco industry for decades ... of research showing that their product was carcinogenic.

Krieger also talks about the obstacles researchers find, when it comes to funding. Scientific investigations that would hurt the profit system are not paid for, while research on therapies and rehabilitation thrives.

What the federal government agencies do is completely shape who is in power and control of those agencies. They will not fund certain kinds of research if they are politically impalatable to them. (...) When people started to do cancer research a lot of cancer centers were funded initially at the turn of the century, in the early 1900's (...) people who sat on the boards of [organizations] by and large were people who were very wealthy and with strong industrial connections and were less interested in ... [poor people]. (...) The cancer industry and the drug

industry that has risen around cancer that is very interested in shaping understanding of cancer based on trying to fix defects once done ... and accepting that there will be certain kinds of defects ...

She also re-examines the issue of tobacco smoking in a different light and in the global context of capitalistic needs to expand markets -- even if this means the conscious operation of exporting death.

What kind of diseases you have in some form reflect social organization. Social organization of the technological level, as it were, of production and also the mode of production, the form of production and how it is geared. How that plays out is an open question.

For example, in the question of cancer in underdeveloped countries and what the nature of underdevelopment is as opposed to developing and we could get into a trillion arguments on all that. What is clear is that there have been changes in patterns. (...) Those related to *increase import of tobacco* and what not may be. Then you have to look at the economies and look at the trades to understand. Tobacco just doesn't suddenly happen to be important. *U.S. trade policies about getting tobacco in that market.*

Krieger's last statement was the inspiration for one of my secondary questions in the part of my interview that dealt with ethical issues. When time was sufficient, I asked cancer scientists who advocated heavy taxation of tobacco, or its banning, if they would support a prohibition against the export of tobacco from the United States. Interestingly, some of the scientists who would ban tobacco, or make it difficult to access, would not oppose its export to other countries.

A cancer scientist at UCLA connects profit with the chemical industry and the growers. Interestingly, he makes the comparison most of the other scientists didn't between the resistance of the tobacco industry and the behavior of the growers around pesticides.

I am sure that the chemical industry and other industries -- particularly the agricultural, which has a great stake in the use

of pesticide to increase the yield and the profits -- are fighting a holding battle. Eventually they all withdraw and come up with new reasons not to change. I think pesticide is an interesting parallel to smoking ... [Interview N. 37]

The interviewee believes in monitoring the use of pesticides but also expresses the concern that alternatives might "starve people to death." The same concern is shared by other cancer scientists [see Appendix 23].

I suppose we have always been using pesticides, the question is: can we use less pesticides? Can we use less harmful ones? If they [alternatives] are available ... I don't want people to starve to death because their crop is destroyed. There must be a point where you use consent -- on the other hand, if they are using it only to increase the yield of 10% and increase their profit ... someone has to tell them "no." [Interview N. 37]

The interviewee -- as well as the majority of the scientists in the anti-carcinogens group -- thinks that the government should be the agency, the "someone" who will say no to corporate greed. If a generalization can be made, at this point, I should say that the anti-carcinogens scientists are more in favor of regulations and state intervention, while the anti-tobacco scientists share ambivalence about building restrictions to the industry, with the only exception of tobacco companies.

Scientist David Kotelchuck in New York combines the role of profit as an obstacle in cancer primary prevention with the role of profit in diverting the scientists from focussing on environmental and occupational exposure to carcinogens.

You could see very clearly the impact of money ... of research funded by industry ... which kept saying asbestos is not dangerous, and asbestos doesn't cause cancer -- or if it does it's a "minor issue" compared to smoking. And it attempted to divert attention, to hide ... cover up the problem and divert attention from it, if possible. (...) Industries have an impact on research, and of course it has an influence on shaping public opinion. And you see it most clearly now in the tobacco industry, where it tends to shape public opinion, and sometimes very effectively.

Kotelchuck believes that more research on carcinogens should be paid for by the public sector, since industry data is biased. He also argues that often institutions that claim neutrality are controlled by the industry at the economic level. Since asbestos has been proved as a carcinogen thanks to government funded research, which led to its ban, Kotelchuck is convinced this is the way to go.

It's very important that research not simply be carried out by funding from private industry ... and from private foundations that are controlled by industry.

Don't forget: *a lot of the foundations that give money -- while nominally "non-political" -- are controlled by people who are industry people, or from industry people (...).*

Now, so we need to have more research funded by government, and that was what really made the difference in the asbestos field, that *government funded research -- which tends to be much less biased than industry research -- was able to show that asbestos causes cancer*, and I think win the day, if you will.

I interviewed also an engineer at the University of California, Berkeley, who works in the occupational health and prevention; he mostly deals with chemical carcinogens like benzene. He is not a cancer scientist, he is a technician whose job consists of applying criteria to meet standards of exposure that are designed elsewhere. His work consists of measuring and controlling the workers' exposure to carcinogens. He teaches students in Public Health and works with industries. In his experience he found that oil companies do not have problems in meeting "federal standards" of safety about carcinogens like benzene.

We have done work with the American Petroleum Institute looking at benzene exposure in petrochemical refineries. (...) simply to document what the exposures were and we did it. (...) No [they changed] not much: if it had any implication of public policies ... we found that the petrochemical company would have not had many difficulties to meet the federal standards for exposure to benzene. [Interview N. 2]

The interviewee explained that what happens in the workplace in terms of carcinogens is extremely important. Workers provide

most of the data on human cancers. Furthermore the workers are those who are exposed to the highest degree to suspected carcinogens, and by looking at the workplace we can assess the environmental impact of a chemical. Workers are -- to use his words -- "like the canaries in the mine."

Well, simply I think workplace control is always a very important place to deal with specific exposure to carcinogenic agents and workplace has been where much of the actual data comes from in terms of human cancers to do with environmental carcinogens. It seem to me that the main conclusion one could draw is that it does pay to keep a close eye on what is going on in the workplace as a guide to ... it is like the canaries in the mine. (...) If something happens that can be identified around chemical exposures it very often happens in the workplace first. And that's usually where the exposures are higher. [Interview N. 2]

Even though the interviewee describes high exposures to carcinogens and the use of workers as providers of epidemiological data, he strongly opposes workers' compensation.

A huge industry exists in this state about alleging that injuries, illnesses, cardiovascular, stress, are associated with work and it is almost impossible to prove that it isn't, the way the system is structured (...) the unfortunate system we have here basically allows any sort of morbidity to be alleged to be of occupational origins -- PMS, stress, whatever it is. (...) There is an industry built on utilizing the fact that is very difficult to prove otherwise. [Interview N. 2]

From his statement, it emerges that the interviewee would favor a further shift of responsibility to the individual, rather than to the industry. His view is complementary to the industry's interests.

Samuel Epstein is probably one of the best sources for connecting the profit system with the production of cancer. His interview is a document of some importance, since he witnessed certain historical processes from the inside -- and the top -- of the cancer establishment.

In his words, "the profit driven motive is as overwhelming as food, as sex, and one has to recognize this." When Epstein was the

key expert of EPA in the early seventies, he had the power to assess and extend control over industry's misconduct in terms of releasing hazardous chemicals that were not proved to be safe.

Industry put up claims and promotion saying that it was completely safe. When I looked at their data -- the actual raw lab data -- I found out that *they hadn't done most of the tests*. They made claims that were unsupported. They had to open their files to me, completely. And it was from there onwards that I started collecting data from industry files from all over the country. People were sending me letters and packages of things: this is the stage when I became interested in *white collar crime*. I produced a report that resulted in the fall of NTA from the market -- that cost Montsano and P&G half a billion dollars.

In this comment, Epstein described an amazing piece of U.S. cancer history: the birth of grassroots groups based on self-interest and local issues -- mobilized on "the right to know" -- the request for labelling, and the unifying goal among concerned scientists for phasing out carcinogens: the research for replacements of hazardous chemicals and for "clean" energy.²³⁰

Epidemiologist Paul Blanc views the concentration of costs on some social groups and the concentration of benefits on other social groups as a major problem. In other words, the real issue is the relative absence of social costs for those groups who make profit out of the production of carcinogens. He calls this absence of costs "the surplus-value of health."

If the profit does not include the ... If the costs of producing ill health is not taken out of the profit, then there's no incentive from that point of view to make new things any safer. So that's the connection. If the *costs and the benefits accrue to different groups*, then obviously the person or manufacturer or the group that's releasing a carcinogen into the environment or causing cancer in employees or any other health condition for that matter, unless those costs somehow are taken into account... That's really the issue in terms of profit. It's kind of like *the surplus value of health*, you know. That's the real issue. It's not

²³⁰ R. Proctor, *Cancer Wars: How Politics Shapes What We Know and Don't Know About Cancer*, Basic Books, New York, 1995.

that it's profitable to make cancer, it's just that there's no cost associated with it.

Marilyn Fingerhut is a cellular biologist who has done relevant work on dioxin. She is convinced that the profit motive works against workers' protection and environmental safety. Fingerhut also represents profit as one of the obstacles met by scientists who work in public health: she sees a connection between the threat to public health scientists may represent for the industry and the fact they are not properly funded for their research.

Public health has always been a stepchild of the medical profession. Public health, which is occupational health, environmental health, is made up of a small community of people. There are many forces that operate against progress in these areas because *we're primarily societies that are technologically advanced in producing substances.*

So that the cost to ensure that the workers are protected and that the people in the environment ... the environmental health are protected, all of those things are costly. So *the profit motive works against taking care of those things*, so that ... I just think that the community is small and we're generally very under-funded.

Peter Orris, Director of the Health and Hazard Evaluation Program at University of Illinois, Chicago, finds the correlation between profit and cancer as obvious. He defines himself as a socialist -- and is very critical of the "socialist" experience, when it comes to environmental health, nuclear power, use of carcinogens. He analyzes different situations in capitalistic and non-capitalistic countries. In a long section from the interview -- which I offer in Appendix 25 -- Orris also talks about his own philosophy of how prevention should work. It includes phasing out carcinogens and harmful substances, and a shift of emphasis from individual-oriented prevention to socially oriented policies and strategies.

Orris feels that his politics and his career in the public and private sector are in contradiction. He finds there is a split between what he does as a job and what he would like to do. He confessed an internal conflict of interest that often scientists have to cope with --

but not always in a conscious way. On the other hand, he thinks his position is not unethical, the way he has been dealing with it until now: when he works for the public health department he feels he is working for the people. When he works for private companies he feels that he is just selling his expertise -- and does not try to be an activist. His position is that a scientist should draw a demarcation line between his different roles -- between activism and work -- in order not to jeopardize his professionalism [see Appendix 26].

Linda Rae Murray is an African-American MD who works at the Cook County Hospital in Chicago. She thinks profit plays an important role against cancer prevention. She argues that every time "other concerns" -- could be profit or planning -- are put before human health, this is going to create problems. For Murray the issue is: where morality and values are located? Which are the social priorities and who has control over prioritizing? She also, as other scientists, took the opportunity offered by my question to talk about her own world view and concerns about human health in global terms [see Appendix 27].

John Gofman -- nuclear physicist and former director of the Livermore Laboratories -- strongly opposes the interference created by the profit system in the scientific research. He pointed out how companies in this country as well as in other parts of the world knowingly poison people in the pursuit of profit.

I think incentives to profit personally a bad thing, but an *incentive to profit personally at the expense of somebody else's health, or life, or well-being is a crime. It's a violation of the rights of others.* And so it's my opinion that somebody who says, "Well, we'll go ahead and produce this stuff, even though we know from our own work that it's dangerous, or over the long term will produce some bad effect, without telling people" ... I think that's cruel, and I think that's done every day. There are some industries, companies—worldwide—who have shown no conscience at all, about poisoning people at a profit.

What Gofman argued is a position shared also by epidemiologist Richard Clapp in Boston, who thinks that economic

and political interests are obstacles in primary prevention. He also argues that career concerns among scientists stay in the way of developing research in "controversial areas." Clapp offered as an example the tobacco industry and the Agent Orange exposures during the Vietnam war. His position is in favor of phasing out carcinogens and banning dangerous production [see Appendix 29].

I asked the question -- "what should we do, when there is a suspected carcinogen?" to an epidemiologist and bio-ethicist at the National Cancer Institute. I offered him three theoretical options:

- a. stop producing it until when proved safe;
- b. a cautionary lowering of the exposure;
- c. continue to produce it until when it is proved to be a carcinogen.

The interviewee answered that stopping producing the suspected element would not be possible because if you stop people from being exposed to it, you can't study it. His concern seems to be carrying out epidemiological studies and being able to access human data -- since he does not believe research on other mammals can show if a substance is really carcinogenic to humans. I found his statements of extreme importance and gravity. Here I provide all the context needed for a full understanding.

I. 32 So you're saying, yeah, so you're saying, "If something is suspected to be carcinogenic, what should we do about it?" Should we remove it, that is stop production, or stop using it, or stop exposing people until we know for sure that it's not?

L.C. *Umm-hmm*

I. 32 Okay, that solution of course is *impossible ... because if you stop people from being exposed to it, you can't study it*. If you can't study it, you can't ever know whether it's carcinogenic or not, assuming that the studies must be done on people.

L.C. *Which is not commonly accepted...*

I. 32 Oh, yeah, it's very commonly accepted. I mean, it's not that you can't do studies on things other than people, it's just that you have to do some studies on people if you're going to make recommendations about things on people. *I mean, if you stop exposing people to something you've effectively stopped any*

human research. You could do research on other things, but I think that's an impractical solution.

(...) the fact that a substance is a carcinogen in one rodent species or two, does not necessarily mean that it would be carcinogenic in humans. So it is good to have human studies if you have to make decisions about people.

L.C. But if having human studies put a population in danger of exposure ...

I. 32 It doesn't have to. Most of the studies ... many studies can examine past exposures. Most of the work is done that way, in which you look at exposure that people have already accumulated up to a certain period of time. And then you look at their disease risks over that time. Of course you are not requiring that people become exposed to something in order to study it, absolutely not. You can do it retrospectively and look at what they have been exposed for many years and explain some of their risks.

L.C. But you were saying that you would not stop the exposure immediately when there is a substance suspected, because this would stop us giving evidence....

I. 32 I said it depends. What do you mean by being suspected? I said also that if evidence are so strong and there is some judgment made -- and this is where everything falls apart because there is no quantitative way of doing it -- if at that point we say "we have a real problem, here" then maybe the product should be stopped. But this is not usually the way it happened. Usually the evidence is kind of ... early on, it is weak or not incredibly strong, or there are some suggestions and you need to do some more research, it all depends ...

L.C. What makes the scientists decide that the situation is worthy [of] investigation?

I. 32 I don't know. Some people are driven by ideas, some people are driven by money, it depends.

In the following sub-section I present the rebuttal of this position by cancer biologist Sandra Steingreber.

7.8. Interview with Sandra Steingreber

Sandra Steingreber's point of view about profit, ethics, and cancer prevention can be considered the very opposite of what expressed above by interviewee N. 32. She believes that nobody

should be exposed to any degree to substances that are suspected to be dangerous to human health -- and that animal data are adequate to assess the carcinogenicity of a physical or chemical element.

Steingreber is also among those scientists who embrace the position of banning all known classes of carcinogens. She travelled and worked in African countries and has more of a comparative approach -- compared to the average scientists I met.

During the interview with Steingreber I presented the arguments of those scientists who oppose the banning of all carcinogens and summarized their arguments in two main categories.

The first argument is that the consequences of banning all carcinogens would have tremendous social effects: the collapse of some industries, more unemployment, and a general loss of comfort or convenience in society. Steingreber offered a very articulate rebuttal. She compared the structure of such arguments to similar arguments made to protect slavery and child labor.

Let me take the first one, the "social consequences." I think it's a false argument. I think that the argument has been made every time someone has said "people are dying by doing things this way and we have to change it." People said that about slavery, that *the entire economic system would collapse if we got rid of slavery ... "we couldn't grow food cheaply enough."* They said it about child labor "we have to have these children working in the factories." They said it about exploitation of immigrants ...

Steingreber suggests that the idea of sacrificing some people for the benefit of others has profound implications. As a person who had cancer she does not agree to be the sacrificed minority -- for others' profit.

I think that the economic system is more resilient than that. And I also think it's arrogant to say: *Some of you have to die because we are afraid that the social system will be so disrupted if we make changes to prevent you from dying, that you have to be the human sacrifices for our current system.* As a person who suffered with cancer, I don't want to be the human sacrifice that allows the system to keep going.

Steingreber talked about a cost-benefit analysis made by the state of Michigan, which was involved in building the world's biggest incinerator. This is the story she offered.

In Detroit, when I lived in Michigan, they decided to build the world's biggest trash incinerator. Even the state said there would be more cancer deaths because of the trash incinerator than without it. By their own data, they predicted that in the state of Michigan there would be *75 additional cancer deaths due to the incinerator*. Now: that exceeds the number of people who are employed by the incinerator, and the big reason for building it was to help employment, to help the economy, because this community needed the incinerator. *So it was going to employ 55 people and it was going to kill 75 people*. Now: they went ahead and built it anyway.

Steingreber suggests that even though that decision didn't imply the direct homicide of 75 persons, from an ethical standpoint there is not much difference. The fact that these deaths will occur ten or twenty years from now, and the anonymity -- at the present time -- of those who will get cancer made the decision possible. There will be no bodies piled up in the street, Amnesty International will not investigate the death of 75 persons, no institution will consider what happened a violation of human rights.

If they said, in order to build the incinerator we're going to go house to house, *choose 75 people, shoot them, and leave their bodies in the street*, they would never be allowed to do that, it would be a human rights violation of the worst kind. Amnesty International would be here investigating it. That's not allowed. But *we allow people to be killed by cancer* because we say well, a certain number of human deaths are acceptable because of our wonderful system of capitalism, which has to go forward because there is "no alternative."

Steingreber is convinced there are already alternatives: phasing out carcinogens; subsidizing those who are going to lose their job -- instead of subsidizing tobacco growers, retraining workers -- the same way it was done after the second World War.

I think it's a failure of imagination. There are other ways that we could grow our food and produce what we need besides the way we

are doing it. I wouldn't make the changes overnight. I think there's a way of phasing things in, phasing things out. There's a way of subsidizing workers who are going to be laid off, for example, and retraining them. These aren't my own ideas that I'm just inventing. *There's a whole movement out there who are all thinking about these issues, how we could minimize the impact of the social issues we know are necessary.*

And so, for example, I'm very influenced by the ideas of Tony Mazzochi, his idea that there can be something similar to a "GI bill" that could send all these workers who are going to be displaced from the evil chemical factories, whose health is now being affected, and send them all to school. *Even if it takes four years to retrain them to do something else, if we could do that at the end of World War II we could do that now.*

The first argument against the banning of carcinogens I presented to Steingreber is usually made by scientists who are concerned about "the economy" and who feel that producing "harm to business" is not socially responsible. The second argument against the banning of carcinogens I presented to Sandra Steingreber is a matter of concern for scientists who would approve the radical banning from an ethical point of view -- but who think regulation would be more effective. Steingreber's answer is that regulations already exist, but they fail to protect people: they are easily manipulated, levels of thresholds become the object of negotiations and monitoring exposures is expensive.

Barry Commoner in the book "Making Peace With The Planet" argues that the regulation, as it currently exists, trying to limit people's exposure through regulation rather than banning has failed again and again. He presents many case studies to show how it's pseudo-regulation. And then he looks at the incidents in which they just outright ban things, like lead in gasoline. Those are our far more successful stories than the regulation part. *They're cheaper and they really work.*

(...) That seems to me a very compelling argument. History really shows that banning is more successful, not less successful than regulation. It's certainly cheaper, because regulation requires endless bureaucracies to monitor levels of things; if you simply make it illegal it's one gesture.

Steingreber also told me success stories about the banning of some chemicals; her strongest argument was that banning is cheaper

than regulating -- it doesn't need a bureaucratic apparatus -- and where it happened, it worked. She concluded by stating that the idea of monitoring the exposures to carcinogens, instead of banning them is predicated on the assumption that we know how these chemicals work, once they are released in the eco-system -- which she believes not to be true.

You have to make sure people aren't still producing it, but that's an easier thing to check on than to check on levels in air and food, because once it disperses in the environment it can travel anywhere ... It can travel according to physical forces that we don't know very much about. We don't know very much about how wind currents, and air currents, and ground water travels. We don't have the science. We don't know basic things about the earth to be able to monitor how things move around in the eco-system, which argues for a ban.

Some concerned scientists are convinced the banning would not work from a technical point of view. They argue that industries' scientists would endlessly invent similar substances with little molecular variation -- and the little control we have today over such processes would be lost. Steingreber admitted that this happened several times, e.g., with women's hair dyes based on coal tar -- which is highly carcinogenic. When the industry was questioned about that, they simply changed the molecule a little bit, added a carbon -- or subtracted one -- so they could call it a different name. But essentially, in the body it acted in the same way.

For this reason, Steingreber argues that banning should not be done one by one, but by class of carcinogens -- so as to prevent industry "hopping to discover something else."

That's why I think the Greenpeace idea of *phasing out an entire class of compounds* when the weight of the evidence shows that the majority of them causes problems is more efficient than testing them one by one. So the whole idea that chlorinated hydro-carbons as a group almost always in the body act a certain way. (...) The whole category of them was invented after World War II as a weapon of war, to fight chemical warfare in the Pacific theater. They don't exist in nature; chlorine and carbon don't come together that way. They were developed for the sole

purpose of harming living things. They do that very well. So if you can ban the whole class of them, then I think you get around that problem of industry hopping to discover something else. There is a precedent for doing that. For example, when epidemiologists were concerned that fecal matter gets in our water supply and creates disease because we're exposed to bacteria, they didn't just say we'll ban fecal matter from people, or from cattle, or from wild animals ... They said: "No fecal matter: *we don't want any shit in our water*" -- essentially. It doesn't matter who it comes from.

Steingreber is convinced profit is the main obstacle in primary prevention. The very fact that many heads of corporations involved in the production of carcinogens have decision power in institutions such as the American Cancer Society is seen by Steingreber as the reason why people do not know what the causes of cancer really are [see Appendix 30].

She also mentioned the activities of ICI (Imperial Chemical Incorporated) a corporation targeted by cancer activists because it produces pesticides -- which have been specifically linked to breast cancer -- and Tamoxifen, the most commonly used drug for breast cancer treatment.

I'm fascinated by the word "imperial" in their title ... [ICI] who manufacture solvents for car paint, which is directly linked to breast cancer. They also own a pharmaceutical company that produces Tamoxifen which is the major drug that breast cancer victims are treated with to cure the disease. It's a straight conflict of interest: *They make money causing cancer by selling paint and then they make more money by curing it.*

Molecular biologist, Richard Strohman shares the same concern of Steingreber. He sees profit first of all as an obstacle in discovering the real causes of cancer -- and he talked specifically about the enormous gains made by the pharmaceutical industry. Strohman contextualized his answer in an historical perspective -- looking at the reasons why most of the efforts go into cure, rather than into prevention [see Appendix 31].

7.9. Conclusion

It is interesting to notice in several scientists' statements that a certain degree of risk is always accepted as necessary, as *a priori* . Several among the scientists interviewed do not take the position that we should do everything necessary to get the highest degree of safety -- and stop producing a substance if the testing is not satisfying.

The subjects often take the point of view that industries should do the *minimum* required by the law to prove that the product is not going to do an 'immediate' harm to people. Scientists often use a very moderate vocabulary -- and expressions such as a 'reasonable degree' of insurance, 'sufficient' care, and 'adequate' responsibility are quite common.

While care, safety, and responsibility are represented as relative, most of the scientists are aware of the difficulty in "relativizing" -- i.e., reducing -- the profit industries are designed to create; any activity that would harm companies is perceived 'off limits.' The tone of their statements when talking about occupational hazards is more often defensive, rather than outraged.

Also when it is not mentioned, the profit motive appears as a shadow that informs the answers of most of the scientists -- like a primary loyalty, not explicitly requested of them but included in the context of their work -- as a natural factor, like the air they breathe, the ground they step on. Even among progressive scientists there is much concern about "to-be-respected" limits -- which are not written anywhere, but emerge as a common perception. Such limits are represented by the iron cage of profit.

CONCLUSION

This dissertation demonstrated five main points:

1. There are two main groups of actors in the cancer arena, scientists and activists. These groups are in conflict over cancer causation and different strategies of primary prevention. Scientists, more than activists, are divided on issues such as genetic research, known and suspected environmental carcinogens, and "lifestyle factors," i.e., those elements that can be attributed to the social environment.
2. Scientists have different positions about genetic research on cancer and give different degrees of importance to individual genetic predisposition in cancer causation. There are also "technical problems" in genetic research and some controversy over how genetic research is performed, what it is today, and how it is related to human cancers. These issues do not seem to affect the debate over cancer causation yet, despite the gravity of their implications.
3. The meaning of the term "environment": its meaning seems to range from "the air" to everything that is not considered to be genetics, as in the epidemiological tradition. The category "environmental carcinogens" is highly debated. The definition of this category can be defined so narrowly that it is almost synonymous with "second hand smoke," or can be defined in a broader fashion to include radiation and all classes of chemicals proved to be carcinogens on animals.
4. The debate over "lifestyle factors" is based on the degree of choice scientists and activists attribute to people. Options about diet, age of pregnancy, and other lifestyle factors considered to be risky behaviors are connected to class, race, gender, age, culture, and sexual preferences. Scientists who believe that individual genetic predisposition is a main factor in cancer causation, also have an

individual-oriented view about the prevention of risky lifestyle factors. Scientists who believe that environmental carcinogens are main factors in cancer causation tend to look more at the ways in which people's choices are socially constructed.

5. There are key words and concepts around which the scientific conflict consolidates. These include "multiple exposure;" "threshold of tolerance;" "burden of proof." These phrases can be considered signifiers upon which the scientific community produces its differences and struggle for the control of the arena. The scientific debate on genetics and the environment often assumes a dichotomous form; a dialectical approach that looks at the interactions between genetics and environment is often missing.

Scientists and activists alike shared ideas about the different ways in which profit produces untimely and avoidable deaths. I also culled insights about the ill body as a source of subversive subjectivity. As it has happened before in the context of AIDS, those who were diagnosed became activists; they involved those around them, found allies, and built a social movement which produced material and symbolic changes in that specific arena and throughout the rest of society.

Unlike the claim of some postmodernists, I think that the emerging of new political identities is still based on elements of material life. The 'cultural' is produced *also* through dynamics of everyday life. Current theories of the subject do not satisfactorily explain cancer activism. Perhaps a combination of approaches and a heroic dose of sociological intuition are needed.

According to the eco-marxists, health is a "personal condition of production,"²³¹ which suggests an inner connection between the damage that capitalism does to human nature and non-human nature. In the reproduction of surplus value non-human nature

²³¹ Seminar with Jim O'Connor, University of California, Santa Cruz, 1992.

provides raw materials. Humans provide a special quality -- their physical and intellectual labor force -- that transforms these raw materials into commodities.

The production process is a valorization process, since its main motivation is the extraction of profit. It combines human and non-human natural resources in a lethal embrace that consumes and exhausts both. A synthesis is produced: the commodity, symbol itself of capitalistic relations. The commodity embodies an uneven exchange since it presupposes that more labor is incorporated in it than is paid for. Natural resources are often not paid for, and even human labor has been appropriated, as in slavery.

Historically, groups who retain economic, technological and military supremacy benefit from these appropriations, while expropriation and exploitation hurt people such as workers, indigenous populations, women, and those who are situated at the bottom in the power structure.

These subjects are sources of profit, directly or indirectly. When the iron cage of profit requires human sacrifice, it is these people who are deemed expendable. Yet, in special moments of history the exploited, the dispossessed, the sacrificed, raise their heads and their voices, struggle for their lives against oppression and indifference, in attempts to break the horizons of the *status quo* and assault the sky. The cancer movement is one of these challenges.

The status quo is represented in some concepts expressed by the scientists I interviewed, and it is contested by others. Concepts underlying the scientists' statements displayed different degrees of complicity and autonomy with dominant ideologies. Some of these concepts legitimize capitalistic exploitation and racial and sexual discrimination, while other concepts offered by scientists have the potential to be used by cancer activists and community leaders.

I was motivated in part by the desire to understand the possibilities of the social change the cancer movement is incubating. While early detection -- usually defined as secondary prevention of cancer -- can avoid the spread of the illness, it cannot avoid the

illness itself. However, cancer primary prevention -- the field that deals with the reduction, and eventually the elimination, of preventable cancer causes -- is a strategic place for finding the contradictions, struggles, and germs of social change. Since the causes of cancer are primarily socially produced, any attempt to eliminate these causes is a struggle for social change.

These struggles differ based on ideas about cancer's main causes. Scientists who tend to think of cancer causation in individual terms (genetics or personal behaviors) will support primary preventive plans that differ dramatically from those scientists who identify environmental degradation as a central factor in cancer causation.

Although the diverse sample of scientists I interviewed seemed divided on everything else, they agreed that profit is a main obstacle in doing primary prevention of cancer. Some scientists believe profit is an obstacle when it comes to the tobacco industry, which they consider enemy number one of those committed to fighting cancer. Other scientists have a broader perspective: they also identify the profit of chemical industries, electric power companies, other corporate polluters, and governmental choices that are controlled by the military industrial complex as the major obstruction in the war on cancer.

In this dissertation I tried to keep a dual focus, in order to allow the reader to listen to different voices in both groups, among the scientists and among the activists. By looking at the formation of a cancer movement in its *statu nascenti* -- in its early stages -- I discovered a trend within the environmental movement to reconceptualize the human body as part of the environment. The recent interest in cancer demonstrated by organizations such as Greenpeace, and the centrality of the cancer discourse in the Environmental Justice Movement are symptomatic of a shift of attention from the non-human part of nature to the human aspect.

In addition to links between the environmental movements and the cancer movement, I also found a convergence in the cancer movement between different groups of social actors who have been conducting separate battles in the last decades: women, workers, people of color, concerned scientists. While feminism, Marxism, race studies, or lesbian theory alone cannot account for the cancer movement, looking at class, race, gender and sexual preferences does provide some clues about the different subjects in the cancer movement and its leadership. Facing the production of avoidable cancer, several antagonistic subject groups have found a common ground on issues of survival: they are women who had cancer, workers who are exposed to carcinogens, people of color who live near toxic waste sites, and those scientists who believe all chemical and physical carcinogens are responsible for the cancer epidemic, not just tobacco.

As a final note, I also wish to advocate for an increased inclusion of cancer activists of different groups, political orientation, sexual and ethnic backgrounds in those arenas where decisions over the direction of cancer etiological research are made, and where strategies of primary prevention are formulated and prioritized. I strongly believe that a mass movement -- mobilized around issues of resistance to expropriation and exploitation, the destruction of nature and the environmental threats to human health -- is necessary to create a space where cancer primary prevention can be achieved.

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APPENDICES

Appendix 1: Notes on the Division Between Manual Labor and Intellectual Labor. The Intellectual Cast and the Secret Code of Access.

We know that any society starts to produce an intellectual class only when enough surplus is available to support professionals who will take care of issues related to the non material world. Holy "men" are probably earliest example of an intellectual class: shamans, wizards, enchanters, magicians, priests. They were those dealing with our spirit -- before we started calling it "intellect."

The intellectual class tends to grow with the development of productive forces - when a society can rely on its surplus of wealth, it is also able to support a specialized class of intellectuals, whose job is to formalize disciplines and sub-disciplines, discover scientific laws; produce hypotheses and theories, ideas and perspectives about human and non human nature, subjects that were previously framed into divinatory systems.²³²

Institutionally intellectuals have a monopoly on knowledge, on its production and on its use: they are also those who administer such knowledge -- in the form of oral and written words, images and concepts. In all ages, intellectuals are those who write history -- and this is why history traditionally records the lives of the rulers of society. This is one of the reasons why art produces their portraits -- and poetry tells us of their generosity, accomplishments, beauty and heroism. This does not mean that

²³² The intellectual class also codify mores and rules. Intellectuals were involved in elaborating systems of punishment, reward and coercion. The social position of intellectuals becomes clear with the development of history: they can only be given their portions of surplus by those who have control over such surplus -- i.e. the ruling class. If we look at ancient Egypt, at czarist Russia, at the Roman or Chinese Empire, the intellectuals in these societies were those who had the power of advising the authority in the decision making process, of providing "Him" with the human "wisdom" and possibly with the blessing of the gods. Intellectuals were the only ones who could write, who possessed the "gift of scripture". They had the power to define categories of reality, to control the meaning of social practices, to evaluate what is relevant and set criteria and methods for everyday life interactions and symbolic events. Their primary task was to support the dominant social group and actively legitimize its hierarchy.

In the past, intellectuals and scientists were always men -- women weren't "rational" enough, according to Aristotle, to detach themselves from the object of study. Since then, the intellectual exploitation of women has been implemented systematically. Plato transcribed and interpreted Diotima's thought. Through the first half of the second millennium the European universities, which didn't admit women, used and expropriated their medical knowledges and suppressed those who didn't submit to the male authority: the largest sexual genocide history can remember.

there was no dissent: the history of dominant classes is also the history of disconformities, heresies, and splits in the intellectual oligarchy.²³³

We cannot talk of a revolutionary intellectual class in Western countries until after the formation of working class organizations.²³⁴ For centuries, the working class couldn't afford to support its own intellectuals: the working class had advocates among sensitive and progressive politicians; in the underprivileged sections of ecclesiastic hierarchies, and in the most rebellious zones of the enlightened bourgeoisie. It was in the latter group that utopian socialism was first conceptualized.

The working class also borrowed intellectuals from the humanitarian sectors of the landowner aristocracy and from those educated families of the city nobility -- impoverished by the economic victories of the new ruling class. The same father of scientific socialism, Karl Marx, did not come from the working class, or from the petit-bourgeoisie.

The Italian philosopher Antonio Gramsci -- who wrote most of his works during the years of his imprisonment under fascism -- was the first thinker who theorized that sooner or later the working class would be able to produce its own intellectuals, which he called "organic intellectuals." He gave historical legitimacy to the popular "common sense" -- what today we would define as a form of "located knowledge."

The professional worker, the technician in the factory, the one who knows any segment of the productive process is the new social actor at the basis of Gramsci's theory. The professional worker is not simply a supplier of labor, the technician performs manual jobs -- but cannot be defined as a manual worker because he/she has a knowledge of the technology employed in the production. The professional worker knows how the productive process works and how it can be invisibly damaged. This kind of worker knows the quantity of production, and has an idea of the profit extracted. He/she has a vision of the productive process as a whole: from the raw materials to the use of the workers. The professional worker can also have a better grasp of the level of exploitation because of access to information -- and because he/she has more time to think, than the assembly line worker. In fact, what makes the professional worker different from the others is that his/her tasks tend to "recompose" manual and intellectual work.

We know that at the very base of class division there is a social division of labor. What we often do not know is how and why the more a society becomes capitalistically advanced, the more the division between intellectual and manual labor becomes necessary

²³³ Even though not every intellectual division can be traced to some material interest within the ruling class, conflicts between intellectuals often reflected conflicts among different factions or parties of the ruling class struggling for supremacy.

²³⁴ Here I am not considering as "revolutionary intellectuals" all those who participated in a Revolution. In the French Revolution the new class -- the emerging entrepreneur bourgeoisie -- replaced the old aristocratic order. Intellectuals played an important role through the whole process of substitution, on both sides. The "Revolution" led by the new class became the formal model of other class revolutions in western countries -- but wasn't concerned with the elimination of all classes and privilege.

When we think of manual labor we do not usually think about painting, sculpturing or gardening as occupations; we associate the term "manual" with the execution of task. Such execution usually does not have a meaning in itself, and it is a waged form of labor, segmented and in a necessary industrial setting. We know how taylorism -- the scientific division of labor that created the assembly line -- has systematized the fragmentation of the productive process. There are many studies of the effects of working on a production line, what it means doing always the same movement for hours, in terms of alienation and psychological problems²³⁵ -- but there are no studies comparing the degradation of manual labor with the degradation of intellectual labor.

Intellectual labor is still seen as superior to manual labor. Intellectual labor includes the work of artists, social and natural scientists, and large part of the technocracy. Intellectual labor is often chosen as a criteria for evaluating the degree of civilization of a people -- disregarding its material culture. Intellectual labor is more valued in our societies than manual labor: if you are a manual worker you do not talk much about what you do. While if you write articles, if you teach, if you do research, you feel more legitimated to expose yourself and your achievements to the world. As Italian sociologist Giuliana Chiaretti wrote, intellectual labor is often perceived as labor for oneself -- while manual labor is perceived as labor for somebody else. Intellectual labor -- like artistic labor -- allows us (not always but usually) to put our name on what we do.

Braverman introduced an important distinction that crosses both intellectual and manual labor: the distinction between creation and execution. Creation and execution are present in both intellectual labor and manual labor. More precisely, we can say that there are parts of manual work that are creative and parts that are mere execution of tasks. The same in intellectual labor -- and we know how, often, the "execution" of our work does have very little creative elements. Many of our tasks as intellectuals are characterized by repetition, boredom, lack of sense -- I am referring to all those tasks that we would like to get somebody else to do.

Many times we get students to do bibliographical searches, secretaries to make our calls, lovers to type our footnotes and everything else we consider as boring. Nevertheless, intellectual labor is considered to be more free, more rewarding, more socially recognized.

Alfred Sohn Rethel introduced the concept of "fetishism of intellectual labor" which is strictly related to *the division between the head and the hand*; division which stays at the very bases of bourgeois relations of production.²³⁶ How do "hand" workers relate to "head" workers? Intellectual labor is seen by members of the working class, and by laypersons, in general in a very ambivalent way. On one hand it represents a path of upward mobility and emancipation. Any member of underprivileged sections of society, any factory worker would like to see her/his children getting an

²³⁵ R. Blauner, *Alienation and Freedom. The Factory Worker and His Industry*, University of Chicago Press, Chicago, 1964.

²³⁶ In so doing, Sohn Rethel specifically deconstructed the role played by Kant in his theory of cognition -- as expressed in the "Critique of Pure Reason."

academic degree. On the other hand there are manifest discomforts and communication problems between those who have knowledge -- be they intellectuals, scientists, or teachers -- and those who don't have much access to what Bourdieu called "cultural capital."

Members of the working class perceive the power intellectuals have in defining, analyzing, and prescribing as means of control and oppression as "element(s) of (their) subordination to an external (cultural) hegemony."²³⁷ Ordinary people often do not trust intellectuals -- and sometimes they are right. Manual workers also perceive that something has been taken away from them, the ability of expression has been monopolized by the intellectuals, who get honor and power for their job.

In 1604 -- 390 years ago -- Christopher Marlowe in his *Doctor Faustus* wrote:

These metaphysics of magicians
(open another book raptly)
And necromantic books are heavenly;
Lines, circles, letters, characters --
Ay, these are those that Faustus most desires!
O, what a world of profit and delight,
Of power, of honor, and omnipotence
Is promis'd to the studious artisan!
All things that move between the quiet poles
Shall be at my command. Emperors and kings
Are but obey'd in their several provinces
But his dominion that exceeds in this
Stretcheth as far as doth the mind of man -
A sound magician is a demi-God.

The Intellectual Cast and the Secret Code of Access

Being an intellectual is also a matter of access. There are some theories of closure that can help us to understand the practices of selective exclusion from the intellectual resources.²³⁸

Lower classes, oppressed ethnic groups, women, people of color and sexual minorities have been systematically kept outside the competition for the access to the resources. In the recent debate over affirmative action we can notice a considerable gap among those intellectuals who want to understand class, race, and gender stratifications and how these categories affect the production of theory. For instance, the "problem" of black students performing worse than white students in theory classes, is "explained" looking at the ways black students are socialized, their family background, learning disabilities produced by social and economic conditions, by the heritage of century of oppression.

²³⁷ A. Gramsci, *Selections from the Prison Notebooks*, edited by Q. Hare and G. Nowell Smith, International Publishers, New York, 1971, p. 420.

²³⁸ R. Eyerman, L. G. Svensson, T. Soderqvist (editors), *Intellectuals, Universities, and the State in Western Modern Societies*, University of California Press, 1987, p. 67.

Despite good intentions, the focus on these issues allow other problems to remain uncovered, such as the problem of what is learned. If I say black students perform poorly in theory classes I am focusing on black students -- and making a number of assumptions.

1. I am assuming that theory is solely the white (European and U.S.) theory taught in the Universities;
2. I don't recognize that there are other kinds of theory;
3. I do not acknowledge that black thought has the status of theory.

Resistances in acknowledging a scholarly value also occurred to feminist studies, which have been until recently struggling for the status of theory.²³⁹ And in Italy the debate is still about feminism as "perspective."

In not acknowledging that black thought is a theory, I re-inforce the bias that blacks do not have intellectuals, or have less, or they cannot be as good as whites. You can teach sociology seminars on Durkheim but not on Du-Bois. In understanding these issues the Foucaultian "power of defining/naming/classifying" and the Lacanian concept of "control on the signifier" play a central role.

There is a theory called "bifurcation theory," which assumes an essential division between skilled and unskilled labor, and that the presence of very qualified employees requires that unqualified workers do unqualified work for them. According to this theory, bad jobs are created in order to employ those who are unable to do good jobs. A filtering system is created for ensuring the cloning of a loyal elite in the reproduction of what Bourdieu called "the scholarly field": universities, libraries, journals, research institutes, and presses. This system uses a number of demarcation criteria in order to distinguish insiders from outsiders. Among those signs Bourdieu mentions physical appearance, behavior in public, mastery in the use of language, ethnicity/nationality, display of wealth markers, and other features which altogether constitute criteria on which *la distinction* is predicated.

In our minds, manual work is related to execution, repetition, boredom and passivity. As at the beginning, we do not think of an artist or sculptor as doing manual work, because the component of creativity makes them belong to a different category -- the arts. Painting is a very active relationship with the world. As Edgar Degas said, a picture is first of all a product of the imagination of the artist; it must never be a copy.

Under capitalism the expression of intellectual work and artistic creativity has taken the commodity form, which increasingly characterizes all kinds of production and relations. Paul Lafargue, Marx's son-in-law, talks about the "degradation" of intellectual labor due to the transformation of intellectual faculties into merchandise.

Never would the free citizen of the ancient republics of Athens and Rome have submitted to such degradation. The free man who

²³⁹ What is theory constitutes a contended field. In the definition, which emerged during a discussion with Carolyn Martin Shaw, theory is as a complex body of verbal abstraction meant to be explanatory (of present and past events) or hypothetical/predictive (of future events), or to offer a systematic view of relationship among different facts and ideas.

sells his work, says Cicero, lowers himself to the rank of the slaves. Socrates and Plato were indignant against the Sophists who required pay for their philosophic teaching, for to Socrates and Plato thought was too noble a thing to be bought and sold like carrots and shoes. Even the French clergy of 1789 resented as a mortal insult the proposition to pay a salary for worship. But our intellectuals are accustoming themselves to such degradation.²⁴⁰

Paul Lafargue analyzes how selling intellectual merchandise has become an all-absorbing principle -- and how, the more intellectuals raise their heads (and prices) the more they bow their knees.

At the same time that the division between intellectual and manual labor becomes more dichotomized, both intellectual and manual labor undergo a process of degradation, segmentation and hyper-specialization, which allow both manual and intellectual labor to express the maximum level of capitalistic productivity. In advanced capitalistic country, the intellectual stops being an artisan/inventor and becomes a salaried worker.

On the other side we have a working class that can count on very little "cultural capital" -- as in Bourdieu's definition. From their childhood, the limitation of the theoretical discourse legitimizes their marginalization and, later their expulsion from the arena of the production of knowledge. If their family does not provide the "symbolic mastery" -- the orthodox use of grammar, the correct terms, their language (jargon, slang, dialect) or their accent -- defines and labels them as outsiders despite their intellectual achievement beyond any subjective effort of achievement. Of course there are "exceptions."

Yet, the working class produces culture. Gramsci analyzed common sense as "the philosophy of non-philosophers."²⁴¹ Sometimes common sense has been discussed as the base of philosophy itself, sometimes as the construction through which hegemonic ideologies become popularized. The tie between common sense and religion is particularly clear to Gramsci:

The principal elements of common sense are provided by religion, and consequently the relationship between common sense and religion is much more intimate than that between common sense and the philosophical systems of the intellectuals.²⁴²

With the emergence of science and technology, good sense loses the legitimacy of self-evidence, tradition and truth. As in an epigram by Giusti

Good sense, which once ruled far and wide
Now in our schools to rest is laid

²⁴⁰ G.B. de Huszar (editor), *The Intellectuals. A Controversial Portrait*, The Free Press of Glencoe, Illinois, 1960, p. 322.

²⁴¹ A. Gramsci, *Selection from the Prison Notebook*, Q. Hare and G. Nowell Smith (editors), International Publisher, New York, 1971, p. 419.

²⁴² Ibidem p. 420.

Science, its once beloved child
Killed it to see how it was made.²⁴³

Even though Gramsci believes in the capacity of the working class to produce knowledge, he criticizes Croce's proposition that "all men are philosophers". In fact Gramsci thinks that common sense is not a single unique vision of the world. Its most fundamental characteristic is that

... it [common sense] is a conception which, even in the brain of one individual, is fragmentary, incoherent and inconsequential, in conformity with the social and cultural position of those masses whose philosophy it is. At those times in history when a homogeneous social group is brought into being, there comes into being also, in opposition to common sense, a homogeneous -- in other words coherent and systematic -- philosophy.

Common sense, intuitions, spontaneous theories are at the very bases of systematic theories. The philosopher who will translate and give scholarly format to popular intuitions and beliefs is the organic intellectual of a specific social group whose ideas are emerging.

Appendix 2: A. Writing in English

When I was in NY, after the field research was completed, I faced the decision about which language I would use to write the dissertation. The reflection wasn't easy, it took time and I want to offer a segment of it, through an excerpt from my journal.

Why should I write this work in the English language -- and not in my own, beloved one? Is it just to make it more accessible to other people? To a larger number of people? Are there reasons for me to making that decision? Any margin left to reconsider the whole issue from a different perspective? What does it mean, "being bilingual?" Is it a matter of being able to express yourself in two languages or is it a way to think in different perspectives? It is difficult to answer to these questions, but at this point I have the urge to do it.

First: when I write in English I write different things from those that I would have written in Italian. Basically, I think different things in the two languages. Until last year I used to have my best ideas in Italian -- and then I was working on them in English, sometime losing the meaning in that process. Then I learned to write the ideas in the language they occurred -- Spanish, sometimes. Maybe I should leave the flow open: at the end I will translate in English what I wrote in Italian and vice-versa. It will be more work -- or maybe less. For sure if I don't force myself to write either/or, I can write more. When I will write about the interviews probably the reflections will come up

²⁴³ Ibidem p. 423.

in English. when I will write about psychosomatic approaches to cancer etiology, I will think in my language. (...)

I should start being more systematic about corresponding with a certain number of people about my work -- in both languages, so I don't have to switch completely.

The problem is also style. I do not have a style. India will help me in offering a way of appropriating English, because I will never speak or write as a person who was born here -- and if I could, I would choose not to.

I think in my work I should display the ambivalences I have about writing the dissertation in English. In many cultures English is considered to be the language of the oppressors -- as it used to be for French and for Latin.

In the collective experience of my political generation we used to have a perception of English as the language of West Coast music, the beat generation. I remember when translating songs of Crosby, Stills, Nash, and Young was a way of communicating with the forms of transgression happening overseas, and the attempt to look at their recent past, and understand the student revolts in Berkeley, the anti-war movement, the Black Panthers, the George Jackson Brigades, the Weathermen ... It was the myth, but it was too far or too brief, for a change of English as a signifier of oppression -- or maybe ten years of Reaganism re-enforced the perception of his language as the enemy's. While Spanish was always perceived as the verb of political exiled from South America, *guerrilla* people, generous and brave, similar to "us". Admitting ambivalence about writing in English is also a way to understand other generations of immigrants from Italy, with whom I share the specific cultural ways in which we tried to resist assimilation/"americanization," and the specific fears, angers, tears of nostalgia. Italians didn't write much about this. If I want to reconnect the particular to a (partial) general, I think the closest expression of resistance is the one to the assimilation of African and African descendants in the Caribbean French culture. (...)

In some way what is happening to me is the same dilemma that happened to African writers at a certain point: writing in the native language [mother tongue] or writing in English? For some it was an important political choice: rejecting English and becoming accessible to their own people -- which is not just a matter of nationalism but a concern about the degree to which the act of possessing another language objectively detaches you from them. (...)

My inability to fall in love "in English" has been one of the expressions of not accepting this language as my own. This didn't happen with Spanish. I don't know why I perceive English language as cold -- as inappropriate for expressing emotions (...) Thanks to Samir, in these days I have been thinking my feeling (and even writing poems!) in English. He promised to step on me, when I will be a spider -- but only by inadvertence. Brahmins ...

Appendix 2: B. Obstacles in the Interviews

Scientists were much harder to get for a one hour interview than activists were. Some of those I wanted to interview are not in the sample, they weren't available when I reached their site because of a sudden departure for an important meeting or other emergencies. In some cases I have been able to follow up later with a telephone interview.

Several times I couldn't go through the "filter" of the scientists' secretaries, few times their institution didn't allow scientists to be interviewed: "It is a policy." Other times the tactic was indirect, by discouraging the request, by displaying suspicious and defensive behavior, by stating that their scientists are busy, asking to call again and again and again.

In some cases I could reach the scientist's home number. Some scientists accepted, some were working out of the country, some were not interested in being interviewed. By and large, my telephone calls were kindly returned. Only a few scientists I contacted denied me the possibility of an interview after talking to me on the phone.

The kind of questions scientists asked me before a refusal to be interviewed expressed some concern -- or anxiety -- about their own career, more than lack of interest in my project itself. A "screening" question the scientists asked me was about who were the other scientists I had already interviewed. I usually refused to engage in "name dropping" (though it would probably have been effective).

I was asked if my work was going to be published as book, and by whom -- or if it was going to be for an article. I was asked who was funding my research, who my sponsors were. In negotiating the interviews with the scientists I realized that being just a doctoral student was close to nothing -- and that insisting on the social utility of my research wasn't going to make any difference. Often, the main concern underlying their questions seemed to be "what can I get out of it?"

In some cases what I perceived as an obstacle was the scientist's assessment of the importance of my project, how many chances for their name to show up in a book, if this was worth spending an hour with me. They liked that somebody from University of California was interested in them. But they wanted to know the names of my committee members -- whom they obviously had "never heard" of. They were probably concerned about which kind of connection could be extracted from me.

I didn't do anything to convince them that I was worth it (by their standards) nor to reassure them that they would gain something by talking from me other than giving me useful information and opinions. When the phone conversation was leading to this "delicate" point I knew the scientist was going to deny an interview. I usually felt turned off by that acquisitive attitude, by the greed of so carefully evaluating their advantages.

Most of the scientists whom I interviewed, regardless of their professional and political positions toward the cancer movement, had a genuine attitude and declared themselves available to share their knowledge with a foreign scholar interested in what they do and think.

I didn't get a business card to show them before the interview or after. They always asked my name and address at the end of the interview -- and in most cases told me they were satisfied or happy with our discussion. In a few

cases they thanked me for helping to focus on problems they do not have the time to think about because of the routines of their work. The only place where I felt hostility was at the ACS -- while at NCI the scientists were more open to being questioned.

With cancer activists I didn't encounter problems. In a couple of cases I was denied an interview because the women were overwhelmed with work, activism and family obligations. Some of the activists were cold or defensive at the beginning of the interview -- but the fog faded away during the interaction. In most of the cases women made me feel welcomed and supported: I have been given hospitality, lifts to and from Greyhound bus stations, I have been mailed materials and letters, kept updated on activities, called for advice and encouragement.

Appendix 3: Excerpts from the interview with Richard Strohman.

Far from being a genetic determinist I am quite the opposite. I take the point of view that there are very serious genetic diseases in all Western or industrialized countries ... these diseases are clearly genetic. They are so called myelogenic diseases where you have a clear ability to trace scientifically in molecular terms, precisely trace that disease to a single gene. But, these genetic diseases constitute -- and there are thousands of them -- only 2% of our total disease load and you'll read that in the papers I'll give you.²⁴⁴

So if we were to eliminate all these genetic diseases tomorrow, we would still have left unattended the 98%, all the other diseases which have a very broad genetic background. By that I wish to say -- and there is agreement with this, most sophisticated geneticists would agree -- that a disease that has a very, very broad genetic causality rather than a precise, linear genetic cause, is a disease for which the genes may be necessary, but not sufficient. That is to say that a particular gene -- or set of genes - - doesn't guarantee anything, but what it does guarantee is that these genes be put in a particular environment.

So my position [is that] 98% of the diseases -- all the cardiovascular diseases and most of the cancers -- are not genetic diseases. They are environmental diseases for which genes may be implicated, but in the presence of an amicable environment, these diseases are all correctable. All have the appropriate genome to deal with these things as long as we live in an amicable world.

²⁴⁴ This estimate -- although it sounds surprising -- is not far from the official "truth," which has been re-stated at the Breast Cancer Symposium held in San Francisco September 25-27, 1994 -- a symposium heavily focussed on genetic issues because of the recent "discoveries." During the three days, even the most fervent speakers had to admit that genetic factors do not explain more than 4-5% of all cancers.

Appendix 4: Dermer's Critique. Analysis of Three Paradoxes in Genetic Research.

A. About the stability factor, the first issue that emerges is that

In contrast to the known genetic stability of both normal and malignant human cells *in vivo*, genetic instability is an inevitable side effect of a cell that survives a crisis period and emerges as an immortal tumor cell line from a primary culture of tumor cells.²⁴⁵

The pronounced genetic instability of the MCF-7 line [which is the favorite experimental model of breast cancer] was first described by a group at the NCI in 1983. Experiments already in the 1950s were calling for discussion about genetic instability of cell lines. As K.H. Walen, M.R. Stampfer explained

After immortalization of human cells in culture, the previously very stable chromosomal complex has become unstable, spontaneously breaking and rejoining to form new genomic combinations. (...) Transformation of human cells to immortality is associated with gross chromosomal mutation changes²⁴⁶

Let's take an example. Despite the fact that chemicals tested as carcinogens on animals are not considered to be carcinogens on humans in legal trials, today the mainstream cell line for cancer genetic research is 3T3 - which comes from rodents.

Although they are supposed to be models for normal cells in the body, these cells behave nothing like normal cells. They do not age, are unstable and underdeveloped, have an abnormal number of chromosomes, exhibit chromosomal mutations, and are easily transformed to a malignant-like state

The 3T3 cells have been in culture in laboratories throughout the world for a generation; yet because of their genetic instability, these cells no longer contain the normal karyotype of mouse cells from which they were derived. Instead, 3T3 cells exhibit the abnormal numbers of chromosomes and chromosomal mutations that are fundamental characteristics of malignancy. Normal cells in our bodies would not recognize 3T3 cells as even the most distant of relatives.²⁴⁷

²⁴⁵ Ibidem, p. 49.

²⁴⁶ K.H. Walen, M.R. Stampfer, "Chromosome Analyses of Human Mammary Epithelial Cells at Stages of Chemical-Induced Transformation Progression to Immortality," in *Cancer Genetic and Cytogenetics*, N. 37, 1989, pp. 249-261.

²⁴⁷ G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994, p. 51.

While pathologists have established that the feature of human tumors are fixed, cancer researchers think that characteristics in human tumors undergo processes of progression -- since this is what happens in cell lines, because of their instability.

Surgical pathologists know that progression stops once a cell becomes malignant. Most cancer researchers do not. They believe that progression is a characteristic of malignant cells themselves.²⁴⁸

B. About the differentiation factor, Dremer reviews how pathologists have known since the nineteenth century that real tumors always retain features of their normal parent organs. By contrast,

on the bottom of a dish, a lung tumor line looks like a breast tumor line, which looks like an ovarian tumor line, which looks like a prostate tumor line etc. ad infinitum. The differentiated features of the tumors are lost by the lines as they adapt to life under the artificial conditions of the culture environment. In other words, cell lines become undifferentiated. It is also common for lines to lose their sex chromosomes (...) No animal or human cell *in vivo* is without a gender, but cell lines often are.²⁴⁹

One of the scientists I interviewed -- a molecular biologist -- gives an explanation of what a tumor is, entirely based on cell lines observations.

We work on a very molecular level through biochemistry and molecular biology (...) looking at transcriptional regulation. What that means in a basic sense is that although the genetic information in each of our cells is identical whether it is a skin cell, eye cell or liver cell. Obviously skin cell is not a liver cell, your liver has information that tells it to form a liver. So what we want to know is what types of molecular machinery picks and chooses along the genetic information available to each cell to have it become that kind of cell and then to have it maintain itself as that kind of cell. Certainly in the case of cancer, many of the cancers there is uncontrolled growth that is the hallmark of cancer, but often it is uncontrolled growth in cells which have made the decision to become say a liver cell and they are not going to become a kidney cell ... but when they become transformed, therefore proliferate madly like cancer cells do, they lose some of the controls that have prevented their utilizing some of the other genetic information that is available. The idea I suppose from a molecular person's point of view is if you can understand what is correct what the proper controls are that allow a liver to become a liver cell and stay a liver cell and

²⁴⁸ Ibidem, p. 52.

²⁴⁹ Ibidem, p. 54.

behave when you are in the liver, then we can understand what was wrong in all kinds of pathogenicities including cancer. We work usually with purified proteins purified nucleic acids and are trying to understand some very fundamental mechanisms in genetic control in the hope that they would extrapolate just the specific types of questions we ask. The most directly cancer-related type of project we work on is one of those genetic sequences that we work with and codes what is called a proto-oncogene. It turns out that a variety of other proto-oncogenes actually are controlled in getting the information from the gene to the cell. They are controlled during transcription and they are controlled at exactly the part of transcription that my lab is focused on. That is an example that we study, we didn't actually pick it because it is involved in carcinogenesis or in cell transformation. We picked it because of the position in the gene in which it is controlled. Because the gene product is involved in cell transformation, we have to understand something about how to control the information that leads to the production of the gene product then we can understand how that control can go away because you don't want a lot of this protein in cells that have done what is called terminal differentiation at the final stage of development. [Interview N. 53]

Cell lines are so undifferentiated and underdeveloped that gross errors can be made even by highly experienced teams of scientists -- who can be led to wrong conclusions.

A cervical cell can be mistaken for a prostate cell by experts (...) Millions of dollars were spent on projects concerning breast tumor cells, prostate tumor cells, and so on, when all the cells were really HeLa.²⁵⁰

Finally, during the seventies, the information about HeLa cells -- and how they "contaminated" many laboratory cultures in prominent scientific laboratories -- was disclosed and the results of years of scientific research were questioned. Yet, such information didn't discredit the postulates of genetic research based on cell lines.

C. About the initiation factor, I will only briefly mention two determinants -- the first being that cells are most sensitive to the effects of carcinogens during their developmental period. The second determinant is that in tissues that do not undergo significant cell replacement (e.g., heart and nerves) cancer is extremely rare. In other words, carcinogens hit normally *aging* cells, by interfering with the process of its maturation/differentiation.

These two determinants are results of observations -- yet contradicted by the theory of oncogene. It might be interesting to notice how Noble Prize Winners Harold Varmus and Michael Bishop discovered the genes that are

²⁵⁰ Ibidem, p. 55.

believed to cause cancer when they "malfunction" -- by using a cell line (3T3). Their experiment did not initiate cancer in normal cells (supposed to carry 'oncogenes'), but in a model which has been in culture for at least a generation.

Like all cell lines, these cells have an abnormal number of chromosomes and chromosomal mutations, basic characteristics of malignant cells. (...) 'Normal' 3T3 cell lines can even form tumors, when inoculated into some kinds of mice. In addition to exhibiting genetic and phenotypic instability and being immortal, the 3T3 line is very close to, if not actually, malignant.²⁵¹

Two years before Harold Varmus and Michael Bishop at UCSF were awarded the Nobel Prize, a famous molecular biologist, Peter Duesberg from U.C. Berkeley, was already stating that normal cell lines are not a reliable model for experiments meant to test the cancer-causing activity of genes -- for the reason that cancer hits stable cells which develop and age -- while cell lines are unstable, underdeveloped and ageless.²⁵²

Only differentiating, aging cells are susceptible to cancer (...) Data from a model that neither develops nor ages cannot be relevant to the cancer process in humans.²⁵³

D. The last factor we are analyzing in order to understand the critique of cell-lines based genetic research is metastasis. This is the process of invasion and destruction of vital organs by a primary cancer. The question in the research related to metastasis is about what allows a cancer cell to separate from the primary cancer, travel through the organism and colonize other organs.

Treatment of metastasis has the goal to stop such a process which has different stages. But most of the research is not done on cells from real metastasized tissues, it is done on cell lines.

Not surprisingly (given the documented instability of cell lines) the picture is one of pronounced change and instability" with the result that now it is believed that cells with high metastatic potential are rare in tumors. They are supposed to arise only on the rare occasions when a particular but unknown characteristic is suddenly 'turned on', giving this rare cell the ability to metastasize. This contradicts thousands of studies made by pathologists on real tumors: it is widely accepted that the capacity of metastasize is related to the differentiation of the tumor:

²⁵¹ Ibidem, pp. 60-61.

²⁵² P.H. Duesberg, "Cancer Genes: Rare Recombinants Instead of Activated Oncogenes," in *Proceedings of the National Academy of Science USA*, 1987, pp. 2117-2124.

²⁵³ G.B. Dermer, *The Immortal Cell. Why Cancer Research Fails*, Avery Publications, New York, 1994, p. 62.

"Poorly differentiated tumors are generally aggressive, with high metastatic potential, whereas well-differentiated tumors are usually less aggressive, with lower metastatic potential.²⁵⁴

A valid example of the inadequacy of cell lines when it comes to metastasis research is given by the fact that, while real human tumors spread either to the lungs or to the liver or both,

... when tumor cell lines are injected into the veins of laboratory animals, metastatic lesions appear virtually everywhere, in many different organs.²⁵⁵

Data from cell lines and data from the observation of human disease seem to go in different directions -- and this constitutes one of the most amazing paradoxes of the dominant paradigm in cancer research.

Appendix 5: Excerpts from the Interview with Nicholas Petrakis.

I would think first of all ... you have probably ... genetics has to be a ... probably a key one, obviously (...). Well it really fits into ... everybody goes with the current dogma of the time, you know, the model that everybody ... and so we consider that it's a complex interaction of many factors. *There has to be either a genetic inheritance or a susceptible gene, like is being postulated now. We know that's probably so.* Certain families have inherited risk of breast cancer, but that isn't the whole story ... because they need to have other things happen as well. You can inherit a gene, two maybe, but *why doesn't it start right away?* Why does it happen, you know, twenty years later? Thirty years later? Forty? So we then have to assume there are other factors. Hormones and dietary factors, and gradually with time in some people this leads to more and more severe changes. It's the standard model because that's what we work with. We tried to find genetic markers in association with this. Mary Claire King worked with me for four years over here when she just got out of a post-doc, and we tried at the time, using the methods of the Seventies, to see if we could detect risk markers, you know, genetic markers, but we couldn't at the time. (...) We can't even prove that a mutation, necessarily having a mutant gene, means you're going to get cancer, you know. You may have to have two of them, or you may have to have... the colon, it's now known, there's about six or eight, six genes may be involved, or six steps. So you know, one of them may not be enough, so we have these techniques that you need to have, only come in in a big way in the last three or four years, you know. So

²⁵⁴ Ibidem, p. 63.

²⁵⁵ Ibidem, pp. 64-65.

in the future, that's what it's all about, you know. (...) *It's all very well to find mutant genes. We've got the hottest place in the country here for genetic research, Berkeley too, and Stanford, you know.*

Appendix 6: Excerpt from interview N. 37.

Starting with the first and most important category of causation I think probably [it is] genetic abnormalities . We don't know what they all are but I am sure there is vast a number of different genetic abnormalities that lead the cancer

(...) Yes, I think there is a real hope [to use oncogene research for prevention and cure]. I never would have thought it five years ago but I think that -- without getting overly enthusiastic about molecular biology going on *there is real reason now to believe that there is a way one can change the molecular events that can lead to the cancer -- or modify them or put them off.* It might not be as simple as ticking genes into cells ... it may be a new kind of intervention that derives from that knowledge - genes make proteins, proteins circulate in the body ... maybe we can find the proteins of the genes that are made and block those that cause cancer ... So it might not be a direct line, but using the information that we are getting about genes and cancer we may be able to develop new strategies to stop the process (...) It is hard for me to understand how one can *introduce* a gene or *change* a defective gene throughout the body billions and billions of cells but obviously those genes are doing something and we might be able to do something about what they do ...

Appendix 7: Excerpt from the interview with Richard Strohman.

Cancer is clearly a disease in which the cells of the body lose control of their growth regulation, everybody agrees to that. *The question is what is it that causes the cells to lose growth control.* From a developmental point of view it seems to me that growth control is something that comes up in the very process of the formation of the body.

From a fetal and an embryonic state, growth controls are always very precise. (...) One cell gives rise to millions of cells in a tissue and there is much growth ... but then that growth is regulated so that tissues reach a certain size and then stop. This is true of all tissues, but at some point in the life of the organism that growth control needs to be altered as cells are damaged, so cells need to grow, to replace, to regenerate. That's a developmental process that goes on in the adult.

Cancer then, is seen as an aberration of these normal growth controls. So, what is the basis of these aberrations in which growth controls become defective and produce tumors? My sense is that *that's not the result of a mutation, or something that goes wrong with genetic information*, although that can arise. Some

radiation damage will create mutations and chemicals will create mutations and so on, but *my sense is that the environment in general, the conditions that organisms are exposed to, including humans, will produce, before there are any mutations changes in the growth, the [morula] around the cells and these cells will then be forced to undergo what I call a sort of creative, adaptational response.*

You give the cells some environments like a chemical environment, a nutritional environment, an oxygen environment, an oxidated environment, these cells will, out of their normal creative process, attempt to cope with these new environments and they will grow in different patterns in order to avoid or to compensate for whatever this new challenge is. In so, in this compensation growth, or changing new pattern, that's reflective of what they do in development anyway and they will continue to do this over time.

If they have to do this chronically over a long period of time, change their growth regulation, they'll grow in different patterns, they'll continue to grow. The more they the grow and divide the more they're open to mutational events and then the mutations will happen.

But - before the mutations happen - as they [cells] change and cope ... those changing, the coping mechanisms prior to mutation *are all reversible.*

So a tumor, at this point, may still be reversible if they're still in this adaptational mode before mutations set in.

Once a mutation is there, there's a reversible process. But up to the point where the cell of the tissue is full of a variety of mutations its all reversible.

So my position is that if one can understand the response of the normal adaptational or developmental responses of cells in adult organisms to change ambiance or environment, then we are on the way to understanding how we can approach the cell's raw reversible process (...). So then we can look at tumor regression or natural ways of spontaneous tumor reversal - which of course the literature is full of - rather than waiting until the mutations are there and then you are faced with the enormous, if not the impossible, problem of dealing with cells which are so horribly damaged as indicated by mutations ... reversing the tumor is extraordinarily difficult, in fact, so far its been almost impossible except for rare cases.

A comparison should be made between the statement above and the one I am going to present next. While Strohmman is a geneticist who talks like a social scientist interviewee N. 6 is a sociologist, who talks like a cell biologist. He gave genetics a high rank in cancer causation. From his statement what emerges is a concern about how some forms of cancers, mutating specific parts of the DNA, can become "hereditary." Another reason why he considers genetic factors as important refers to the theory of "errors in the transcription."

A good deal of it [cancer] is unquestionably genetic. I mean, you have some risks of certain cancers being several times higher among individuals whose parents or siblings had certain forms of cancer. There are linkages that have been established as etiological factors in some cancers. Some forms of lung cancer, for example, contribute to particular mutations occurring at definite points in the human genome. A fairly rare cancer, retinal blastoma, is directly linked with a particular point where [descent] occurs on the human genome, et cetera. So there's a lot more out there that haven't been identified, but it seems to me like every few months scientists come up with the actual genetic anomaly that gives rise to particular cancers, so my guess would be that a large part of it is genetic. There's [also] an accidental factor just because you have (...) mutations occurring in the process of mitosis, and you also have genetic pre-dispositions which raise the possibilities of individuals contracting certain malignancies. [Interview N. 6]

Appendix 8: Susan Love's interview on the New York Times.

Research is the only way we are going to solve this thing, and I don't mean research into new chemo formulas, I mean research into the cause of breast cancer' she said as she walked through an empty parking lot to a new Volvo station wagon 'and we are so close' she said 'We know it is genetic. Some people are born with the gene, others develop the gene. We don't know what causes the gene to change. Pesticides? Food additives? They are all possibilities. All we know is that a gene is involved. And we are very close to finding it. Unbelievably close.' Sliding behind the steering wheel, she distilled the latest breast cancer research with the same kind of down-to-earth smiles that she uses to explain the disease to patients. 'You see, the gene is like a robber in the neighborhood,' she said. 'We have the neighborhood roped off. Now all we have to do is knock on every single door.'²⁵⁶

Appendix 9: Excerpts from the interview with Betsy Lambert.

Genetics—that's not away from the agenda, because part of the genetic research could help us obtain perhaps enough information to determine if there's a way to shut down the malignant cell activity. (...). You can have breast cancer, unlike other kinds of cancers, and if it can be controlled, you can buy yourself a lot of disease-free life. The point is you just don't want it to spread; you need the body to recognize that it's cancer and to

²⁵⁶ M. O'Neill, "A Day with Dr. Susan M. Love. A Surgeon's War on Breast Cancer," *The New York Times*, Wednesday June 29, 1994, p. B6.

do whatever needs to be done. And those of us who have cancer not recognized by the body, maybe that's the genetic defect. Those goals are long- and short-term goals. Maybe tomorrow somebody will find something ...

(...) Let me break down genes. I believe that there is a genetic factor, that either you get a predisposition—a little bit like some people used to die of cholera, some didn't; some people died of yellow fever, some didn't. For those of us who's bodies don't recognize the cancer, don't kill it off ... or there's some major defect ... let's just call that "genes" let's just say I got a gene from my father or my grandmother, that made me more susceptible to cancer. Maybe it's not a breast cancer gene, maybe it is. Maybe I have it, and I have always had a gene that was defective before ... I got it—lucky me, right?

Then, I think there is the possibility. But I don't classify that as "true genetics". I classify that as "environmental damage" done to the genetic systems or to the body, to the cells. (...) It could be that you have the gene, and it still takes a certain series of factors to trigger it. You could have the gene, but maybe you wouldn't develop it at 48 (...). I think most of the people who have cancer these days probably don't have a true genetic link.

And it's really interesting, there's a woman in Boston who said something really interesting at a seminar I went to. She said that her family was from Ireland, and that there were two sets of children. And one set came to the US; there were the Irish parents who had an older set of children, and then they had a younger set of children. And three children continued to live in Ireland, and four children came to the US. The mother and the father and three children stayed in Ireland, and had no cancer. The four children who came to Massachusetts; all four of the parents, and now the children of those, have all had some sort of cancer. Now I think that's some fairly compelling evidence. And she says, "When does family history begin?"

Appendix 10: Excerpts from R. Doll, R. Peto, *The Causes of Cancer*, Oxford University Press, 1981.

The potential scope of cancer prevention is limited by the proportion of human cancers in which extrinsic factors are responsible. These [factors] include all environmental carcinogens as well as 'modifying factors' that favour neoplasia of apparently intrinsic origin (e.g., hormonal imbalances, dietary deficiencies and metabolic defects). The categories of cancer that are thus influenced, directly or indirectly, by extrinsic factors include many tumors of the skin and mouth, the respiratory, gastrointestinal and urinary tracts, hormone dependent organs such as breast, thyroid and uterus, haematopoietic and lymphopoietic systems, which collectively account for more than three-quarters of human cancers. It would seem, therefore, that the majority of human cancer is potentially

preventible. (...) Unfortunately, the phrase 'extrinsic factors (or the phrase 'environmental factors', which is often substituted for it) has been *misinterpreted by many people to mean only 'man-made chemicals,'*²⁵⁷ which was certainly not the intent of the WHO committee. The committee included, in addition to man-made or natural carcinogens, viral infection, nutritional deficiencies or excess, reproductive activities, and a variety of other factors determined wholly or partly by personal behavior. To avoid similar misunderstandings, we shall refer throughout this report to the percentages of cancers that 'might be avoidable' in various ways, rather than to the percentages that are due to various 'extrinsic' or environmental' factors, and have used the term 'avoidable' in our title²⁵⁸

Appendix 11: Excerpt from the interview with Samuel Epstein.

Waxman held hearings in Summer '87 and he asked me if I would have time to have lunch with him. Then he said 'You know in Congress they are still very confused about what is happening with cancer. The NCI are telling us that we are doing very well, but somehow it doesn't all add up: everyday we read articles on this and that ... it creates a great deal of confusion. Would you please prepare a position paper -- which we can put in the congressional record -- which will make clear to Congress what the real situation is with cancer?' So I wrote this paper in 1987 (...) and then the ACS wrote a rebuttal to it. The rebuttal was unsubstantiated ... Waxman didn't put it in the record. (...)

Appendix 12: Excerpts from the interview with Bruce Ames.

If you're not efficient, if you spend your time on minor things when you should be spending them on major things or you have solutions that don't really work very well, then you're killing people because you're not doing the important thing. It's like,

²⁵⁷ My emphasis.

²⁵⁸ Yet, most of the established human carcinogenic agents listed by the IARC are occupational. The discussion of the extent to which agents and conditions affect the incidence of cancer in U.S. is discussed from p. 1220 to 1256. A whole chapter is devoted to the discussion of the "role of genetic factors, luck [sic] and age." There are three determinants: "nature" which relates to the genetic makeup; "nurture" which relates to "what people do or have done to them (in the womb, in childhood, or in adult life) and is of public interest as a determinant of cancer risk because it is the only thing that can be influenced by personal or political choice; and "luck" which determines "the concatenation of events that brings about specific changes in particular molecules in individual cells at particular times." Getting cancer is represented by Doll and Peto as being hit by a lightning: they explain with a magic what psychosomatic medicine already explains with science.

doing research, I'm always thinking, " there are twenty possible problems I can work on, and I'm always trying to see which project is going to have the most impact and open up the most new things. If I spend my time working on minor problems then I'm not a very good scientist. A good scientist always tries to solve major problems. So it's a matter ... and the same thing with a business. If they do spend their time on trivia and don't take care of the important things then they're lost.

(...) I don't know anybody who thinks that. No reputable scientist thinks that. I mean, if people ... No person, I don't really know of anybody ... Nobody I know in the scientific community thinks pollution is very important. I mean, maybe a little bit of cancer, but ... I mean, there's sort of crazy people out there, but there's nobody respectable who thinks that.(...) It's hard to do something for somebody who doesn't want to help themselves. So I think we're spending much too much money on worrying about pesticide residues and little bits of pollution. You want some rules, but you don't want to spend hundreds of billions of dollars on that, and that's just what we're doing. Because it's very hypothetical, and I think unlikely that the ... *I don't think pesticide residues have ever caused a case of cancer*, and yet pesticides lower the price of fruits and vegetables. So they lower cancer rates 'cause they make fruits and vegetables cheaper. And so you spend a lot of money on worrying about pesticide residues, then it's counter-productive. It's money that you're not spending educating people about diet or educating them about other things or doing research to understand the causes.

Appendix 13: Excerpts from the interview N. 43

And the cancers they tend to cause are not the most common ones. I think about polivynil chloride in angio-sarcoma: very rare. And asbestos: asbestos got a lot of publicity: Arizona is the state where they actually still mine underground the asbestos. But the asbestos that is mined *here in Arizona is supposedly much less carcinogenic* than some other types.

Environmental exposures from ceilings with asbestos has been a tremendous controversy for the EPA in US -- they made the decision that they are no longer taking the asbestos away from ceilings that are sealed -- it suggest that the exposure level of the asbestos outside the occupation is very small. There are occupations where exposure is very large, but asbestos, I don't think it is a major cause of cancer in US -- in this decade. Thirty years ago, maybe ...

(...) Certainly if you look at which chemicals are mutagens and assume therefore that they are potentially carcinogens ... there is thousands. The WHO [World Health Organization] has classified a hundred, two hundred now, of chemicals ... My impression is that the general exposure is very low [here by general exposure he probably means the exposure of people in general, again without

accounting for the workers] for the majority of the American population.

Appendix 14: Excerpts from interview N. 56.

I. 56: There's components of the diet that help reduce the risk of cancer -- but if you sort of roll those together as having an influence on cancer diet is number two.

Then I think there are several other things that come in roughly at the same level. I think that occupation is probably number three for causing cancer. But then there's environmental exposures -- like radiation -- genetics, host factors ... those are all roughly at the same level. (...)

L.C. Your list would also include physical factors like electromagnetic fields?

I. 56 Absolutely: radiation, cosmic radiation, all that is an environmental exposure.

L.C. Low frequency waves?

I. 56 Yes.

L.C. How much to you think that physical and chemical carcinogens do account for cancer?

I. 56 For ionizing radiation it is a very clear carcinogen -- but it doesn't account for a very large proportion of them. Maybe 1% of all cancers. We have control of a lot of these exposures -- although it is a clear carcinogen. The non-ionizing radiation, ultraviolet is probably the main one which causes skin cancer which is a big ... that's quite a lot. But fortunately most skin cancer is not lethal. Most of it can be detected because it is on the surface and you can have it removed and so it doesn't lead to mortality.

The one that is sort of unclear is the electromagnetic radiation. The epidemiologic studies at least make you worry about it. I mean: the amount of worry depends on how you look at things philosophically ... but it is possible that this could be a bigger chunk than we originally thought. It tended to be focused on lymphatic tumors, and brain cancer. But there is some hint of breast cancer. Breast cancer causes a lot of ... its a big burden and it's not out of the question that ... it might become important in the future. I think the answer is clearly not in yet as to whether it [electromagnetic radiations] really is a risk factor -- or if it is, which tumors and at what level.

L.C. What about chemical carcinogens? How much do you think they account in the production of cancer?

I. 56 Well, the estimates that are made come in at around 2% to 15% and sometimes are up around 30%. But *typically* it is around 5%. And that's probably not too far off, if it's 10% or 15% it's still roughly in the same ballpark.

What's important to keep in mind is that this is an estimate of exposures that came some time ago and only for the risk factors that we know about. The way we get these estimates is that we add up all the extra leukemias caused by benzene, and all the extra lung cancers caused by arsenic, and we just keep doing all that through the sights. And when you get done, you see what proportion of the cancer that is.

Of course that is dependent on what you know. If there are a bunch more things out there that cause cancer that we don't know -- and there are a number that we think might -- those don't get added into this, and our estimate is too small. So, I think it's important to look at this as the baseline estimate. It is not likely that it is any less than that -- but it could be bigger than that, than the 5%.

There are sort of two trends going on, that you don't quite know how to factor these together. One is that, in general, occupational exposure numbers have probably been going down in the developed countries. With regulation and control of exposure it is generally going down. But at the same time, the number of exposures -- the number of different things people have been exposed to -- is going up. So, what does this actually mean, in terms of the overall cancer burden? I don't really know. But I think 5% is a reasonable estimate, it's not likely to be an overestimate. It is more likely to be an underestimate.

Appendix 15: Excerpts from the interview with Sandra Steingreber.

But of all the other things in the 80 percent I would include as environmental, I don't think it's possible to rank within those, unless you're talking about a specific kind of cancer. For example, bladder cancer: It seems that chlorine is one of the major causes behind bladder cancer, exposure to aniline dye, exposure to chemicals that the rubber industry uses in manufacturing tires, for example, are really key, they seem to be the leading causes of bladder cancer. They may not be the leading cause of breast cancer; radiation may turn out to be a bigger cause of breast cancer than chemicals or something in the air, whereas with lung cancer it may be airborne pollutants that are more important than what's in your diet.

(...) There's growing evidence that childhood brain tumors are very closely linked to pesticide exposure now. There's new evidence showing that children who live in houses in which the parents have sprayed for insects or who use garden herbicides, or whose pets have flea collars on them, which are just pesticides which are vapor that surrounds the pet, have many times higher brain tumor rates than families that don't use household pesticides. So it may turn out that for childhood brain cancers exposure to chemicals is the key thing. (...) It does look like exposure to radiation causes cancer many years after the initial exposure: Between 13, 20 even 30 years. So that may be an important factor to explain adult cancers, but may not be important in explaining childhood cancers.

If you go back even further, the things that we're exposed to before we're even born may have a different affect on us when we're in uteri than they do when we are adults, because the chemicals are being taken up and incorporated into the structures that become our bodies, and have a very different effect. So the picture is very complicated.

Appendix 16: Excerpts from the interview with Betsy Lambert.

I think that there is an environmental link, as number two. I lived in the Southern part of the US, and I was exposed regularly when I was a young child...they were always controlling insects and they were crop dusting the crops and we would watch them sometimes as kids, and they would come to the cities and they would spray for mosquitoes on the insides of the houses and for roaches—for bugs. In the Southern part of the US you have a lot of bugs, and so there was probably a lot of PCB.

I ate a very high-fat diet, as did my father and my grandmother, as does my mother still today, however. I would have to say, coupled with the environment, possibly lifestyle choices.

(...) in the 1960s I took very, very high dosages of birth control pills. The doctors all said it was safe, and I did it. And I remember they were so strong I was nauseated. But my fear of becoming pregnant with an unwanted pregnancy was bigger than the dosage. But for three or four years I took very high dosages of estrogen. They began after to reduce the dosages. But I certainly had my share of birth control pills I took, after my second daughter. I had a couple of miscarriages, and I took a drug (which we cannot identify at this time; I don't know what it was, it wasn't DES), I think there were some factors like that that gave me a higher risk or a greater hit of estrogen. So I don't know if those are lifestyle choices (I was able to go to the doctor and get the birth control pills, etc.) or whether or not that falls under environmental or whatever. So there were some factors in my life that my mother never had, for instance. My mother never took birth control pills; assuming we were equal, that we had the same genetics—I'll never know whether, in fact, that was a factor at all. (...)

[among the causes of cancer] definitely electromagnetic [waves] ... depending on the exposure, though. I think that electromagnetic waves have been around a long time. I think that probably for the whole world, there has been a lot more exposure to radiation than maybe we thought, going all the way back to the 1950s in the US. I think there's just a lot more low-level exposure to radiation, whether it be from x-rays. I remember when we were little kids we'd go to the store, and you could see your feet; you'd put your feet in these machines and, you know, it was like a little X-Ray. We did that all the time; we thought it was great fun. I think a cumulative of all exposure to radiation from a lot of different factors, the normal x-rays, etc.—I

think there's a *cumulative effect* for all of us, and it may very well make a difference as to when you were exposed, you know, younger, older, etc. So I think there's kind of an overall ... So I'd put radiation as a factor, as an environmental hazard. PCBs, various amounts of chemicals that are really unknown that were discharged into the rivers and the waters (and still are), but in the 1960s and 1970s I think there was a great deal of chemical discharge from plants (manufacturers) into the drinking water. So I would say contaminants that would involve, you know, just the amount of food products that have been exposed, you know, animals exposed to steroids and various other types products to stimulate their growth. When you put all of that together for one person, you know, depending on the time that you were exposed, the levels of exposure, the continuation of the exposure, and the physical condition of the person, you could have a genetic defect, it could damage your genes.

Appendix 17: Excerpts from the interview with Arlyne Draper.

San Diego activist Arlyne Draper was diagnosed with breast cancer in 1976. In 1990 she had another diagnosis of cancer of the other breast. She underlined how -- 14 years later -- she was offered the same treatment options. Her theory of cancer causation is articulate and includes the role of the immune system.

I think everybody has cancer cells in their body. And the immune system takes care of them, and something triggers them, something outside the body triggers a mutation, and it doesn't take one mutation, it takes two or three mutations to form a cancer cell. So I believe it's environmental; I believe there is something in our environment that is causing a cancer epidemic. Air environment. And then pesticides. And then chemicals in the things that we touch and in the things that we clean with. (...) I think stress has a little bit to do with it. When the immune system goes down, that's what causes cancer. And stress does that.

Appendix 18: Excerpts from the interview with Bonnie Withley.

A. Department of Health and the Center For Disease Control and National Cancer Institute now say you cannot do public health in the way it had been done throughout the years, that you have to find new models because of the ethnic diversity in this country. And that you have to do health according to people's culture, and that people adhere more to their culture than anything else, so that you find people that are of one black culture that like to be with people within their culture and they adhere more to the rules and regulations and compliance and all those other things, than what someone else is doing. And so the health programs in this country have not been successful, and so now they are trying a new paradigm for doing health care within ethnic

communities. But it just has not worked, and you have millions and millions of dollars given to researchers and given to people who are not part of that community, so therefore the programs are failing.

B. I think the profit comes in when the government bestows upon researchers \$5 million dollar grant for four years, out of my money, out of tax money, and then the researchers research the issues around breast cancer, and goes back to the community in which they're researching, and still leaves with nothing or nothing that is tangible, to be used by that community or any other community, and mind you the results are never given to that community. The government and the researchers are prostituting the communities in this country with their research. And for that reason, the profit margin should be taken out. Or, I think that if they're going to allocate that amount of money to research, then they should split it. Half goes to research, half goes to community empowerment. Community empowerment will be education, prevention, transportation. Around issues that affect communities, and communities of color. The example is people think about the profit of breast cancer issues around people of color. And I know that I've advocated on behalf of poor white women. Nobody ever thinks about those women. Everybody thinks that these women fall into some category, but it isn't true. (...) everyone runs for the bucks. Even the people of color, but the people of color never get it. Because the "don't have enough experience." But they have enough experience to tell you what is happening in their community, to give it to the researchers, to write up.

Appendix 19: Women With Cancer Confront Corporate Polluters

Wednesday October 26 at noon, more than 50 women gathered downtown San Francisco in front of the Chevron Office. With them, environmental activists from Greenpeace, Calprig, and the West County Toxics Coalition.

For the first time the cancer movement in San Francisco -- openly and in unity -- confront corporate polluters identified as responsible for their illness, and the cancer establishment, for its conspiracy of silence.

Who are the targets in today's demonstration? Women with cancer, their supporters, and people of color who are fighting environmental racism decided to march in front of five sites having great political meaning for both the cancer movement and the environmental justice movement.

In the flier, the organizers invite the citizens to "Join the cancer industry tour of Downtown San Francisco," to protest in front of:

- Chevron USA for producing some of the most toxic dioxins -- known to be a cause of cancer

- Bechtel, responsible for building half of the world nuclear power plants
- Time Magazine, which recently became a national target for the Zero Toxic Alliance: each issue published produces 3,450 pounds of organochlorines that are dumped into American waterways -- even though chlorine-free paper is available
- The American Cancer Society, for its silence about the environmental causes of cancer. This organization is also responsible of encouraging people to think that prevention can be reduced to personal (genetic) susceptibility and individual lifestyle (smoking, diet)
- The Environmental Protection Agency to encourage real prevention and support the Delaney Clause of the Food, Drug, and Cosmetic Act; the Clean Water and Safe Drinking Water Acts and other environmental legislation.

Appendix 20: Excerpts from the interview with Amanda Hawes and Flora Chu.

A.H.: The doctors are uninformed and the people who are at risk are uninformed and so we try not to be intimidated by that -- and try to do our own research and try to advance the level of knowledge and understanding. That's difficult because you have to educate judges, members of the scientific community, physicians, our opponents who pretend to be stupid because their job is to not turn over information that could be used to prove a case ... That's an obstacle but when you have legal tools to go to battle that's what you're using for, try to open things up and stop some of the *conspiracy of silence, particularly for workers*: what can happen if somebody works in a dangerous environment for some time, I think most workers do not choose to take a risky situation and are never given a choice. So we are trying to change some of that balance. (...)

F.C.: What we find in this country is that a lot of the work that is high hazard and exposes people to potential carcinogens is done as low pay jobs, and dirty. And a lot of time they are done by immigrants who have very little language skills and very little knowledge of how to fight back on this. One of the biggest obstacles is finding out information and *telling the company that they should at least give the workers* a sufficient health and safety education -- so that they can handle a chemical safely -- in a language that they can understand. And this doesn't happen in the workplace at all even though on the books, especially in California, they are supposed to do that.

A.A.: One of the obstacles is that *the employers use every advantage they have*: they take advantage of the ignorance and the economic needs of the workers to keep people working in dangerous jobs and without making information available to

them -- and use their economic desperation as excuse to not change the work environment: "if you don't like it, you can leave". So we also try to fight those dynamics -- some of our work take us into other countries to advocate in other places where the same companies do the same thing and even worse to working people. And we try to use our ability as speakers to share the information so it becomes well known that sometimes the best weapon against their tactics is to make the information widely known.

F.C.: Another big obstacle is people's philosophy about what they think it is a carcinogen. In this country if you are developing a drug, the government requires that there are not carcinogens before they could sell them. But (for most chemicals) companies are not required to do testing on the chemicals they sell. *The general philosophy of the governmental agencies and chemical companies is that until it is proved to a very high degree of scientific probability that these things can kill people -- until you can count the number of workers that are dying to the extent of an epidemic -- they are not going to acknowledge that this kind of environmental chemical can cause problems.*

So they are trying to patch up the system rather than look at it in terms of a preventative approach [i.e.]

1. try to test chemicals before being used widely and
2. assume that chemicals are dangerous and try to encourage people to have the lowest possible exposure. Rather they say "we are going to expose you as much as we can unless the state says that it is not safe." We run across that over and over again. Which means the unless the workers have the job approving that the chemical is dangerous and can cause cancer -- and cancer doesn't happens over night, it takes 20-30 years for the epidemiological data to accumulate -- if at all because a lot of times nobody takes those epidemiological data. Sometimes the chemical can be used 30-40-50 years causing a lot of death before people would even notice that the cause might be a carcinogen.

A.A.: We have a law in California that says that if you expose people to a carcinogen you must tell them ... and the companies fight that because they would be much more comfortable if they don't have to do anything. And the mere fact that they have to give information to people is very threatening to them. And the purpose of the law is to have them to stop doing what they do, to take the chemical away.

F.C.: I would say: to prove a case in the court the existing rules of the game make it possible. It is difficult, it is expensive, it is hard and you run into a fight but you can do that. *The rules of the game do not create incentives for someone to stop using the chemicals today -- they make us wait ten years from now when we have a problem ... the workers' compensation system which is*

supposed to pay when somebody is hurt on the job is such a poor remedy ...

If you had done the correct thing in the first place, you'd save money because even when they have to pay, they don't pay very much .. so that system is ... *there is no incentive to prevent illness* -- it means it needs to be changed. We talk about that all the time. But it is not an issue that most people in the legislature understand: they hear about how the workers take advantage of the system and try to cheat the system -- and that is outrageous.

A.A.: It is the rules of the game and how the game is played. For instance most of the federal OSHA standard are just the reverted of 1968 standards ... which means you can die of carbon monoxide poisoning and still be ok for OSHA standard. Theoretically OSHA has the power to set correct standards for carcinogens, but because of the way it is set up, industry can put up a lot of barriers to essentially delay a standard that should be set. An example was that in 1977 everybody knew that benzene can cause cancer. It was so well known ... and OSHA set an emergency standard around that. Industry forced [the issue] into the court system. They took it all the way to the Supreme Court, that OSHA didn't do certain paper work. It ended up that it took OSHA 10 years from the time that they set emergency standard to fill all the paper work needed to satisfy the standards. *And in 1987 they put in a new OSHA benzene standard that they had proposed in 1977.*

Appendix 21: Excerpt from the interview with Nicholas Ashford.

Nicholas Ashford at MIT thinks that profit is a main obstacle in doing primary prevention of all environmental causes of cancer. He believes in strict environmental regulations, banning carcinogens, and in reversing the burden of the proof when a substance is suspected to be a carcinogen. He advocates an overall preventive approach.

Ashford thinks that changing the industries' mindset is difficult: he argues that we should have a different way to produce, which does not imply harm to the environment and to those who inhabit it. He concludes by stating that a different way to produce goods is technologically possible.

[Profit] ... is a great obstacle. Once a company has a product in the market they will do everything they can to prevent it's demise. *People rationalize all kinds of uncertainty in favor of continued production once the investment is made. (...)*

I would like to see very strict regulation and bans. And I would like to see *the burden of persuasion* -- or what sometimes is more popularly called the burden of proof -- shifted to industry. Chemicals which have structures, or which have positive Bruce-Ames-tests or are possible or probable carcinogens, you know, the 2A and 2B on the IARC list, I would argue that they create a legal presumption of significant human carcinogenic risk, and I

would place the burden on the industry to produce, to prove that the substance is not carcinogenic rather than the other way around.

(...) It may not be possible for existing industries to change because they have a very uhh ... rigid mindset. But it is possible technologically to produce products which are not harmful to the environment. But you may have to change the industries that are producing those products.

Appendix 22: "Profit As Stimulus for Prevention"

Steve Pike is a toxicologist and the director of a private company "EnviroMD" -- which makes money out of prevention of occupational and environmental illnesses. Since cancer prevention is a consistent part of his business, Pike's perspective is one of broadening controls, measurements and to expanding the field of scientific investigation on the connection between products and illnesses.

The perspective of his business is opposite to the one of those business who make their money on such products. It is also a different perspective from those businesses involved in the cure of environmental and occupational illnesses. His agency represents a quite new type of entity in the panorama of my investigation.

The existence of his company *per se* states the possibility of making money out of prevention -- a possibility denied by some of those interviewed.

Looking at where his business fits in the social division of labor, objectively this agency consumes part of the surplus extracted in the place of production in the same way an insurance company would. What other companies are paying for -- when they hire "EnvironMD" is to make sure that the final profit will not be cut by lawsuits and compensations because too many workers have died.

Pike's agency produces a body of guarantees for other companies that they are acting within the limits of the occupational and environmental laws when they are exploiting the labor force. A sort of "compression test": "if the company passes the test, they are good for the market."

EnviroMD controls and tests all the variables in the productive process: from the air to the machines, everything gets analyzed. At the end, they give the company a guarantee that there will not be lawsuits. This process can lead to unexpected development. On one side the very existence of such agencies reflects the level of social struggle: the limits to legality in the exploitation of the labor force are historically negotiated between classes.

Even though laws are in large part produced under the control of the dominant class, sometimes they express a right to protection that labor has been able to impose. So, on one side agencies like EnvironMD play a role of simple execution and respect of the laws -- on the other side the agency itself, like the whole body of laws, is subject to pressures.

Moreover, since these kinds of agencies are not public, they live on contracts. Pike told me his company is unique in its field. But in a while there will be competition and industries will be able to choose between agencies that make "rigid" or in "flexible" tests.

Eventually also workers and community will have some access to this new arena -- and certainly such agencies will represent a further terrain of struggle and pressure.

I believe that for a new material ... the manufacture of a new product ... I think the proof that the products are safe has to be on the manufacturer. When I say that ... it's difficult if not impossible to ever prove that a substance will always be safe -- but I think sufficient emphasis and care should be made on adequate testing of new materials by manufacturer, so that we have a reasonable degree of insurance through that testing which may include animals and non animal testing, may include genetic testing through bacteria and other tests. And in some cases maybe through historical reviews of similar compounds that have been used either for medicinal or occupational uses. That responsibility I think has to fall on the manufacturer, on the employers. *The employee, the worker has too long in the history of the world been the experimental species* ... When you look at the tragic history of the asbestos workers, chromo workers, cook oven workers, you see all af these deaths in workers and then the recognition that something was bad. But those lives should not have been lost. Of course now we have a regulatory apparatus in this country that is emphasizing and requiring these things to be done ... we have a battle as you know between regulatory forces and those that are regulated regarding how stringent the testing should be, and how much testing there should be ... and that battle gets played out in the political arena with regard to rule making, standard setting, and so forth. The other force that is driving manufacturer to exert caution in this country is the tort system, our legal system for tort whereby those individuals who have injuries sometimes bring allegations against the manufacturer, for liability as result of the damage occurred from the use of their products. That exert a very powerful force in this country for caution on the part of manufacturers. (...) The bottom line is that the creator, the one who introduces something new into the environment or sell to the consumers, to the masses, has responsibility. (...) No matter what anyone is producing, engineering control should be employed to *minimize the exposure to the minimum possible level* -- even when we are dealing with something that is not carcinogenic because of other hazards associated with its use. We should not be casual about these substance and we know enough in a general sense to employ engineering practices that minimize the release of gases, of vapors, dusts, so that those exposures are minimized. Protective measures in equipment and clothings and other devices that the workers themselves can use; releases into the atmosphere or into the water, or into ground should be done as careful and minimized as possible ... because we have such a tragic history of things that have been deposited in landfills or dumped in holding ponds ... resulting in ground water contamination, cases of injury in the population that was not

working -- basically the community (...) Certainly once we know that the animal studies or other evidence are pointing in the direction of things that are very very hazardous substances, the manufacturer has a duty to immediately minimize those exposures.

Interviewee N. 33 at ACS believes that profit motive could be directed toward providing opportunities for alternative and healthy businesses, non-polluting companies, and to support "clean" energy and the production of preventive technology.

You could take the opposite point of view and say profit making might also provide an opportunity. You might say it is true that in the case of say tobacco that profits come before lives. However, you can also say that profit making could conceivably work for you because there are nicotine patches, and there is environmental pollution control equipment. There could be a whole economy based on alternatives and production that would have *less pollution ... It doesn't have anything to do with cancer ...* But in energy, I think our dependence on oil and coal is partly because of the industries that control that. Alternative energy sources, solar and so on could themselves be profitable if we just envisioned a different scenario.

A National Cancer Institute top epidemiologist thinks that profit is an obstacle in cancer primary prevention, as in the case of cigarettes, but it can also be a promoter of prevention too. For example, on occupational exposure his position is that larger industries, whose profits are greater, do a better job in protecting their workers and respecting environmental regulations -- while small companies need "to maximize their profits and sometimes they don't pay enough attention to workers health."

If there are so many obstacles in primary prevention, the interviewee argued, it is not just because of profit or corruption, it is mainly because of what he calls "the conservative nature of science" and the research funding criteria. His reflections have epistemological relevance and the conclusion he draws constitute an important statement: he argues that scientists needs to be pressured by external forces and to be re-oriented in terms of social utility.

I realize there are people that are biased, and I think not honest in what they do in science, just as in every other field. That is no different. But I think [that] mainly the problem is the *conservative nature of science*. The scientific method is a conservative approach. You go very slowly and you document everything before you decide what is going on. The nature of the process is conservative and without special pressures it is even more conservative.

The easiest project to get funded is something that advances science a little bit, so you build it very strong. There is a tremendous file of facts that you know a lot about, you are going

to look at one little wrinkle. That is the easiest project to get funded because people look at it and say, yeah, this is probably right and this will probably work over here because it is such a gamble. The hardest thing to get funded is to jump way over here. And most of them are probable wrong. The risky study is the one that leads to the real breakthroughs.

What the pressure groups have done is *put pressure to try some of these risky things* and scientists as a group are conservative. I realize that within the large spectrum of scientists you have a wide range there, but I believe -- as a group -- we are cautious. *So we need pressure.* [Interview N. 56]

Paul Blanc -- whose epidemiological work is mostly on environmental causes of cancer and communities at risk -- sees *the lack of profit* possibilities in doing cancer primary prevention as an obstacle too.

P.B.: Because of the way our health care system is, there's no incentive for prevention. Whereas, the health care system, you know, is geared towards hospitals and high-tech interventions and chemotherapy and, surgical interventions and technology. You know, there's very little technology associated with prevention. And very little reimbursement for it, so the health care system doesn't have a huge interest in primary prevention.

L.C.: *What I am hearing is that primary prevention is not as much profitable as early detection and therapy.*

P.B.: That's correct. Yeah.

Paul Blanc also argues that profit *per se* would not be the obstacle in primary prevention. This is also the position expressed by Samuel Epstein. Among the preventive solutions Epstein also mentions "marketplace pressures," or the use of capitalistic profit drive to "correct the system."

Which is using the tools of capitalism, namely you create a system of tax incentives. In other words you say to an industry 'if you phase out this particular method of production we will create tax incentives for you, to substitute this product which may cost you more.'

And you have tax penalties for industries which refuse to do this. (...) We are not going to have a revolution, the whole world is going to go capitalist. All you have to do is to use the tools of capitalism: you create economical incentives to capitalism to encourage them in the direction to use safer products.

And on the other hand you also make it clear what the costs are to society: leave alone morality, leave alone ethics. Make it clear that from an economic standpoint it is *not good business to pollute, it is not good business to kill fish, it is not good business if half of your workers die at 45* and you have to file a lot of workers' compensation claims, and you have to pay several million dollars in a toxic tort.

Epstein believes that profit produces cancer, but also that profit can become a stimulus in preventing cancer. He is optimistic about the capacity of self-correction of the system and quite confident that with an appropriate set of laws based on the concept of "environmental crime" most of the abuses to nature and to human health would become a memory of the past.

I believe the system is able to be fixed, change (...). You can create incentives to industry to create safe products, to inform workers, you can create penalties to industry that don't, you can create major penalties for when an industry for example damages a lake, and suppresses informations. You can *take the chairman of the Board and all the Board Directors and put them in jail for twenty years ...* Which is what I have been talking about since 1978. I told Congress: criminalize the whole procedure. We have a saying: we have two systems of justice in America "jail for crime in the streets and bail for crime in the suites." If you have an industry where you can show that the top management was aware of this sort of thing and ignored or suppressed information, *you take executives, you bring them up on murder charges, throw them in jail for 25 years ...* Appeal to self-interest: reward industries that behave adequately and penalize the others financially.

Appendix 23: Excerpt from Interview N. 44

A woman cancer epidemiologist at the School of Public Health, University of Illinois, Chicago, pointed out that industries are concerned about how to maximize profit -- but she is preoccupied that, if forced to implement control measures industries would lay off people because they need to be competitive.

You could say that, insofar as it relates to industrial pollution and occupational exposure -- sure: because they'll want to maximize profits; and sometimes that comes at the expenses of the rest of us. But it's not just profit, though, because sometimes issues are raised about laying people off; and if they have to put in certain control measures, it's going to cost them more money and they're not going to be competitive. Whether that's true or not is a different question, but that sometimes is an argument they use too, that it would be too expensive to put in the controls that they would need to reduce certain exposures. I'm not saying that I agree with that, but that is an argument that's used, that people would be thrown out of work, et cetera.

Appendix 24: A. Excerpts from the interview with social scientist and cancer survivor Joel Maister

Maister in Tucson, Arizona, talked about the *maquiladoras* and the awareness that industries have about the hazards they produce to human

health. He is convinced that business would never be responsible if they are not forced to be.

To me the connection is very clear because there have been numerous documented cases in US of situations in which *companies were aware of the toxic nature of their products or their byproducts* ... They kept that information out of the public arena for years, until when was accidentally discovered by somebody else. It seems to me very clear that *one cannot expect producers of pollutants to exercise appropriate self control, an appropriate level of self-responsibility*. It simply doesn't happen. And the maquiladora industry on the border is a perfect example of that: when you have American companies that have gotten out of the border for several reasons, among which is their desire to escape environmental regulations. The major pollutants that are coming across the border of Arizona are created by American corporations that are sitting right across the border. So to me it is almost a non-issue -- in the sense that I don't think it is open to much debate any more as to the lack of corporate responsibility for environmental pollution, for carcinogens

Maister also offered some reflections on people's denial about environmental carcinogens. I am presenting his statement in this section because he connects such behavior to the ideology of private enterprise and the positive characterization of profit in this country. He ends his statement by criticizing the myth of progress -- so strong among scientists and people in general.

Even though Maister is also an activist, he is not hopeful about the possibility of social change and embraces a position of "active pessimism" I found also among other cancer activists I interviewed.

Well, it gets no surprise that in a society that is so ideologically committed to this myth of private enterprise and profit -- probably most people are going to be blind about the negative role that corporate profit orientation plays in a whole bunch of things, including environmental pollution in the causation of cancer.

So I am not sure that biological sciences are more prone than lot of other people -- you mentioned epidemiologists ... sort of like *willfully blind about what is going on around them*: it seem to me that it is part of what ideologies are for ... it is to do precisely that, to create blind spots like that ... I don't find that surprising, it is just distressing (...).

Well I am growing more pessimistic and cynical by the day ... at this point I think we are doing ourselves in -- in one way or another, *polluting ourselves to death* -- so I am not even sure that transformation is possible at this point. But it seem to me that there are numerous myths that we still have to deal with, like the *myth of progress* -- we really have to get it out of our system, which I don't know if it is possible to do ... We need to get to the

point where people can no longer say 'Well that's the price of progress ... 50,000 people a year will die and whatever' ... I still keep working as that would happen but I am not particularly hopeful.

Appendix 24: B. Excerpts from the interview with Martha Monroy

Martha Monroy's background is in sociology and most of her interest is in community development. She started to do research on cancer causes and prevention at the Mexico border -- focussing on cervical and breast cancer. In Nogales she works with six health *promotoras* on cervical cancer, breast cancer, colorectal cancer, diabetes and heart disease. She is also campaigning for people's access to and knowledge about health care, community development about health and cancer is one of the main areas.

Right now I am running a research and a health promotion program in two rural communities in central Arizona. Primarily what we are doing there is providing women over 40 with information on breast and cervical cancer and helping them get access for screening for breast and cervical cancers. We are also doing a fairly large community based survey: we are going to interview 600 people in both communities on colorectal cancer, prostate cancer, diabetes, cardiovascular disease and access to health care. My function is to coordinate the work. I am also the co-chair of a bi-national coalition on maternal and child help in Nogales, Mexico and Nogales, Arizona. The program we just completed in Nogales was a bi-national cervical cancer campaign to get women to get pap-smears on both sides of the States' [borders].

Monroy thinks that pesticides play a big role in terms of profit at least in the short run. But in the long run, an unhealthy workforce would become a burden and hurt business. She believes that eventually worker compensation will discourage companies from polluting and creating diseases.

What is missing in her statement is the consideration that profit is privately appropriated, while the whole society pays the costs for those people who get sick in the process. And worker compensation -- up to the present -- didn't seem to correct the attitude of corporate polluters.

Pesticides (...) I think it is not much profit but perceived profit. I think what happens is that these businessmen and engineers have an education that they don't see the bigger picture ... *For example: if you have a healthier workforce, you are going to be more profitable -- if you don't pollute the communities they can stay there longer* (...) Sometime it is not profit, they just don't think -- they never had an appropriate training and now it is costing them more money, when they get caught -- not all of them, but most of them -- and they have to pay to get it cleaned out. This is what is going on with the TCE at the United Instruments in Nogales. Maybe it is lack of knowledge or stupidity

or disregard ... there were chemical containers in the ground that polluted big part of the aquifer -- the government came down and they had to clean it up -- a process of spending millions of dollars ... Somebody is going to make a profit cleaning up ...

Yes, there is big money in cleaning up -- I can introduce you to people who are making money detecting pollutants and cleaning them up. When I started to work in Nogales and people wanted to know what pollutants were in the area and if they were carcinogenic or not ... I went through the list of hazards, things that you have to do if you are going to use these chemicals, safety factors, exposures, public disclosures ... There is a whole list of things that the companies have to do. Now, the good companies do it, there are some companies that don't do it (...) It happens here too. Now there are these huge environmental consulting firms going in to make big money. They have environmental lawyers who represent the companies.

Appendix 25: Excerpts from the interview with Peter Orris (part A).

There's obviously a profit to be made in cancer and the fact that it's an epidemic ... If there weren't a profit to be made in that, if there was a profit to be made in preventing the cancer, then we would prevent the cancer — the country is directed toward profit. Now, if you're talking about *societal costs as a whole*, then obviously there are societal profits to be made in not having cancer, but that's not how profit and loss is calculated in this country and in this economy. *It is calculated based on the individual power groups and the large corporations and the power groups that make a profit off of them (...)*

And certain people's cancers are less significant to this society than other people's cancers. That's the name of the game. And with the triumph of short-term counter-revolutions throughout the world—that's the New World Order. That's certainly not something that will be permanent. It would be nice to say that the first experiment with international socialism made a significant break from that approach, and that it really did consider cancers and the environment and the social costs, but that's not true. It is clear that *the countries that considered themselves socialist paid little or less attention to the environment even than the capitalist countries, and to carcinogens even than the capitalist countries.*

To say they couldn't afford it begs the issue. They couldn't afford not to do it if they had a long term approach. And their structure did not allow for superstructural contradictions within the expression of superstructural non-antagonistic contradictions within the society, to use the jargon.

And it's the same problem Cuba has today with their structure. In Cuba today, if you're a housewife in Havana, or an engineer in Cienfuegos, you cannot get together with a picket sign and say, 'Don't build a nuclear plant here.' You cannot organize to do

that, around that superstructural issue. And because of the pyramidal structure of their politics and economics, your criticism in your local areas is filtered out as it goes up the central line, very specifically. Now that's functional for the immediate period of being under attack and long-term unstable and dysfunctional. When you've settled the people's basic problems, food etc., people want to be involved on the superstructural level—that's my two cents on the world.

(...) Our current *priorities are to individual behaviors and are directed toward individuals correcting those behaviors individually*, and that's a misapplication. It's not that that doesn't need some emphasis. But that's not an effective way of changing behaviors of large populations. Large populations generally, I find, will base their behavior on their perceived best interest, given the environment, and it's important to change the perception on a social level of what is in people's best interest. Now how do you do that? Well, there are a variety of ways to do that. One way is laws that force people to behave in certain ways in public, especially when their behaviors impact on others or when they are exposing people to carcinogens that the other people don't have control over. *The old argument that you can't change people's minds by legislating behavior is just not true.* You do need more components to it than just the law; you need the law, you need a dominant ideology that supports the law, and then you must force people to do it despite the fact that they said no beforehand.

A good example, which utilized what the sociologists call cognitive dissonance and which was used in the civil rights movement here a great deal—integration was a good example in this country. You had a situation in which *whites said they would never go to school with blacks, that they'd never eat at the same lunch counters with blacks, that they'd die first, that they'd fight to the last on it.*

You then had a situation in which the economic powers that be decided it was in the economic best interest that integration occur. You then had laws passed which mandated integration. You then had people who were forced into integrating despite the fact that they didn't want to do it. You then go back in there and ask them about their attitudes some 5 or 10 years later and they have to have an explanation of why they did it and they didn't die before they did it. And their explanation is that it wasn't as bad as they said it was. Well, it's the same thing with cigarette smoking and a variety of other things, but you have to produce it in that way. Therefore, the current emphasis on individual behavior under individual control is misplaced.

We need an emphasis on primary prevention, which is *removing carcinogens that people are exposed to through no fault of their own and through no volition of their own.* The problem with moving in that way is that all of those movements affect some major power group's profits, and therefore it is easier to tell the individual, 'Stop smoking,' rather than telling the tobacco

companies 'We're not going to subsidize your production of tobacco anymore.'

(...) First, I would take away the economic support that the Federal government gives to tobacco growers. Second of all I'd put in a mechanism by which small and medium size growers could have some economic support to move to other crops and to change their production. Third of all, I'd make it illegal to smoke in public where other people are exposed. Fourth, I would make it illegal to smoke in the workplace. That's a controversial issue. The labor unions in this country, a good deal of them don't want it to be illegal in the workplace. I think that's not a defensible position, and I don't think it's consistent with their other positions. There are things that the employer demands at the workplace that nobody objects to, and it's the old question about, when you go into a plant and people aren't wearing their hearing protections to fight the noise, the boss tells you, 'I just can't get them to do it'—it's not true. It's a failure of management. When the boss says, 'I can't make them do it,' the response is, 'If a guy walks in in the morning without his pants on, is he gonna work?,' 'No, he's going home to put his pants on.' But if he walks in without his earpiece.... And the same thing with cigarette smoking. The boss can say no cigarette smoking in the workplace. That's true here at the hospital; you have to smoke outside. And that's fine, and the individuals should be disciplined for doing that. That's not the major issue.

The major issue is the amount of junk that we're putting into the environment, and that's where Greenpeace I think really has a very good and important approach to the issue, and that is reducing the use of products that produce the carcinogens. And trying to find, not just how do we dispose of them or how do we control them, which is what we're emphasizing today, but how do we reduce their use and find other things that are less toxic; the 'input' part of the equation. That's hard to do.

(...) First of all, the Vollstead Act, the prohibition against alcohol, was never controlled by the powers that be, by the economic leadership of the country—everybody was drinking. So law on its own is not the only thing; there has to be a dominant ideology. Therefore, you don't want to ban something outright, you want to leave the individual, if they want to do, to do it.

But, one, you have to make it difficult for them to do it, and, two, you have to make it so they don't affect anybody else. And it's got to be along with a very strong educational campaign about what, in fact, one's self-interest is. Then are you going to find individuals who do self-destructive behavior? Absolutely. And does it matter? No, not too much; you have to let them do that. I would not put them in jail for doing that. But on the other hand, you limit the amount; you're dealing with large numbers, and if you can cut down the amount. And then the question of retraining them, we have a resolution for the American Public Health Association this year about chlorinated organic chemicals,

and part of the resolution is a retraining of workers involved. Retraining the workers in the industry.

We're talking about substituting less toxic alternatives, and a very important part of that is to emphasize the need to retrain workers and to approach point of view. So the issue of workers jobs is very important, but it is not insurmountable. And when raised by unions as an insurmountable objection, it's an error, I think.

(...) There are significant proportions of capital and capitalists at every level who have a better and a broader perspective on that from the point of view of future generations. I don't think they're dominant, but ... (...)

For instance, the differential between the length of perspective of US capital and Japanese capital around the pure issues of building the economy, it is clear that *the Japanese capital had a much longer range perspective and was much more effective in doing it.*

And that's based in their perceived long-range self-interest and their culture with respect to their children, etc., which is not true here. It is not at all clear to me that that kind of thing can't be applied in the environmental area. It is not at all clear to me that you can't make tremendous advances in the environmental area without socialism, under capitalism.

And it's pretty clear to me that being socialist and constructing a socialist country does not necessarily mean that you are going to have a long enough range perspective to understand the limitations of nature. After all, *the whole Marxian analysis is built up on the contradiction between nature and man.* So that, we're in a new era, and how you talk about the transition to a communist economy in a *situation in which you have a limitation of natural resources* is a whole interesting other concept. On the other hand, it may not be. (...) I mean, it's an interesting era, right? Everything's being redefined. There's not clear alternative hegemony; it has to be redefined. They tell me it happens in every era, the victory of counter-revolution. Capitalism, in the ultimate, can't overcome [its tendency toward death], I think that's true. On the other hand, I don't think we've conceptualized the socialist organization yet that is guaranteed to overcome it either. Only a non-exploitative society provides the possibilities of doing that, but I don't know that we've figured out how to do it yet. (...) *I'm just worried about the day-to-day. I cannot conceptualize the society or the organization of a society that understands those priorities* as yet, because I haven't seen it and I haven't seen the kernel of it within other societies. I have seen the kernel of alternative hegemony in revolutionary movements, but only for brief periods when the people are mobilized against the common enemy. I haven't seen it yet, but I'm interested

(...) Everybody defines their career; what they want to do. I'm not dependant on Federal grants. We have clinical activities. I also spend part of my time as a company doctor, and I used to work for

the Federal government. There are things I will not be asked to do in this society because I'm who I am, but I've self-chosen to do that. So, *without a significant change in the political environment of the country, I'm not eligible for any high-level Federal health jobs.* Now, given my experience, training, background, if I had different politics I would be. But that's my choice.

Appendix 26: Excerpts from the interview with Peter Orris (part B).

It's important not to make the mistake, which I think is an idealist mistake that most of our middle class professionals make, and that is they say, 'Well I have to take this job because I have to survive in this society, but because I'm doing it, I'll do it right, and I'll do it for the workers. But I'm a company doc, I'm a company doc. I'm not doing anything dishonest, I'm not doing anything that would deliberately screw anybody.' But on other hand I'm a company physician, and I talk to management, and I help management with how to figure out how to proceed in their best interest. And when a worker comes to me in that setting and says, 'What should I do about this and that,' I say, 'What, are you crazy? Where did your mother raise you? Go talk to your doctor. Don't talk to me as the company doctor.'

On the other hand, if they come to me in Cook County and I don't have that relationship and I don't have that conflict, then I'm their's. It's structural; it's your relationship to the means of production, it's not your individua ... It's a split, for sure. I spend about 10-12 hours a week as the medical director of corporate health services for Northwest Community Hospital, and as such I'm a consultant to a variety of industry. And parenthetically, they pay me more for that 10-12 hours a week than I get paid for my 90 percent time here, my 50-60 hours a week here, and I get paid next to nothing at the University of Illinois. But that's how capitalism likes to do it. Either I get paid an incredibly increased amount for my time, or I get next to nothing. The rate I'm making at Northwest Community is about a third of what I would be making in the private sector working for a corporation. But my career and what I do is defined by what I believe is interesting and what's in the best interest of, I think, working people, in general. I have never been able to have a single employer who agrees with my vision of that, per se. So it's not unusual to have different bosses paying me for different things.

Appendix 27: Excerpts of the interview with Linda Rae Murray.

Linda Rae Murray shares some of Orris' concerns around the failure of environmental health policies and long terms perspectives in state capitalist countries.

I don't think it is just profit making. I think profit making is clearly ... in a world where capitalism is the dominant socioeconomic formation ... is so you can't ignore that. Clearly under socialism, in the Soviet Union and Eastern Europe, we have horrible environmental and occupational exposures. It is not just simply profit in the traditional Marxist sense.

When you have planning and decision making where human health system is bad and the profit or production of commodities are the only thing you are concerned about ... *When you place that above human health then you are going to have trouble.* We can see the kinds of horrible things we are doing to the planet and to our health as well as the health of others.

We need to change that equation. It is clearly possible to do this in a way that doesn't compromise you or at least doesn't do it as frequently as we do. It may mean we go slower. It may mean we don't reach that production goal in 5 years, it might take 20 years. It might mean your profit margin is 10%, it might be 3%. All of those kinds of questions come into play.

It means a conscious decision in terms of our value system and our priorities. That depends on who has control. I think the average person, certainly in the US, given some rather narrow parameters, if you have basic things that you need to live, I don't think most people really give a shit whether General Motors profit margin is 10% or 8% or 5%. Clearly what happens to asthmatics and bronchitics in this country it definitely makes a difference to them. (...)

Here is an example that I find very distressing. I am not 100% sure that this is the case right this second in Cuba, but it certainly was the case a year or two ago, a minefield of asbestos. The Cubans had launched a campaign where they were using asbestos cement piping throughout their construction. We know what happens when you use asbestos in production.

We were trying to ban asbestos, so that you go down and say, *"comrade, why are you using asbestos?"* ... What they will tell you is "well, we haven't had any problems with asbestos." ... You say "there is a latency period of 20 or 30 years" ... They are still using asbestos pipe.

I guess what I am saying is that I think you have to be really careful and humble about simply saying profit. I think there is another demand even in socialist economy that maybe is not properly called profit. *Perhaps it is called production goals*, call it whatever the hell you want.

Operation you have it throughout eastern Europe and the Soviet Union *anytime that human health will be ignored will be the production goal.* I don't think people is an exception to that.

What it means is that people who have power to make policy decisions in society, what role does human health play? Not in a direct way. I don't think it is because people are necessarily evil. (...) We really have to have a more complicated notion of disease causation. Most of us really have a simplistic view (...)

The biggest problem I see in the future, should we ignore sort of national issues like the US does with Canada and what South Africa does, and you look globally. Here we are in the world and it is easy to say, well, don't cut down the rainforests or don't industrialize. Most of the world is poverty stricken. The fastest way for them to not be poverty stricken is to industrialize. *If they industrialize the way the west has industrialized, the impact on the health of their people and the world environment is going to be horrendous. If they don't we are going to have people starve and die of diseases.* What do you do ... I don't think the problem can be realistically solved without a redistribution of wealth. I don't think that is going to happen.

I would not, as an American, tell some Latin American to not go industrial. I may argue about a better way to industrialize, but the bottom line is they are trying to prevent the immediate impact on the health of their population. If you are going to lose half your kids or 35 % of their kids before they reach the age of 5 because you don't have clean water, who cares. That is a problem to deal with later. I am not one of the rich environmentalists. I don't think environmental issues are fundamental. We ought to be able to do both. The only way we are going to be able to do both is if there really is a redistribution of wealth. If we don't do that then the world will have to suffer some more until something else happens.

Appendix 28: Excerpts of the interview with Sandra Steingreber.

I asked Sandra Steingreber if prevention and health promotion in general could become profitable. I asked her if she thinks an historical change in the creation and meaning of profit would be possible. Such a change is envisioned by scientists like Samuel Epstein who thinks we can switch from a "evil" profits derived by the creation and cure of life threatening illnesses like cancer, to "good" profits by the creation of good environment and health promotion.

The big answer is that as long as there's a market economy with very little government regulation you can only do so much. But, even if we leave the basic political-economic structure the same there are things that could be done to make it less profitable. For instance, if industry was forced to *internalize the cost of clean-up, rather than paying for that with tax dollars*, then I think it would be in their best interest to minimize the health effects, not because the community of people who live there is going to be any healthier - they don't really care; but if they know they have to pay for damages ...

If we criminalized causing people to get cancer; if I could only sue whoever gave me bladder cancer, and say: That's like assault and battery. You took five years from my life, you're going to go to jail for that. *You killed this many people in the community. We're going to charge you with murder*, then I think you can

leave the legal system to make some changes without changing any of the whole economic basis and if you *start putting the heads of the tobacco industry in prison for a while*, that would change things really quickly without making any other changes, I would bet.

(...) If we had a single payer system in which the government paid for medical services through taxes, then *the U.S. government would have an incentive to keep people healthier*. It would lower the amount of cost. If they looked at it really rationally, and looked at one out of every three people in this country get cancer (and that's up from one in every four), that means that tens of thousands of additional people are getting cancer because of environmental exposure. It would be in the government's best interest to lower costs by forcing clean-up. (...) If you give someone cancer that should be the same as if you shoot someone with a gun; after all, you actually die a more miserable death with cancer than you do if you're shot anyway. Criminalize that through the legal system, and if you had a single-payer medical system I think you would have an engine to force some of these changes through.

Appendix 29: Excerpts from the interview with Richard Clapp.

Basically, there are political reasons ... and by political I mean there are interests ... for example, there is an industry that is based on chlorinated products. There are many companies that make chlorinated organic chemicals like pesticides that depend upon acceptance of their product to have a market to make profits. People who point out that chlorinated hydrocarbons are carcinogenic threaten that industry or threaten the market and the ability to make profits (...).

It is very polarized along political lines. People who think that dangerous chemicals being produced by industry are causing harm to people are directly opposed by scientists who work for the industry who say there is no proof or there is no clear cut evidence one way or the other about whether such and such chemical causes cancer.

Often scientists shy away from political debates like that and think that their careers will not advance if they wind up in a lot of controversy all the time, or that they won't get grants to do their research. While I was working for the state, getting grants to do research was not an issue because I was a state employee and was employed anyway. In fact I took it as my responsibility to explore the cancer registry data in as full a way as possible. That included where people worked or where communities had contamination in their drinking water and what the result of their cancer rates were. I haven't shied away from political debates and arguments in the past before I had this job. I certainly was active in the campaign against the war in Vietnam and before that, the campaign for Civil Rights in this country.

Both of which are highly politicized mass mobilizations of people and a lot of polarization happened during those campaigns as well. I guess *I felt in some ways this was a continuation of that same work.*

(...) The tobacco industry lobbies state legislatures, federal government, to prevent the taxing or even labeling of tobacco products because they are carcinogenic. I am sure the basic motivation for that lobbying is that they expect that adverse publicity or higher taxes is going to cut into their profits.

(...) I think I mentioned that *some scientists who are looking to do etiologic research will try not to get into areas where there is going to be controversy.*

I had a friend actually who told me that he had appeared on a panel, or had been a member of a panel for the National Academy of Sciences that was looking into studies of Vietnam veterans and Agent Orange exposure. The question was whether veterans exposure could be adequately characterized by their military records.

They decided that they would basically come down on the side that it was not possible to do perfect characterization of exposure using existing records because there were too many gaps in the records. Therefore, their recommendation was that *a study that was based on military records should not go forward.* I think that was a purist position meaning that if you can't get perfect records you should not do a study. In the real world, one almost never gets perfect records for estimating exposure.

He did say something to me, you know he has a career to think about and that he was reluctant to go out on any limbs because he was concerned about his future ability to do research which was not particularly on Agent Orange -- but *if he would have made a controversial recommendation it might have affected his ability or his reputation,* that ability to get grants in other areas. I think that that is a small example from my own personal knowledge of where a government researcher has been shy about bending recommendations of research based on worries about his own career.

Appendix 30: Excerpts of the interview with Sandra Steingreber.

I think it's primarily a problem. It wouldn't have to be a primary problem, but it seems like it always becomes one. The way I see it operating now, in a way that I'm really interested in, is the fact that *so many corporate heads of industries that produce cancer-causing products, sit on the board of the American Cancer Society and determine how the public comes to understand cancer and how it's constructed, how much individual choice and lifestyle is a factor, and how much these other larger issues like workplace exposure and environmental pollution is or is not a factor.* It seems to me that one of the major reasons that most people in this country *when they get cancer don't think of themselves as a*

human rights victim is because these profit-making companies have successfully de-politicized what cancer is and what causes it.

They really lie about the biology of cancer because of their influence on the American Cancer Society (...).

[The Imperial Chemical Incorporated] also sit on the Board of the American Cancer Society and they are one of the sponsors of Breast Cancer Awareness Month, which means they also get to determine how we talk about it and understand cancer in this country. They can successfully black out any discussion of environmental carcinogens because they are that powerful. And then they can look like the good guys, because they hold the patent for Tamoxifen, and they treat all these women and save their lives. Those women may not have ever gotten sick if it hadn't been for ICI. So I think that the root cause of the fact that they can sit on the Board, produce cancer-causing agents, and cure cancer -- they can do all three of those -- is because of profit-making motive.

It seems to me it's taboo in this country to criticize that. The things I'm telling you now are not things, when I'm interviewed by newspapers and magazines, that I'm supposed to really talk about because people listen to that and they stop listening to the biology. I'll go on record for a project such as this that I think that profit-making motive is the main problem here.

Appendix 31: Excerpts from the interview with Richard Strohman.

We don't know enough about chemicals and cancer for a variety of reasons, but my guess is that the most important reason is that *we are more interested, in the U.S. at least, in waiting until after the disease is there and then they find a therapy for it.* Now, I think there is a good socio-economic and political reason for this: if you have a therapy you can make money. You can invent drugs, you can invent therapy procedures, you can do all these things which are *enormously profitable.*

To prevent the disease by eliminating the chemical does not allow you to engage in a profit motive. And, indeed it is anti-profit motive because you would have to eliminate the chemical, you would have to take the position of being an environmental activist, rather than a someone who is looking for therapy after the fact. This might, and does in the minds of some people at least, threaten jobs and threaten the economy, when actually if you looked at it from the other point of view you would see that it would generate jobs and new technology in cleaning up the environment and testing and doing all the kinds of things you would need to do would generate another completely new technology, a most sophisticated basic science.

So I basically think that we don't follow with the chemicals because it interferes with our ongoing status quo industry, *it threatens a well ensconced, or set up, status quo in our research*

hierarchy -- and for all the usual socio-political reasons we don't support these environmental measures because of the reasons I just said (...). We don't seem to learn the lesson and we don't seem to extend the success of cigarette primary prevention to other possibilities. Well, why is that? It's money again. *It's profit. There is no money to be made ... you can't generate drugs from primary prevention. That's the attitude, it's hopeless.*

Most of the complicated research programs in the U.S. and every other industrialized country are set up so that they work hand in hand with "well meaning" private corporations which want to do something in a therapeutic modality. Everything we do in the last ten years, even Mitterand in the so-called "socialist" government in France wants their basic researchers to have some kind of relationship with the biomedical thing. But that's antithetical to good science in many ways.

The whole thing is set up so that basic research feeds the development of some product which can then be sold to people which can help them do what? To cope with and live in a world which is then left to decay in its own way. So we are making a biomedical program which doesn't help most of us live in a better world.

It assume that the world's going to get worse and we're going to have drugs and medicines to help us out after it all happens. It's totally upside down. You don't have to look any further for reasons why we are not expanding the paradigm. Basically it runs against what's been built into the system from the very beginning. One needs a change in the attitude and perspective in which we view all of this. Without that *basic epistemological shift in perspective*, it's going to be very difficult.

(...) We always used to say back in the 1960s here at Berkeley, coping with political pressures here, the war in Vietnam, the free speech movement, the civil rights movement and so on ... the academic community, the professors would make big protests and then we found out exactly how powerful we were.

We always thought we were powerful, but then we were all these scientists and faculty people are always on tap, but very rarely on top. That lead us to the realization that other social critics have known for a long time that we as individuals didn't have any power. That is to say in science specifically, that what we did in producing basic research with some ... application that once we did it and produced it we were on tap, so to speak, but then *we had no control over the use of that research.*

The physicists were, of course, in modern history the first to make that clear: they produced a weapon which then was out of their hand and used politically. But then, biologists have come to that in a different way. I know many cases of departmental chairmen and head professors who have come to terms with it by joining it. So they've turned their laboratories, not over to, but have established close relationships with profit-making institutions.

(...) Directly, of course. *Many of them are now CEOs or corporate executive officers. They own companies or they have partial ownership or they have stock in the companies,* so that this profit relationship is everywhere in the biological sciences in the U.S. and I'm sure that's true in Italy and European countries as well.

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