Illnesses as Interests:  
The Rise of Disease Advocacy and the Politics of Medical Research

By

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A dissertation submitted in partial satisfaction of the requirements for the degree of

Doctor of Philosophy

in

Sociology

in the

Graduate Division

of the

University of California, Berkeley

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Spring 2012
Abstract

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In the past 30 years, people with serious diseases have organized politically to an unprecedented degree. They founded hundreds of nonprofits, launched fundraising drives, publicized ribbons and walks, and lobbied Congress for funding for research into their conditions. In the first longitudinal study of the field of disease social movements, this dissertation asks why disease advocacy expanded so quickly and how it changed the politics of medical research funding.

I combine quantitative and qualitative data to track the emergence of disease advocacy and document its effects. For 53 diseases from 1989 to 2005, I collected data on the advocacy targeting each disease, the number and characteristics of the people each disease killed, and the amount of federal medical research funding for each disease. I combine statistical analyses with qualitative analyses of congressional testimony, reports, and secondary sources.

Studying the emergence of a field of interest groups allows me to test competing theories about the causes of group emergence and the political effects of advocacy. First, I ask how diseases became an established category for interest group politics. I find that changes in science, medicine, and the experience of illness laid the groundwork for the emergence of disease advocacy. But disease advocacy organizations did not proliferate until after the AIDS and breast cancer movements institutionalized a model that diffused rapidly across diseases. These findings suggest that to understand how forms of organizing emerge, we need to look at processes of social movement spillover and the diffusion of organizational forms.

Second, I ask how the emergence of disease advocacy changed the politics of medical research funding. Previous research on the political outcomes of advocacy has focused almost exclusively on whether movements achieve benefits for their constituents. I find that the effects of disease advocacy went far beyond simple increases in research funding for organized diseases. Disease advocacy reshaped the funding distribution, shifting
money away from diseases that primarily affect women and racial minorities. Disease advocacy also changed the perceived beneficiaries of policies, introduced metrics for commensuration, and made cultural categories of worth newly relevant to policymaking. These findings highlight movements’ cultural effects on politics.

Third, I ask whether disease movements influenced each other’s effectiveness. Researchers generally examine social movements in isolation. But since movements may fight for space on the government agenda or create political opportunities for each other, their outcomes are unlikely to be independent. As disease advocacy expanded, some critics worried that organized diseases would siphon funds from less-organized diseases in a zero-sum game. I find that on the contrary, disease advocacy was synergistic, with gains spilling over across diseases. An analysis of congressional debates suggests that particularistic politics led to increasing budgets by creating new constituencies and by expanding the boundaries of the competition for funds. These results demonstrate that to understand social movement outcomes, researchers must consider their interactions.
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Acknowledgments

I am extremely grateful to my dissertation committee members, Mike Hout, Ann Swidler, Lauren Edelman, and Ann Keller. Their comments on drafts and stimulating discussions in committee meetings pushed me to elaborate on my ideas and deepen my analysis. Other faculty members at Berkeley were also incredibly helpful in reading and discussing sections of this dissertation. I thank Claude Fischer, Neil Fligstein, Marion Fourcade, Dylan Riley, Calvin Morrill, and Margaret Weir. This dissertation has also benefited immeasurably from my conversations with other graduate students. I am particularly grateful to Hana Brown, Alex Janus, Daniel Laurison, Laura Mangels, and Sarah Quinn for their insightful comments on chapter drafts. I also discussed this work in several workshops on the Berkeley campus. I would like to thank the participants in the Inequality workshop; the Research Group on Multilevel Modeling; the Center for Culture, Organizations, and Politics; and the Empirical Legal Studies workshop for their comments and assistance. Scholars at other universities also generously commented on drafts of Chapter 3. I am very grateful to Phil Brown, Paul Burstein, Isaac Martin for their insightful comments.

Many people provided assistance with data collection and analysis. Michael Boyle of the NIH Office of Budget and David Cantor and Barbara Harkins of the Office of NIH History provided invaluable assistance with data collection. James Danowski provided instruction in using his WORDij software. Caitlin Green, Sophie Harrison-Wong, Katherine Hood, David Lee, Willie Jo Marquez, Greg Mooney, Kate Sousa, and Shanna Zhu provided incomparable research assistance. Research funds were provided by the Office of NIH History; the UC Berkeley Science, Technology and Society Center; and Berkeley Law’s Empirical Legal Studies fellowship.

Finally, I would like to thank my parents, Arthur Best and Hannah Kahn, and my partner, Holice Kil. Their loving support energizes me to begin each day’s work.
Chapter 1

Introduction
In the past 30 years, people with serious diseases have organized politically to an unprecedented degree. They founded hundreds of nonprofits, launched fundraising drives, publicized ribbons and walks, and lobbied Congress for funding for research into their conditions. Diseases had been public issues in the past, when philanthropists launched crusades against tuberculosis and polio and the government announced a War on Cancer. But the new disease movements were different: they viewed patients as their constituents. This model for disease interest groups spread like wildfire and reshaped health politics and policy. Well-organized diseases saw huge funding increases, and the overall NIH budget expanded. The funding distribution was reshaped as advocates introduced new metrics for commensurating diseases. And as Congress and the public began to think of patients as the beneficiaries of medical research funding, stigmatized diseases were at an increasing disadvantage in the competition for funds. In the first longitudinal study of the field of disease social movements, this dissertation asks why disease advocacy expanded so quickly and how it changed the politics of medical research funding.

**Disease Advocacy**

Previous studies have remarked on the increase in health social movements but have neither documented the change nor investigated its causes systematically. Theorists have remarked on the growing politicization of illness, calling it “the politics of life itself” (Rose 2006), “biosociality” (Rabinow 1992), “embodied health movements” (Morello-Frosch et al. 2006), or a feature of “biomedicalization” (Clarke et al. 2003). Meanwhile, dozens of empirical studies of single disease movements have been conducted (for reviews, see Epstein 2008 and Hess et al. 2008). These studies reveal how the AIDS movement challenged science (Epstein 1996), how the breast cancer movement changed women’s experience of illness (Klawiter 2004), and more. But these individual studies can neither document the growth of the field, nor give conclusive answers about why it expanded, nor document its aggregate effects. A few researchers have conducted surveys of existing patients’ organizations (Allsop, Jones, and Baggott 2004; Keller and Packel 2007; Wood 2000), but these cross-sectional data cannot accurately track the increase over time in disease advocacy organizations or conclusively document their effects on medical research policymaking. By taking a birds-eye view of the growth of disease advocacy, this dissertation provides important insights into a major change in American health politics. This study also lets me test theories about why fields of movements emerge and how they affect politics.
The Emergence of Political Identities

In almost all social movements and interest groups, participants classify themselves based on one aspect of their identities and make political demands based on that category. The civil rights movement and the women’s movement organized around race and gender; at other times, people have mobilized around social classes, occupational groups, and inclusive categories like citizens or consumers. Depending on which groups we use as categories for mobilization, we will define our interests differently, perceive different political enemies, and judge policies differently. The emergence of disease advocacy constituted a change in the categories people mobilize around in the United States. By studying the emergence of this new category for mobilization, I gain insights about how political categories emerge and how they shape policymaking.

Traditionally, research on social movements has not paid much attention to the question of which identities become categories for mobilization. Earlier research assumed that movements arise from a society’s primary cleavages and political and economic structures (Armstrong and Bernstein 2008; Lipset and Rokkan 1967; Polletta and Jasper 2001). This line of research is ill-equipped to explain the quick emergence of disease advocacy. I argue that to understand the rapid growth of the field of disease advocacy, we need to focus on processes of diffusion and spillover between social movements (Meyer and Whittier 1994; Minkoff 1995; Sewell 1992).

Advocacy’s Effects

Research on social movements traditionally focused on mobilization and paid little attention to outcomes (Amenta and Caren 2004; McAdam et al. 1988). Despite a growing body of research on the outcomes of advocacy (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998; Burstein 1999; Giugni 1999; Smith 1995), there are still major limitations to our knowledge about movement outcomes. First, researchers who study the political outcomes of advocacy have focused on the extent to which movements secure concrete gains for their constituents. While we know that social movements can have cultural effects on society at large (Amenta et al. 2010; della Porta 1999; Earl 2004), researchers have largely neglected the possibility that movements will

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1 Researchers traditionally distinguished social movements from interest groups, arguing that the former lack access to institutionalized channels of political influence (McCarthy and Zald 1977), engage in disruptive tactics (Tarrow 1994), and make moral claims (Lofland 1996). Today, a growing number of scholars argue that these variables are all continua, making it problematic to draw a clear line between social movements and interest groups (Andrews and Edwards 2004; Burstein 1998; Clemens 2005; Tarrow 1999). Since the organizations I study share some of the characteristics traditionally assigned to social movements and interest groups, I call them “advocacy organizations” (Andrews and Edwards 2004) and draw on both research literatures.
achieve cultural effects within the political sphere. Second, previous longitudinal studies of social movement effects have focused on organizations within a single social movement industry (McAdam and Su 2002; Meyer and Minkoff 2004; Olzak and Ryo 2007; Olzak and Soule 2009) or a small number (Giugni 2004; Soule and King 2008). This case-study approach makes it hard to conclusively document effects across cases. It also limits the types of questions researchers can ask about movement effects. Looking at single movements means we cannot ask how fields of movements reshape distributions of funding or other benefits. Nor can we ask how movements’ effects interact: if one movement is successful, does that increase or decrease the likelihood that related movements will achieve their goals?

Studying the emergence of an entire field of interest groups gives my analyses more statistical power and allows me to measure advocacy’s concrete effects more conclusively. I also avoid a weakness of most studies on social movements: they sample movements, not problems, meaning that they study only issues with relatively high levels of mobilization. Sampling diseases instead of movements allows me to compare diseases that were and were not targeted by advocacy, enabling stronger conclusions about causality. Additionally, diseases are a useful test case for exploring movement effects. Unlike other social problems, diseases have common metrics of severity (mortality and prevalence) and political outcomes (medical research funding). These comparable, quantifiable features of diseases make them an ideal empirical site for exploring the influence of advocacy on political outcomes.

More importantly, though, looking at the whole field of disease advocacy allows me to ask different kinds of questions. How did the emergence of disease advocacy change the overall funding distribution? How did the participation of a new category of political actors change the political criteria for evaluating claims? Was advocacy a zero-sum game, or did gains spill over across diseases? Expanding my focus beyond individual movements allows me to address these broader questions.

Data

To track the emergence of disease advocacy and document its effects, I collected both quantitative and qualitative data. My quantitative dataset includes information on 53 diseases from 1989 to 2005. The unit of analysis is the disease. For each disease in each year, I collected data on the advocacy targeting the disease, the number and characteristics of people it killed, and the amount of federal medical research funding for the disease. This unique dataset allows me to answer several questions about the emergence and effects of advocacy. In chapter 2, I ask what predicts the emergence of disease advocacy. In chapter 3, I ask whether diseases with more advocacy got more federal research funding, and how the overall funding distribution changed as advocacy became more influential. In chapter 4, I ask whether disease advocacy was a zero-sum game by exploring the interrelated outcomes of movements targeting various diseases.
Data on Disease Advocacy

Nonprofits

Most of my information on disease advocacy comes from nonprofit tax data that I aggregated by disease. I purchased the National Center for Charitable Statistics’ (NCCS) Core Trend File PC, a longitudinal data set compiled from nonprofits’ IRS forms covering the years 1989-2005. I converted all financial data into 1987 dollars using the CPI-URS (Bureau of Labor Statistics 2008). I focused on nonprofits in two categories: “Diseases, Disorders, and Medical Disciplines” and “Medical Research.” For each of the approximately 15,000 unique nonprofits in these categories, I coded the disease or diseases the nonprofit was related to, if any. Having linked organizations to the diseases

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2 This dataset includes those 510(c)(3) organizations classified by the IRS as “public charities” and excludes those designated as “private foundations.” (The latter make up only 10% of 510(c)(3) organizations). Since most private foundations distribute funds to charities, including both types of nonprofits in my sample would risk double-counting their financial data (National Center for Charitable Statistics 2006).

3 Gronbjerg (2002) notes that these IRS data paint an incomplete picture of the nonprofit sector. She finds that of a list of nonprofits in Indiana, only about 10% filed financial information with the IRS. However, this gap does not bias the data used for this study. First, many of the nonprofits not represented in the IRS data are absent because they have revenues below $25,000; since excluded nonprofits tend to be very small, the IRS data likely capture most nonprofit revenues (Gronbjerg 2002:1747). Second, some discrepancies at the local level occur when nonprofits file their tax forms using the address of a headquarters organization. Nonprofits operating in Indiana with headquarters in other states would show up as discrepancies in Gronbjerg’s (2002) data but would not pose a problem for my national aggregations of the data. Third, the types of nonprofits Gronbjerg (2002) found to be least likely to appear in the IRS data (preschools and religiously affiliated nonprofits) are not included in this study. Thus, while Gronbjerg’s work raises serious concerns for using the IRS data to measure the nonprofit sector in local communities, these problems are much less severe when studying health nonprofits at the national level.

4 Organizations with budgets below $25,000 do not file the tax forms that are included in the NCCS data. Since the IRS does not adjust this cutoff for inflation, I drop all organizations with budgets below $25,000 in 1987 dollars to avoid inflating the number of organizations in later years.

5 While there are many problems with the full NCCS nonprofit classification scheme, it validly classifies organizations at this broad level (Gronbjerg 1994:311).

6 I was able code disease affiliations (or lack thereof) from the names of approximately three quarters of the organizations. Web searches for the remaining (approximately 4000) organizations allowed me to identify all but 600. I coded an additional 169 organizations...
they target, I summed variables from this organization-level data to create two disease-
level variables: the total number of organizations targeting the disease and their total
lobbying expenditures\(^7\) in a given year.\(^8\) These data allow me to document the growth of
the field of disease advocacy organizations and serve as independent variables denoting
the level of advocacy surrounding each disease.

**Witnesses at Congressional Appropriations Hearings**

For another measure of disease advocacy, I collected data on the participation of disease
advocacy organizations in congressional hearings.\(^9\) I collected data on the witnesses at
House appropriations hearings for Labor, Health and Human Services, and Education,
which include NIH appropriations.\(^10\) For every fifth year from 1965 to 1985 and every
year from 1989 to 2007,\(^11\) I downloaded lists of witnesses and their organizational
affiliations from LexisNexis Congressional. With a team of seven undergraduate research
assistants, I classified the witnesses into 16 categories.\(^12\) I then coded whether witnesses

\(^7\) 501(c)(3) organizations are allowed to lobby the government, but this lobbying must not
constitute a “substantial part” of their activities (Internal Revenue Service 2010).

\(^8\) Since the nonprofits studied have various missions, including service provision, public
education, and research funding, the “total organizations” variable is a broad measure of
the organizational activity targeting a disease. The lobbying variable is more narrowly
targeted, since it represents financial attempts to influence government bodies. However,
not all of this lobbying is focused on research funding. When I use these variables to
predict federal research funding, this heterogeneity likely biases my results downward,
since not all of the measured activity is focused on lobbying for research funds.

\(^9\) Witnesses at hearings are not a perfect reflection of all the advocates in society—
committee chairs exert influence over witness lists, and groups with more organizational
resources are more likely to be invited to testify (Leyden 1995). But committee testimony
is an important way advocates gain access to lobbyists (Hansen 1991), and witness lists
reveal who has this access.

\(^10\) Prior to 1980, the hearings are for Labor, Health, Education, and Welfare. Hearings are
held in both the Senate and the House, but the House hearings tend to include the same
witnesses as the Senate hearings, along with many additional witnesses. Therefore, I
analyzed only the House hearings.

\(^11\) I collected annual data beginning in 1989 to create independent variables for the
statistical analyses.

\(^12\) During each week of coder training, all research assistants coded the same hearing, and
we then resolved disagreements and refined the coding scheme. After five weeks,
intercoder agreement percentages ranged from 80%-90%, with Krippendorff’s alpha
classified as health advocates represented a disease or diseases. Within each year, I summed the number of advocates testifying for each disease. To document the increasing prominence of disease advocates, I graph the annual percentages of witnesses in various categories. In statistical analyses, I use these counts as a third measure of disease advocacy.\textsuperscript{13}

**Mortality Data**

Next, I collected mortality data for each disease. I use CDC data on the annual number of deaths recorded for black, white, and “other race” men and women for each disease. I calculated the percentages of blacks and women among fatalities and also created dummy variables equal to one if over 95% of fatalities are women (breast, cervical, ovarian, and uterine cancers; pelvic inflammatory disease) or blacks (sickle cell anemia). I use this mortality data as a control in all statistical analyses. Additionally, I ask whether advocacy tended to shift funding toward or away from diseases that primarily kill women and blacks.

**Funding Data**

I also collected data on the amount of federal medical research funding each disease received from the National Institutes of Health (NIH) and the Department of Defense Congressionally Determined Medical Research Program (DOD-CDMRP). The NIH is the primary public funder of medical research in the United States, and the DOD-CDMRP also allocates a substantial amount of medical research funding.\textsuperscript{14} I used the Freedom of Information Act to obtain historical information on NIH research funding. I also compiled data on funding for leukemia, skin cancer, and pancreatic cancer (which were not tracked in the NIH data) from National Cancer Institute publications. DOD-CDMRP funding data were available online. I converted the funding totals into millions of 1987 dollars using the CPI-URS (Bureau of Labor Statistics 2008). I use these funding data as a dependent variable in statistical analyses of the effects of disease advocacy.

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\textsuperscript{13} Compared with total nonprofits and lobbying expenditures, this variable is more narrowly focused on research advocacy. All the witnesses are attempting to influence federal appropriations, and 80-90% of witnesses focus their testimony on research funding.

\textsuperscript{14} Since DOD-CDMRP expenditures are much lower than NIH expenditures, all analyses were also run with only NIH funding as the dependent variable. All results were substantively unchanged.
Disease Categories

To combine these data sources, I had to align several disease classification schemes. The NIH data included information on 212 diseases, conditions, and research areas.\textsuperscript{15} I selected all diseases at the lowest level of aggregation in the NIH data, matched them with the ICD-9 and ICD-10 codes used by the CDC, and classified nonprofits and witnesses based on these disease categories.\textsuperscript{16} Table 1.1 lists the 53 sampled diseases, which include all of the 15 leading causes of death in the United States besides murder, suicide, and accidents.

Qualitative Data

I supplement this quantitative data with a qualitative analysis of congressional testimony, reports, and secondary sources. In chapter 2, I draw on dozens of empirical studies of single disease movements (for reviews, see Epstein 2008 and Hess et al. 2008). In combination with my quantitative data, these studies allow me to draw conclusions about how and why disease advocacy expanded. To document changes in the politics of medical research funding in chapters 3 and 4, I examined news coverage of NIH policymaking in newspapers (including The Washington Post and The New York Times) and two scientific journals (Science and The New England Journal of Medicine), and congressionally mandated reports from the Congressional Research Service and the Institute of Medicine. Additionally, to collect more nuanced data on how advocates justify their claims, two research assistants and I read and analyzed the testimony of a subsample of approximately 200 disease advocates.\textsuperscript{17} These qualitative data and secondary sources help me document cultural changes in medical research politics.

\textsuperscript{15} The NIH categories are not mutually exclusive. For example, a study of breast cancer would be coded as both breast cancer and cancer. To avoid double-counting research dollars, I only use data on diseases at the lowest level of aggregation.

\textsuperscript{16} Some organizations target broad categories like cancer or diabetes, while others target narrow categories like breast cancer or juvenile diabetes. I collected data on the full range of disease advocacy organizations for the qualitative analyses, but I only include single-disease organizations in the counts of witnesses and nonprofits targeting each disease.

\textsuperscript{17} To allow me to examine trends over time while ensuring that the samples are representative within years, I randomly selected approximately 20 witnesses within each year. The proportion sampled per year ranged from 30%-100%. Two research assistants and I quantitatively coded the witnesses’ claims (see Appendix for codebook). Unfortunately, to achieve sufficient levels of intercoder reliability, we were forced to broaden our codes until there was little variation in the resulting variables. Therefore, the quantitative data from this coding effort are not very informative. However, during the coding process, the research assistants and I wrote memos about the qualitative patterns we observed in the testimony and met to discuss these patterns we observed. I draw on
Chapter Outline

These quantitative and qualitative data provide an unprecedented look at a major change in American health politics. They also allow me to expand theories about movement emergence and effects. Chapter 2 examines the emergence of disease advocacy, and Chapters 3 and 4 explore its effects on the politics of medical research funding. Each chapter includes statistical analyses and also draws on qualitative data and secondary sources.

In Chapter 2, I document changes in health politics throughout the twentieth century to explain how and why diseases became categories for mobilization. Changes in science, medicine, and the experience of illness laid the groundwork for the emergence of disease advocacy. But disease advocacy organizations did not proliferate until after the AIDS and breast cancer movements. Activists targeting both those diseases drew on pre-existing identity-based movements (the gay rights movement and the women’s health movement), spun off disease advocacy into separate movements, and institutionalized a model for disease identity politics that diffused rapidly across diseases. These findings suggest that to understand how forms of organizing emerge, we need to look at processes of social movement spillover and the diffusion of organizational forms.

In Chapter 3, I show that the effects of disease advocacy went beyond simple increases in research funding for organized diseases. Advocacy also reshaped the funding distribution, shifting money away from diseases that primarily affect women and racial minorities. Advocacy also changed the perceived beneficiaries of policies, introduced metrics for commensuration, and made cultural categories of worth newly relevant to policymaking. These findings highlight movements’ cultural effects on politics.

As disease advocacy expanded, some critics worried that organized diseases would siphon funds from less-organized diseases in a zero-sum game. In Chapter 4, I show that on the contrary, disease advocacy was synergistic. Gains spilled over across diseases, with research funding increasing after advocacy targeted other diseases. An analysis of congressional debates suggests that particularistic politics led to increasing budgets by creating new constituencies and by expanding the boundaries of the competition for funds. These results demonstrate that to understand social movement outcomes, researchers must consider their interactions.

The emergence of diseases as interest groups has been a dramatic change in American culture and politics. Collecting systematic data on this sea change yields new insights about how people form groups to advocate for their interests and how political systems respond to those groups.

this preliminary qualitative analysis of the representative sample of witnesses to provide context for my quantitative evidence.
<table>
<thead>
<tr>
<th>Disease/Condition</th>
<th>Condition</th>
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<tbody>
<tr>
<td>ALS</td>
<td>Liver cancer</td>
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<tr>
<td>Alzheimer's disease</td>
<td>Lung cancer</td>
</tr>
<tr>
<td>Arthritis</td>
<td>Lupus</td>
</tr>
<tr>
<td>Asthma</td>
<td>Multiple sclerosis</td>
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<tr>
<td>Atherosclerosis</td>
<td>Muscular dystrophy</td>
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<tr>
<td>Autism</td>
<td>Myasthenia gravis</td>
</tr>
<tr>
<td>Brain and central nervous system cancer</td>
<td>Neurofibromatosis</td>
</tr>
<tr>
<td>Breast cancer*</td>
<td>Osteoporosis</td>
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<tr>
<td>Cerebral palsy</td>
<td>Ovarian cancer</td>
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<tr>
<td>Cervical cancer</td>
<td>Pancreatic cancer</td>
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<tr>
<td>Chronic fatigue syndrome</td>
<td>Parkinson's disease</td>
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<tr>
<td>Chronic liver disease and cirrhosis</td>
<td>Pelvic inflammatory disease</td>
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<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>Peptic ulcer</td>
</tr>
<tr>
<td>Colo-rectal cancer</td>
<td>Pneumonia</td>
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<tr>
<td>Cystic Fibrosis</td>
<td>Prostate cancer</td>
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<tr>
<td>Diabetes</td>
<td>Schizophrenia</td>
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<tr>
<td>Down Syndrome</td>
<td>Scleroderma</td>
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<tr>
<td>Epilepsy</td>
<td>Septicemia</td>
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<tr>
<td>Fibromyalgia</td>
<td>Sickle cell anemia</td>
</tr>
<tr>
<td>Heart disease</td>
<td>Skin cancer</td>
</tr>
<tr>
<td>Hepatitis</td>
<td>Spina Bifida</td>
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<tr>
<td>HIV/AIDS*</td>
<td>Stroke / cerebrovascular disease</td>
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<tr>
<td>Huntington's disease</td>
<td>Sudden infant death syndrome</td>
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<tr>
<td>Hypertension</td>
<td>Tuberculosis</td>
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<tr>
<td>Influenza</td>
<td>Tuberous sclerosis</td>
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<tr>
<td>Kidney disease</td>
<td>Uterine cancer</td>
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<tr>
<td>Leukemia</td>
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</tbody>
</table>

*All analyses were run both with and without HIV / AIDS and breast cancer included in the analysis.*
Chapter 2

The Rise of Disease Advocacy: How Illness Identities Became Interest Groups

Abstract:
This chapter explains how disease advocacy in the United States changed from philanthropic public health campaigns to interest groups demanding benefits for patients. Drawing on quantitative data on 53 disease movements, qualitative data, and secondary sources, I find that changes in science, medicine, and the experience of illness laid the groundwork for the emergence of disease advocacy. But to understand how forms of organizing emerge, we need to look at processes of social movement spillover and the diffusion of organizational forms. Disease advocacy organizations did not proliferate until after the AIDS and breast cancer movements. Activists targeting both those diseases drew on pre-existing identity-based movements (the gay rights movement and the women’s health movement), but spun off disease advocacy into separate movements. They institutionalized a model for disease identity politics that diffused rapidly across diseases.
Late in the twentieth century, patients seized the public health agenda by organizing interest groups around their diseases. Throughout the twentieth century, philanthropists and physicians had organized mass campaigns to fight tuberculosis, polio, cancer, and heart disease. But it was not until the 1980s and 1990s that patients became interest groups and diseases became the targets of identity politics. This chapter is about why people began to mobilize around diseases. I track the history, expansion, and redefinition of disease advocacy throughout the twentieth century to explain why disease identity politics emerged and expanded.

Previous studies of health social movements have not fully documented this change nor systematically investigated its causes. Theorists have remarked on the growing politicization of illness (Clarke et al. 2003; Morello-Frosch et al. 2006; Rabinow 1992; Rose 2006), and dozens of empirical studies of single disease movements have been conducted (for reviews, see Epstein 2008 and Hess et al. 2008). These individual studies cannot document the growth of the field or give conclusive answers about why it expanded. In this chapter, I combine an analysis of these secondary sources with quantitative data to explain the emergence of disease advocacy.

While changes in science, medicine, and the experience of illness facilitated the emergence of disease advocacy, the organizations did not proliferate until after the AIDS and breast cancer movements. Activists targeting both those diseases drew on pre-existing identity-based movements (the gay rights movement and the women’s health movement), but spun off disease advocacy into separate movements. They institutionalized a model for disease identity politics that diffused rapidly across diseases. These findings suggest that to understand how forms of organizing emerge, we need to look at processes of social movement spillover and the diffusion of organizational forms.

Which Problems Generate Identity Politics?

Not every public issue becomes the target of identity politics. For example, not all advocacy organizations targeting poverty are poor people’s movements. Politicians might target corporate misbehavior without framing it as an issue of consumers’ rights. Diseases were once only public health issues, but are now targeted by patients’ interest groups. Which identities become categories for political mobilization, and when, and why?

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18 By “identity politics,” I mean advocacy that is organized around an identity category. Other researchers have used the phrase to denote advocacy with non-material goals (for a review, see Bernstein 2005).
When political scientists ask how identities influence politics, they tend to measure their independent and dependent variables at the individual level. For example, they often ask how ethnicity shapes people’s political attitudes, behaviors, and beliefs (Brady and Kaplan 2000, Kinder and Winter 2001; Leighley and Vedlitz 1999; Uhlaner et al. 1989). The key question is thought to be “how human beings acquire certain political identities” (Smith 2004:304). Lee (2008) asks when “a group-based politics will emerge and organize” a demographic group into a political group (Lee 2008:461). To measure the extent to which groups “engage in collective politics,” he asks what proportion vote for the same party (Lee 2008:471). Since they focus on individuals, political scientists have turned to social psychologists in seeking to explain which identities become political. These researchers ask how group boundaries are formed and maintained, and how individuals perceive their identities (for a review, see Monroe et al. 2000).

There are three problems with this way of operationalizing political identity. First, focusing on individual behaviors instead of organizations means that we miss important identity-based political movements. By this measure, if women voted heterogeneously in the 1970s, we would say that women were not engaging in collective politics, neglecting the feminist movement. Second, the model runs into problems when we consider the fact that people have multiple identities. Recognizing that “the same person might seek protection and representation primarily as a Jew, or as a Brooklyn resident, or as a member of a radical socialist party,” Smith (2004) argues that we should ask which identity is “most politically salient” (Smith 2004:304). By this measure, if this hypothetical person joined a Jewish organization and a Brooklyn resident’s organization, only one membership would “count” as a measure of his political identity. Third, by focusing on whether group members share political preferences, this approach unnecessarily emphasizes coordination and homogeneity. If one powerful Asian political advocacy organization existed, and another one were founded that pursued different goals, this model would say that there was now less Asian identity politics (Lee 2008); I would argue that there is more. These problems are easily solved by measuring identity politics at the organizational level rather than the individual level. Identities are political when people organize around them to make political demands. To understand the emergence of political organizations targeting identity categories, we must turn to theories about the emergence of organizational forms. To explain the emergence of disease advocacy, I draw on sociological research on social movements, organizations, and culture.

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19 This pattern may be symptomatic of a larger problem: social movements scholars’ “failure to ask questions about the relations among collective, categorical, group, and individual identities” (Stryker et al. 2000:6).

20 Lee recognizes that the reliance on survey data may lead political scientists to focus too exclusively on individuals, and suggests that qualitative historical and organizational analyses or studies of mobilization may be necessary (Lee 2008:472-3). While he frames this as a choice between quantitative and qualitative data, I argue for conducting quantitative analyses at the organizational level as well.
Traditionally, research on social movements has paid little attention to the question of which identities become categories for mobilization. Earlier research assumed that movements arise from a society’s primary cleavages and political and economic structures (Armstrong and Bernstein 2008; Lipset and Rokkan 1967; Polletta and Jasper 2001). The assumption was that grievances and collective interests exist, and then resources or political opportunities let people act on them (Polletta and Jasper 2001:286). This line of research ignores the question of “why collective actors come into being when they do” (Polletta and Jasper 2001:284; Armstrong and Bernstein 2008). One reason for this neglect is that in the most commonly studied movements, people mobilized to protest oppression on the basis of an identity category. The civil rights movement, the feminist movement, and the gay rights movement are all based on identities that were the targets of oppression. Focusing on this type of movement made motivations seem self-explanatory: “of course, people who are politically disenfranchised want to challenge the state to improve their situation” (Armstrong and Bernstein 2008:80).

Indeed, categories targeted by the state for oppression or for the distribution of benefits often become mobilizing identities. Apartheid created inequality on the basis of racial categories that spurred organizing around those categories in South Africa, while the fact that there was less official use of racial categories meant that there was less black mobilization in Brazil (Marx 1998). Viewing homosexuality as an identity, and not an activity, allowed for persecution but also identity-based organizing (D’Emilio 1983). Mobilization may also occur around politically defined categories, even when these categories are not the basis for oppression, as when social welfare benefit categories define groups, and those groups subsequently demand more benefits (Skocpol 1992; Soysal 1995).

Yet official categories and state oppression cannot account for all the identity categories people mobilize around. Some scholars have argued that social movements’ targets are changing, since “state institutions increasingly refuse to ‘discriminate,’ that is, to set policies based on social labels” (Gamson 1989:358). More recent movements “do not usually have an identity imposed on them by the political and legal systems; accordingly, they have more freedom to engage in creative reformulations of who they are” (Polletta and Jasper 2001:287; Jasper 1997). People with various diseases have come to view those diseases as an identity and mobilize politically around the disease category, despite the fact that most diseases are not the targets of state oppression.

Recent research on collective identity and social movements seeks to explain the emergence of collective identities that can provide the basis for mobilization. Explanations have included “large-scale processes such as industrialization, urbanization, and state consolidation” and “the ascendance of new cognitive paradigms” (Polletta and Jasper 2001:287). For example, D’Emilio (1983) argues that “the emergence of a ‘homosexual’ identity” became possible when urbanization and industrialization permitted “an autonomous personal life” (Polletta and Jasper 2001:287). Tilly (1998) attributes the development of “broader identities such as ‘citizen’ and ‘worker’ to the increased salience of the national state in people’s lives and the new patterns of
claimsmaking that resulted” (Polletta and Jasper 2001:288). Once identity categories exist, they become translated into mobilization through networks and institutional contexts (Polletta and Jasper 2001:288). “Institutions removed from the physical and ideological control of those in power,” like the black church, can provide sites for identities to become politicized (Polletta and Jasper 2001:288). I draw on these concepts to illuminate the process through which disease identities became available for activism. But to explain why the field of disease social movements emerged and expanded, we need to explain how a template for organizing diffused.

Sociologists who study social movements, organizations, and culture all discuss processes of diffusion and spillover. Social movements scholars have shown that existing movements can lend expertise, organizational capacity, and strategies to new movements (Freeman 1973; McAdam 1995; Meyer and Whittier 1994; Minkoff 1994, 1995; Taylor 1989; Walker 1983; Whittier 2004). These spillovers help new movements get off the ground, and also lead new movements to resemble older ones. Organizational theorists also predict that existing organizations encourage the foundation of new ones like them. The more organizations that exist of a given type, the more legitimate the organizational form comes to seem, making it more likely that new organizations of that type will be formed and survive (Hannan and Freeman 1977; McLaughlin and Khawaja 2000; Meyer and Rowan 1977; Minkoff 1995). Finally, cultural sociologists discuss the process through which schemas that develop in one context can be “transposed” to new situations (Sewell 1992:8). In this chapter, I show how spillovers, diffusion, and transposition shaped the emergence and growth of disease advocacy.

Methods

This chapter draws on dozens of existing studies of disease movements (for reviews, see Epstein 2008 and Hess et al. 2008) and on academic and journalistic descriptions of health advocacy at various points in time. These secondary sources provide a birds-eye view of changes in the field of disease advocacy across the twentieth century.

To explain how and why disease advocacy changed and spread, I also analyzed quantitative data on the emergence of the field of disease advocacy. My dependent variables are the number of nonprofits founded and the number of congressional witnesses for each disease in each year. The independent variables include the number of pre-existing organizations targeting the disease in question and all other diseases, and the previous year’s witnesses for the disease in question and all other diseases. I also control for three features of the disease (mortality, infectious vs. chronic diseases, and stigmatized vs. non-stigmatized diseases). Table 2.1 provides descriptive statistics for all variables used in the analysis.

In the statistical analyses, I used the Cochrane-Orcutt transformation to correct for first-order autocorrelation. All independent variables are lagged by one year, and all models
use robust standard errors to account for clustering by disease (Rogers 1993; Williams 2000).

Charitable Crusades

Before the 20th century, it would not have made sense to launch a public campaign against a particular disease, since “disease was conceived of… as a physiological state of the individual patient” (Rosenberg 2007:3). It was not until the end of the 19th century that scientific advances, including the germ theory of disease and the development of bacteriology, encouraged people to think of diseases “as a set of specific entities, each with a characteristic and generally predictable course and underlying mechanism” (Rosenberg 2007:3). Throughout the twentieth century, classification systems for diseases became increasingly formalized (Bowker and Star 1999). This differentiation and classification of diseases was a necessary prerequisite to launching public campaigns against diseases (Taylor and Zald 2010:309).

However, the existence of disease categories does not guarantee that they will become targets of interest groups and identity politics. Not every adverse situation is understood as a matter for public action (Spector and Kitsuse 1977), meaning that people will not automatically demand that government and charitable attention be devoted to diseases. And all problems are not politicized in the same way. Diseases could be thought of as public health threats affecting everyone, or as the targets of interest groups and identity politics, with patients organizing to pursue their interests. The first third of the twentieth century saw the formation of large voluntary associations targeting diseases. These organizations launched philanthropic campaigns to improve public health. While they focused on diseases, they differed from contemporary disease advocacy in that they did not view patients as their constituents.

The campaigns against tuberculosis, polio, cancer, and heart disease were not led by patients with these diseases; rather, philanthropists sought out diseases that seemed particularly threatening to public health. The organizations were then run by philanthropists, medical professionals, or both (Kedrowski and Sarow 2007; Rettig 2005). Thus, to the extent that they are interest groups, the constituents are professionals (e.g. cardiologists) not patients (e.g. survivors of heart attacks). The model for citizen involvement was not a patient pursuing his or her interests, but a volunteer devoted to the public good. These charities were described as benefiting scientists, and human health in general, rather than patients of particular diseases: as one contemporary observer explained, “no matter how heavy grows the lump in my throat as I sign the check,… My gift nourishes science, not handicapped children” (Carter 1961:27). And that science would benefit everyone: “I have given so as to safeguard and improve human health, including my own” (Carter 1961:27).
Tuberculosis

The first American disease crusade targeted tuberculosis. At the beginning of the twentieth century, tuberculosis accounted for more than 10% of annual mortality in the United States. The fact that the disease was caused by bacteria had recently been discovered, and death rates were already declining, leading to optimism about containing infection (Carter 1961:72). This was the progressive era, which saw the rise of philanthropy focused on solving social problems and improving social conditions (Oshinsky 2005:51). The charitable campaign against tuberculosis fit in with these other philanthropic projects.

The key innovation of the tuberculosis movement was its focus on a single disease. Founded in 1892, the Society for the Prevention of Tuberculosis was the first organization founded to fight a specific disease (Teller 1988:27; Carter 1961). The single-disease focus was a strategic choice, designed to attract the most charitable dollars to improve public health. Arguing against the suggestion that the Society broaden its mission to public health in general, one prominent advocate argued that “one cannot go to a community to talk generalities and get a response” (Teller 1988:53). Most tuberculosis organizations did not broaden their focus until tuberculosis became sufficiently rare that they risked becoming obsolete; many then rebranded themselves as lung associations (Teller 1988:53). Thus, the single-disease focus did not come about because the organization’s members or constituents were afflicted with the disease. Philanthropists fought tuberculosis as a social improvement project, not to pursue the interests of a group of patients.

Another innovation of the movement was its medical/lay partnership. The physicians who began the campaign sought to get the public involved in a “crusade” against the disease, and early organizations’ memberships were approximately half medical professionals and half lay people (Carter 1961, Teller 1988). Women, initially recruited at churches, volunteered to raise money from their friends and neighbors (Carter 1961:67). The campaign received huge numbers of small donations through Christmas Seals, stamps that donated a penny to tuberculosis organizations (Carter 1961:77-9; Oshinsky 2005:50).

Polio

Tuberculosis campaigners created the idea of a single-disease campaign and a model in which medical professionals and philanthropists joined together to solicit mass donations. A few decades later, the campaign against polio followed in their footsteps. The National Foundation for Infantile Paralysis (later renamed the March of Dimes), founded in 1938, resembled the Tuberculosis Association in many ways (Oshinsky 2005:53). Like the tuberculosis movement, the National Foundation raised money through mass donations, with fundraising in movie theaters and huge numbers of women collecting donations door-to-door. By some accounts, two-thirds of Americans had donated by 1954.
(Oshinsky 2005:188). The campaign raised enormous amounts of money—more than any charity in history except the Red Cross (Oshinsky 2005:69).

Also like the tuberculosis movement, the campaign against polio was a public crusade to eliminate a public health threat, not a push by polio patients to make the government attend to their interests. Franklin Delano Roosevelt founded the National Foundation, but kept his personal history with the disease a secret and did not organize public claims on the basis of his identity as a polio survivor (Oshinsky 2005:46). Another prominent organizer explained that he worked against polio as a charitable cause and “never dreamed… of polio hitting [his family]” (Oshinsky 2005:153). Despite the disease’s stigma, some parents allowed their children to be “poster children” for advertising campaigns showing the ravages of the disease (Oshinsky 2005:63, 72). But these campaigns were not about polio patients coming together to demand help; rather, they were appeals to public sympathy and altruism (Oshinsky 2005:169).

The growth and success of the March of Dimes further institutionalized the model for a single-disease crusade run by medical professionals and philanthropists and funded through mass donations. The success of the polio vaccine in the mid-1950s heightened public confidence in scientific research and would inspire calls for research into other diseases (Oshinsky 2005).

Cancer

The American Society for the Control of Cancer (ASCS), later called the American Cancer Society (ACS), was founded to attract more resources to fighting the country’s second leading cause of death. The Society was founded in 1913, and for its first two to three decades, it was run almost exclusively by medical professionals and funded by large donations from philanthropists. The mass public was involved only as an audience for education campaigns encouraging them to be on the lookout for risk factors (Carter 1961:140-6). In the 1930s, the society incorporated a mass volunteer component, mobilizing a million women into a “Field Army” to distribute educational materials, get people to their doctors’ offices, help poor patients, sew bandages, and raise money (Carter 1961:152-3). In the 1940s, philanthropists led by Mary Lasker became more powerful in the organization. Lasker and her husband controlled the ASCS in the 1940s (Starr 1982:342-3). They dramatically expanded the fundraising campaigns and the representation of lay people on the board (Carter 1961:158). Compared to the tuberculosis and polio crusades, the cancer campaign focused more attention on the government (Carter 1961:140). They helped back the establishment of the National Cancer Institute in 1937 (Casamayou 2001:28-9) and pushed policymakers to multiply the federal cancer research budget 60-fold during the 1940s and 1950s (Carter 1961:139).

Despite this shift in focus, the model was still philanthropic, not interest group-based, with doctors, philanthropists, and volunteers seeking to solve an important public health problem. One mid-century researcher described a typical volunteer for the American
Cancer Society who “tried cancer as one might try window-box gardening or canasta. She might have looked into polio or heart disease or muscular dystrophy, but the Cancer Society was conveniently located, and a friend of hers had died of cancer not long before” (Carter 1961:14-5). Regardless of whether the researcher accurately assessed this woman’s motivations, his statement reveals the public image of cancer as a charitable cause focused on the problems of other people.\(^{21}\) Mary Lasker herself was not a cancer specialist. While her original focus on cancer was inspired by the death of her maid (Strickland 1972:33), and her husband later died of cancer (Casamayou 2001:31), her overall goal was to reduce the human and economic “costs of the major killer diseases.” In pursuit of this goal, she focused on several diseases in turn, pushing for cancer funding, then funding for heart disease. (Rettig 2005:13).

**Heart Disease**

The American Heart Association followed a similar path in that it was a single, national organization targeting a major public health problem. Compared to the other disease associations, it was even more dominated by the medical profession. The AHA began in 1915 as an obscure professional association for cardiologists that focused on things like how to read electrocardiograms (Carter 1961:174). During the 1940s, some administrators pushed it to follow the model of the American Cancer Society, with public partnerships and fundraising drives, but the cardiologists were concerned about opening their association to lay control (Carter 1961:175-6). They eventually allowed Mary Lasker to underwrite a fundraising drive, and a television campaign in the late 40s successfully attracted donations and raised the association’s public profile (Carter 1961:177). By 1960, the association had 1.5 million volunteers (Carter 1961:178). But control remained strongly in the hands of cardiologists. Like the other campaigns, the campaign against heart disease did not see patients as its constituents.

**Neuromuscular Diseases**

The crusades against tuberculosis, polio, cancer, and heart disease institutionalized a particular model for disease campaigns: a single large organization run by medical professionals and philanthropists, with public involvement through donations and voluntarism but little influence of patients and their families. In the late 1940s and 1950s, a new type of disease organization began to emerge, with much more involvement from patients. The innovator of this new form was the National Multiple Sclerosis Society (NMSS), founded in 1946. Ten years later, there were also societies for Cerebral Palsy, Epilepsy, Muscular Dystrophy, Myasthenia Gravis, and Parkinson’s Disease (Carter 1961:204).

\(^{21}\) This pattern began to change in the 1970s, when cancer patients organized to demand changes in clinical trials and access to experimental drugs such as Laetrile (Carpenter 2010; Hess 2006).
In some ways, these new disease associations resembled the earlier campaigns. Like the American Cancer Society, the NMSS lobbied the federal government for MS research funding. They pushed for a research institute for MS, and when the NIH opposed the idea of a single-disease institute, the advocates campaigned for an institute for neurological diseases and were successful in 1950 (Talley 2004:55-57). The National Institute for Neurological Disorders and Blindness and the National Multiple Sclerosis Society “acted as virtually one organization in the 1950s” (Talley 2004:58), paralleling the “interlocking directorates” of the ACS and the National Cancer Institute (Talley 2004:58). Jerry Lewis and Dean Martin adopted the cause of muscular dystrophy, hosting telethons reminiscent of the March of Dimes’ mass fundraising campaigns (Carter 1961:209).

Like the earlier disease campaigns, the new neuromuscular disease associations were supported by scientists. Neurologists in the 1950s were working in “underfunded medical research areas in need of a disease” (Packard et al. 2004:139). The National Multiple Sclerosis Society began to fund conferences and research in the 1940s and 1950s, launching a wave of scientific interest and publications (Talley 2004:42). Multiple sclerosis advocacy gained legitimacy from this growing scientific interest, and its scientific and media visibility may have inspired the formation of the other neuromuscular disease associations.

What was new about the neuromuscular disease associations was the fact that they were “organized in the grief of patients and their families” (Carter 1961:203). Patients and family members formed the bulk of their membership, leadership, and constituencies. The National Multiple Sclerosis Society was founded in 1946 by patients and family members (Talley 2004:43). In a telling episode, a Cerebral Palsy Association administrator sought to enlist the leadership of philanthropists who were not personally affected by cerebral palsy. This decision would have followed the well-established model of the tuberculosis, polio, cancer, and heart disease campaigns. The administrator was fired, and as one association member explained, “We can’t have this organization taken over by people who don’t see CP as we do. We are the ones with the CP children” (Carter 1961:208). These advocates viewed CP not as a public health threat affecting everyone equally, but as a personal problem affecting them and their families.

Thus, these associations represented a new organizational form: they focused on patients with particular diseases, rather than targeting a broader disease category as a public health threat. As such, they faced problems with legitimacy, and encountered a chilly reception from the medical establishment. To some contemporary observers, these proliferating patient-focused disease associations seemed nonsensical and likely to be short-lived. In 1958, the president of the American Neurological Association found it absurd to contemplate the emergence of nonprofits targeting every disease:

Some years ago I was invited to chair a society of amyotrophic lateral sclerosis. Why not one for tuberous sclerosis? And since there is a society for muscular dystrophy, why not another for muscular atrophies, and still others for all the
other myopathies and amyotrophies? Not so long ago a society for myasthenia gravis has come into being, for which there is little rhyme and less reason. There seems to be no end to the popular urge to create more and more societies.

(\text{Dr. Israel S. Wechsler, quoted in Carter 1961:202})

Wechsler’s critique of the various neuromuscular disease organizations stems from their specificity: unlike the American Heart Association or the American Cancer Society, they do not gather a group of related diseases into one umbrella organization. Carter (1961) predicted that this new organizational form would be short-lived, and that the neuromuscular associations would inevitably merge (Carter 1961:203). This lack of legitimacy for patients’ organizations targeting relatively rare diseases may explain why their numbers did not proliferate at midcentury.

\textbf{Initial Growth of Disease Advocacy}

The growth of disease crusades and early patient-centered groups is reflected in an increase in the number of disease witnesses testifying in Congress in the 1970s (see Figure 2.1). Reflecting the fact that most of these disease organizations did not see patients as their constituents, only about a third brought patients to Congress to testify (see Figure 2.2). Instead, the witnesses were scientists and researchers making claims about how to improve public health. Breaking down the witnesses by the diseases they represented reveals that most of the increase did not come from patients’ representatives. Of the disease witnesses testifying before 1980, a quarter represented big disease categories: heart disease, cancer, lung disease, and kidney disease. An additional 10% testified about tuberculosis, following the decades-old tradition of seeking public funds to combat this public health threat. The remaining witnesses are scattered among a handful of other diseases, none of which sent more than two witnesses to Congress before 1980. Of these diseases, only a few were targeted by early patient-centered movements, including cerebral palsy, multiple sclerosis, and cystic fibrosis.

Thus, by the 1970s, there was a strong precedent for large national associations targeting particular diseases, and NIH institutes targeting disease categories. And a few smaller organizations had started to view patients as their constituents. But these smaller patient-centered groups had a much lower public profile than the large organizations, and didn’t send many witnesses to Congress. Things would change in the 1980s with the emergence of the AIDS and breast cancer movements.

In one important way, the philanthropic health campaigns of the mid-twentieth century laid the groundwork for the disease movements of the 1980s and 1990s. The disease crusades succeeded in pushing the NIH to concentrate more of its research on disease categories, setting precedents for earmarks and creating institutes that disease associations could target. Throughout its history, the NIH has conducted both “categorical” research, which targets a particular disease, and “fundamental” research, which focuses on developing an understanding of the human body and disease agents.
Many NIH scientists and officials preferred to focus on fundamental research and avoid using “disease-based criteria” to allocate funds (Sampat 2009:155; see also Guston 2000). However, in light of the early twentieth-century disease campaigns, NIH officials increasingly concluded that “the way to open wide the public’s purse was to call attention to one disease at a time” (Starr 1982:343; see also Rettig 2005:11). Recognizing that a disease focus was crucial for acquiring public funding, the NIH created institutes focused on broad disease categories or renamed existing institutes (Casamayou 2001:35). For instance, in 1955, the “Microbiology Institute” was renamed the “National Institute of Allergy and Infectious Diseases (NIAID)” (Strickland 1972:192). This name change is illustrative of the shift from thinking in terms of scientific categories to medical categories. Beginning in the 1960s, the institutes in turn launched growing numbers of program branches based on disease categories (Strickland 1988:77). This categorical focus set the precedent for distributing NIH funds in disease categories, laying the groundwork for later claims by disease advocates.

Identity Politics for AIDS and Breast Cancer

In the 1980s, large movements emerged targeting AIDS and breast cancer. Like the earlier neuromuscular disease associations, they viewed patients as their constituents. But their size and success quickly overshadowed these earlier movements. Epidemiological features had something to do with the dramatic growth of the AIDS and breast cancer movements. But the key to understanding their growth is the fact that they drew on the gay rights movement and the women’s health movement. These existing movements gave them resources, organizational infrastructure, strategies, and a template for identity-based organizing. Both disease movements spun off from the earlier movements, retaining the model for identity politics but organizing a field of advocacy around disease identities.

AIDS

Some explanations for the success of the AIDS movement focus on the features of the disease itself. AIDS affected young people who might have several symptom-free years after being diagnosed, leaving them time and energy to participate in the movement (Epstein 1996:10). Moreover, activism held out “the promise of some profoundly tangible immediate rewards, most notably access to potentially life-prolonging medications” (Epstein 1996:10). While these features of the disease facilitated organizing, they are not unique to AIDS and cannot explain why AIDS advocacy took off in a way movements targeting other diseases did not.

The key reason for the AIDS movement’s success was its ability to draw on the gay rights movement. When AIDS emerged in the United States in the early 1980s, the gay rights movement was already very strong. Hundreds of organizations existed that focused on gay rights or various components of gay identity. Freedom day parades occurred
annually in cities across the country, and the movement had begun to challenge the stigma associated with homosexuality (Armstrong 2002).

AIDS threatened to overturn the gay rights movement’s gains: the disease “challenged every aspect of the gay identity movement: the lives and bodies of gay men, beliefs about the healthfulness of gay sex, hard-won pride in gay identity, and the movement’s political and cultural organizations” (Armstrong 2002:155). Many initial responses sought to distance the gay rights movement from AIDS. When public health officials suggested that gay men’s sexual practices might be putting them at risk, some activists in the movement were skeptical about whether sexual behavior was actually causing the disease, or whether officials were engaging in moralizing. Fearing that AIDS would further stigmatize homosexuality, some gay people and activists distanced themselves from AIDS. (Armstrong 2002:158-60). Thus, the existence of the gay rights movement did not automatically create an AIDS movement.22

But after this “initial period of fear and confusion,” gay activists founded hundreds of organizations to provide services, raise funds for research, develop safe-sex guidelines, and protest delays in drug delivery (Armstrong 2002:161). This large-scale response was made possible by the resources provided by the existing gay rights movement. First, the movement had a significant organizational infrastructure. Some gay organizations already focused on health or STD treatment (Armstrong 2002:164). Even non-health-related gay organizations served as incubators for AIDS activism; several high-profile AIDS organizations, including ACT UP, were founded at gay and lesbian community centers (ACT UP 2012; AIDS Project Los Angeles 2012). In addition to providing material resources, existing social movement organizations were sites for face-to-face interaction that served as "micro-mobilization contexts" (Epstein 1996:11). The gay rights movement also meant that there was a cohort of men and women who were experienced activists (Epstein 1996:12; Gamson 1989:354). Finally, the strategic expertise of the gay rights movement translated well into the campaign to reduce the stigma of AIDS. The movement could draw on “more than a decade of experience reversing stigma, including that associated with sexual practices” (Armstrong 2002:162), and could mobilize quickly in response to a threat to group identity (Epstein 1996:11).

The gay rights activists who founded the earliest AIDS organizations did not intend to create a separate social movement. “When gay men and lesbians rallied to take care of their brothers with AIDS, they envisioned themselves as serving their community, not as creating a new sector of the medical health care establishment” (Armstrong 2002:156). At least initially, the boundaries between the gay rights movement and the AIDS movement were blurry. Many early AIDS organizations were explicitly connected to gay issues (e.g., Gay Men’s Health Crisis). Even organizations without explicit gay

22 The black community’s response to AIDS shows that the existence of an identity-based social movement does not automatically create a unified response to a disease that disproportionately affects the group. AIDS fractured the black community rather than bringing it together (Cohen 1999, Quimby and Friedman 1989).

23
affiliations often had few non-gay members (Gamson 1989:356), and they organized “actions in which AIDS is not the central issue or in which AIDS activism is incorporated into the project of ‘recreating a movement for gay and lesbian liberation’” (Gamson 1989:355).

However, most of the AIDS organizations spawned by the gay rights movement soon jettisoned their gay identification (Armstrong 2002:170-1). Armstrong (2002) attributes this shift to the fact that responding to an epidemic requires different organizational forms, strategies, and political logics than promoting an identity (Armstrong 2002:173). In order to provide services to sick and dying people, AIDS organizations needed to pursue government funding and forge ties to the medical profession, creating “intense pressure to conform to conventional organizational forms and practices” (Armstrong 2002:171). AIDS organizations became larger, more bureaucratic, more focused on courting donors, and less involved in grass-roots activity (Armstrong 2002:171). Moreover, the biological realities encouraged organizations to define their populations more broadly: the virus could and increasingly did infect non-gay people, meaning that the people being served were no longer a majority gay (Armstrong 2002:174).

As these institutional pressures and biological realities shifted AIDS organizations’ focus away from gay issues, they began to explicitly distinguish themselves from gay organizations. The New York ACT UP chapter sent out a standard correction letter whenever newspapers called it a “gay organization” (Gamson 1989:356). ACT UP explicitly defined its constituents across social boundaries, saying that it served people with AIDS, “whether it is an entire family with AIDS in Harlem or an HIV + gay man in San Francisco” (Gamson 1989:357). As the field of AIDS organizations became increasingly institutionalized, the number of AIDS organizations without explicit gay affiliations soon dwarfed the number of lesbian/gay AIDS organizations (Armstrong 2002:163).

Thus, the gay movement launched the AIDS movement, but spun it off into a separate category for organizing. The gay movement’s organizational infrastructure, political clout, and experience organizing around a stigmatized identity were crucial resources explaining the strength of the social movement response to AIDS. Moreover, the gay rights movement gave AIDS advocates a model for identity politics and interest group advocacy. Activists who had previously focused on building a unified gay and lesbian community now focused on building a community of people with AIDS (Gamson 1989:354). But the realities of fighting an epidemic created pressures for these new organizations to organize explicitly around the category of AIDS, rather than around sexuality. Thus, AIDS activism was a new type of identity politics, born of the transposition of schemas from the gay rights movement to disease advocacy.
Breast cancer

Like AIDS, breast cancer in the 1980s had some epidemiological features that encouraged organizing. The rising incidence of the disease made it seem like a new threat, and few good treatments were available (Anglin 1997:1403-4; Klawiter 2008:3). Increased awareness led to more screening and more diagnoses, creating more patients and also more women who perceived themselves to be at risk (Casamayou 2001:60; Klawiter 2008:xxvii, 146; see also Clarke et al. 2003; Rabinow 1992; Timmermans and Buchbinder 2010). Since it was unclear what caused the disease, all women were potential victims, creating an automatic constituency that was linked to a pre-existing identity group (Anglin 1997:1403-4).

Like the AIDS movement, the breast cancer movement drew from a pre-existing identity-based movement, but spun off from it. Breast cancer advocacy was launched by the women’s movement, and in particular, the women’s health movement. This grassroots movement of the 1960s and 1970s, with roots in second wave feminism, pushed for women’s control over their bodies and their medical care (Morgen 2002; Ruzek 1979; Weisman 1998). Several features of the women’s health movement laid the groundwork for the breast cancer movement.

First, a key goal of the women’s health movement was to educate women about their bodies and encourage them to discuss their health issues (Weisman 1998, Epstein 2007:56). The ongoing push for frank discussions of women’s health raised the public prominence of breast cancer. In the 1970s and 1980s, a series of feminist writers publicized their experiences with breast cancer (Anglin 1997:1405; Kedrowski and Sarow 2007:22). They were joined by a series of influential Republican women going public with their diagnoses of breast cancer (Ferraro 1993; Kedrowski and Sarow 2007). From a private, shameful problem, breast cancer was becoming something you could speak about in public. This declining stigma meant that by the early 1990s, breast cancer organizations quickly received sympathetic media coverage (Casamayou 2001:60).

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23 The women’s health movement was part of a wave of health movements that also served as precursors to later disease advocacy, including movements rejecting mental health treatment, renouncing the medicalization of disability and homosexuality, and seeking environmental justice (Moore 2006). The consumer protection movement of the 1970s also laid important groundwork for patients’ advocacy (Carpenter 2010).

24 I focus on the breast cancer movement because of its size and influence over later movements. But breast cancer was not the only health issue targeted by spinoffs from the women’s health movement. Women also initiated social movements targeting postpartum depression (Taylor 1996) and infant loss (Layne 2006). Many women active in the AIDS movement were also influenced by the women’s health movement (Epstein 1996:12).
Second, the women’s health movement created a network of people and organizations that incubated the breast cancer movement. The women’s health movement created women-run health centers, self-help clinics, and birth centers, encouraged women to go to medical school, and “created a cohort of women concerned about matters of health and health care” (Weisman 1998:76). These organizations encouraged women to meet and talk about their health concerns, inspiring the growth of breast cancer support groups in the late 1970s and 1980s (Casamayou 2001:47). The first national breast cancer organization, Y-Me, was founded in 1978, and it focused on supporting patients and survivors and providing information hotlines (Kedrowski and Sarow 2007:22). The National Alliance of Breast Cancer Organizations (NABCO) and the Susan G. Komen Foundation were both founded in 1982. Following in the footsteps of women’s health educators, NABCO focused on providing information to patients, families, the media, and doctors (Kedrowski and Sarow 2007:24). In the 1990s, groups that were initially focused on providing support to members turned into political advocacy groups (Kedrowski and Sarow 2007:24). In an ethnographic study, Anglin (1997) describes how a breast cancer advocacy organization “literally grew out of a support group;” frustrated with the limited treatments available, the members of a support group founded an advocacy organization to push for the prevention and cure of breast cancer (Anglin 1997:1406).

Third, the women’s health movement established a tradition of challenging the authority of the medical profession. Some of the movement’s key grievances targeted the doctor/patient relationship. Activists claimed that doctors, who were almost all male, treated women with condescension, withheld information from them, and exposed them to risky drugs, devices, and unnecessary surgeries (Weisman 1998). Early breast cancer activism followed in this tradition. Breast cancer treatment often involved the removal of the entire breast. Moreover, doctors routinely put patients under for a biopsy and then, if they found cancer, removed the entire breast without waking the patient to discuss treatment options or acquire her consent. Early breast cancer advocates pushed for better treatment, more patient-centered decision-making, and lumpectomies rather than radical mastectomies (Anglin 1997:1405; Casamayou 2001:50-52; Kedrowski and Sarow 2007). These efforts contributed to radically declining rates of radical mastectomies and the passage of Breast Cancer Informed Consent laws in 18 states in the 1980s (Anglin 1997:1405; Kedrowski and Sarow 2007:23). Later breast cancer advocates also challenged scientists’ prerogative to determine the research agenda, arguing that breast cancer and other women’s diseases had been systematically underfunded (Casamayou 2001:137-40; Weisman 1998:79).

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25 The women’s health movement was part of a general decline in deference to physicians and the autonomy of scientists. Environmental and consumer advocates challenged scientists’ decision-making (Hilgartner 2000; Nelkin 1979), policymakers sought increased oversight of publicly funded research (Guston 2000), and patients refused to remain “passive recipients of medical expertise” (Rose 2007:23; see also Starr 1982).
Just as the AIDS movement spun off from the gay rights movement, the breast cancer movement created a separate niche, apart from the women’s health movement. This process involved defining breast cancer as the movement’s target (rather than women’s health more generally), and also meant adopting more mainstream rhetoric, goals, and tactics. The largest breast cancer charity, the Susan G. Komen foundation, distanced itself from lesbians and feminists and embraced traditional femininity (Klawiter 2008:139). Rejecting the women’s health movement’s critique of medical authority, Komen avoided challenging scientists (Klawiter 2008:139) and focused on research and early detection (Klawiter 2008:144).

The fact that the breast cancer movement drew on the women’s movement but seemed distinct from feminism created political opportunities for the movement in the early 1990s. The Clarence Thomas / Anita Hill controversy created a “climate of heightened sensitivity” about women’s issues in Congress; Senator Tom Harkin (D-IA) noted that “a lot of male colleagues don’t want to be on the wrong side of any women’s issue” (Casamayou 2001:141; see also Weisman 1998:78). However, many women’s issues were politically risky, tied up with the politics of abortion or feminism. Supporting breast cancer funding was a politically attractive option for members of Congress seeking to “demonstrate a commitment to women’s issues” while avoiding controversy (Kedrowski and Sarow 2007:145). Breast cancer’s unique combination of links to and distance from women’s identity politics helped the movement secure large increases in federal medical research funding.

Both AIDS and breast cancer had features that made them amenable to organizing, including quickly increasing prevalence and a lack of treatments. But while these epidemiological and medical characteristics could describe many diseases across the twentieth century, these two disease movements were unprecedented in their size, organization, and influence. They grew so quickly because they could draw on existing identity-based movements. Breast cancer and AIDS drew on the gay rights and women’s movement, but crucially, they spun off into separate identity categories. They retained the organizational strength and social movement expertise of the initial movements, but disease categories carried less stigma than homosexuality and feminism. It was a compelling model that launched a wave of copycat movements.

**Spillovers, Diffusion, and Transposition**

AIDS and breast cancer advocates institutionalized a model for disease advocacy that spread quickly across diseases. In the 1980s, there were steep increases in the numbers of witnesses testifying (see Figure 2.1) and in the proportion of those witnesses who were

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26 Breast cancer lay at the intersection of several policy arenas, and in each one, it was arguably the least controversial option. It was a women’s issue but not identifiably “feminist;” it was a “safe” disease to support, unlike AIDS; and it was a health issue that would not attract organized opposition, unlike health care reform (Casamayou 2001).
patients or family members (see Figure 2.2). This section explains these rapid increases by analyzing the process through which disease advocacy spilled over from AIDS and breast cancer to other diseases.

Disease Characteristics

Some explanations for the increase in activism focus on the characteristics of diseases. First, the rise of disease identity politics may have been facilitated by the shift from infectious to chronic diseases as the primary public health threats. It is harder to involve patients in activism if they either die or recover quickly, as is the case with many infectious diseases (Foreman 1995; Wood 2000). Patients may be more likely to think of a chronic disease as part of their identities (Bury 1991). The history of disease advocacy supports the claim that chronic diseases are more likely to be the targets of identity politics. The early campaigns against tuberculosis and polio, both infectious diseases, did not view patients as their constituents. With the exception of AIDS, most contemporary patients’ movements have targeted chronic diseases. My statistical analyses confirm that fewer nonprofits were founded to target infectious diseases (though these results are not statistically significant) and that fewer witnesses testified in Congress about infectious diseases (see Table 2.2).

Second, people will make political claims on the basis of a disease category only if they are willing to publicly acknowledge their disease. They may be more likely to take this step when the disease is not stigmatized. Breast cancer advocacy emerged after the women’s health movement made breast cancer less shameful to speak about publicly. Prostate cancer has been targeted by less activism, perhaps in part because it is still considered private and shameful (Kedrowski and Sarow 2007). Beard (2004) suggests that assumptions about the incapacity of Alzheimer’s patients make them reluctant to play a public advocacy role. While I lack detailed measures of the changing levels of stigma of various diseases over time, I can classify a subset of diseases as more stigmatized than others. Again with the exception of AIDS, fewer organizations were founded to target these diseases (though this pattern is not statistically significant), and fewer witnesses testified about them in Congress (see Table 2.2).

Over time, chronic diseases have replaced infectious diseases. And arguably, overall levels of disease stigma have decreased as people have become more willing to discuss diseases publicly. But these changes have occurred gradually over decades, and cannot explain the rapid rise in disease advocacy in the late twentieth century. Explaining the rapid increase requires looking at spillovers between movements and the diffusion of organizational forms.

27 AIDS, hepatitis, liver cancer, lung cancer, and chronic liver disease.
Spillovers

My statistical analyses highlight the fact that early disease movements facilitated later ones. In model 1 (Table 2.2), the dependent variable is the number of nonprofits founded targeting a particular disease in a particular year. The independent variables include the number of pre-existing nonprofits that already targeted that disease and all other diseases. In model 2 (Table 2.2), the dependent variable is the number of witnesses testifying about a disease in Congress. The independent variables include the number of witnesses who testified about that disease and all other diseases in the previous year. Both models are consistent with the claim that spillovers facilitated the growth of disease advocacy. Even when including year fixed effects to account for overall time trends, the models suggest that it was easier to get a disease movement off the ground when movements already targeted other diseases. The existence of nonprofits targeting other diseases seems to promote the founding of nonprofits targeting a given disease. And each disease was likely to send more witnesses to Congress following years when witnesses representing other diseases testified.28

Below, I draw on secondary sources and quantitative data to document spillovers across disease movements. This analysis reveals the importance of the increasing legitimacy of disease advocacy and the sharing of expertise, strategies, and symbols. I discuss spillovers from the AIDS movement onto the breast cancer movement and from AIDS and breast cancer to other diseases.

Legitimacy

The more organizations that exist of a given type, the more legitimate the organizational form comes to seem. This legitimacy lowers the cost of founding new organizations (Hannan and Freeman 1977; McLaughlin and Khawaja 2000; Meyer 1987). Legitimacy helps organizations attract participants, impress funders, and gain access to policymakers (Minkoff 1995:76), making it more likely that organizations will survive (Meyer and Rowan 1977). For example, the creation of “a template for organizational growth” allowed the field of gay identity organizations to expand rapidly (Armstrong 2002:115). Similarly, the founding rate of environmental organizations increased dramatically as their legitimacy increased (McLaughlin and Khawaja 2000).

My data on disease nonprofits show the dramatic expansion of the field once the organizational form had been legitimized. Reliable data on nonprofits are available beginning in 1991. That year, there were fewer than 400 single disease nonprofits. By 2003, there were over a thousand. Their share of the health nonprofit field doubled to

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28 The fact that these effects remain significant when including year fixed effects and controlling for a disease’s own organizations suggests that there may be spillovers across disease movements. However, these findings are also consistent with a pattern in which advocacy targeting all diseases expanded at the same time for another reason.
15% (see Figure 2.1, dotted line). And as the model for patient-centered activism became increasingly institutionalized, a growing majority of the witnesses testifying about diseases in Congress were patients or family members (see Figure 2.2).

Between diseases, the first step in the diffusion process was from AIDS to breast cancer. According to the founding president of the National Breast Cancer Coalition, “the NBCC was formed to offer breast cancer what AIDS activists had offered AIDS” (Kedrowski and Sarow 2007:26). Other influential breast cancer activists spoke of being inspired to “follow the AIDS model” (Casamayou 2001:78; see also Ferraro 1993). According to NABCO director Amy Langer, AIDS activists proved that “if you want your disease to be dealt with, you go and you talk about it and you market it and you visit and you stomp and you write letters and you do it” (quoted in Belkin 1996).

When movements succeed, they show other potential advocates that a form of advocacy can work, sparking mobilization by inspiring a “feeling of political efficacy” (Minkoff 1995:31; McAdam 1982; Piven and Cloward 1978). For example, large numbers of organizations pushing for the rights of women and racial minorities were founded after federal civil rights legislation demonstrated to potential advocates that their efforts were likely to pay off (Minkoff 1995:53). Figure 2.3 shows the dramatic increases in federal funding for AIDS and breast cancer research over time. Not all of the funding increases can be attributed to advocacy—AIDS research especially had supporters within the medical establishment. But these dramatic increases attracted notice and attention from advocates for other diseases. The AIDS activists’ successes convinced breast cancer advocates that their efforts would be successful. Fran Visco, president of the NBCC, remembered being “emboldened” by the success of the AIDS movement’s “grass-roots advocacy” (quoted in Belkin 1996). Francine Kritchek, cofounder of 1 in 9, an influential Long Island-based breast cancer organization, recalled that “The AIDS activists were our model… They showed that if the populace became very concerned, then politicians would respond” (quoted in Ferraro 1993).

Later disease organizations followed the AIDS and breast cancer models. For instance, an early prostate cancer group called “US TOO!” derived its name from the breast cancer organization “Y ME?,” and advocates formed a National Prostate Cancer Coalition based on the National Breast Cancer Coalition (Kedrowski and Sarow 2007:32). The AIDS movement also inspired movements targeting Lyme disease and chronic fatigue syndrome (Packard et al. 2004:8-10). Even organizations that had more professional-oriented roots moved towards the AIDS and breast cancer model for patient-centered advocacy. Like the tuberculosis and polio movements, the Alzheimer’s Association was founded with major input from scientists. But some of the founding members came from

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29 These counts refer to nonprofits with budgets above $25,000 in 1987 dollars. Organizations with budgets below $25,000 do not file the tax forms that are included in the NCCS data. Since the IRS does not adjust this cutoff for inflation, I drop all organizations with budgets that would have been below $25,000 in 1987 dollars to avoid inflating the number of organizations in later years.
family support groups and most staff members had a relative with the disease (Beard 2004:803-4). As the patient-centered model became institutionalized, association staff felt pressured to focus more on patients (as opposed to caregivers and scientists). One staffer interviewed by Beard (2004) noted that “the people that we serve [now] are the people with the disease… that’s changed since I’ve been with the Association” (Beard 2004:805). Similarly, the fibromyalgia movement began in the late 1980s when rheumatologists, supported by drug companies, organized conferences seeking to legitimate the diagnosis. But nonprofit patients’ groups soon emerged to partner with the scientists (Barrett 2004:149-154).

In addition to encouraging the founding of new organizations, the increasing legitimacy of a form of advocacy can create opportunities within the political system. Scholars recognize that movements that are “early risers” or “initiators” can create political opportunities that ease the way for later “spinoff” movements (McAdam 1995; Tarrow 1994; see also Goodwin and Jasper 2004). The civil rights movement opened the door for the women’s movement (Tarrow 1994; see discussion in Minkoff 1997:783). After the hard-fought effort to secure affirmative action policies for African Americans, other ethnoracial groups were included “almost immediately and without difficulty” (Skrentny 2006:1763).

The AIDS and breast cancer movements similarly created political legitimacy for later disease movements. Both movements had to work hard to gain access to health officials and policymakers. As “the first social movement in the United States to accomplish the large-scale conversion of disease ‘victims’ into activist-experts,” AIDS activists “established their credibility as people who might legitimately speak in the language of medical science” (Epstein 1996:8-9). The process through which AIDS activists gained the right to participate in NIH decision-making reveals the obstacles they faced in blazing this trail. As the activists became increasingly educated and organized, it became clear that the NIH could no longer exclude them completely. In 1989, Anthony Fauci, the director of the NIAID, gave ACT UP permission to participate in the meetings for the institute’s AIDS Clinical Trial Group (ACTG), hoping that this would encourage greater enrollments in clinical trials (Arno and Feiden 1992:226). However, other NIAID officials and ACTG investigators were resistant, and ACT UP never received an official invitation to the 1989 meetings. They came to protest, and one NIAID official publicly announced that

We didn’t invite them and we wish they weren’t here, but they are here and we have decided to try to avoid the danger of a physical confrontation by allowing them to attend all open meetings. However, they will not ask questions nor be allowed to talk.

(Dan Hoth, quoted in Arno and Feiden 1992:227).

After ACT UP protested NIAID’s “hostility” and “double-dealing,” the ACTG leadership agreed to create an advisory committee for community representation. But activists would not be represented on the committees where decisions were actually made. After a major protest at the NIH in 1990, NIAID announced that they would include patients’
representatives on all ACTG committees (Arno and Feiden 1992:227-235). After a bruising fight, AIDS activists had institutionalized a model for patients’ advocates to participate in the planning of research at the NIH. This victory set a precedent for the inclusion of patient representatives on NIH and FDA panels (Epstein 1996).  

The AIDS movement may also have legitimated claims for NIH funding. Activists first targeted the FDA, seeking access to potentially life-saving experimental drugs. In challenging the NIH to invest more in research, the movement faced a harder challenge in communicating the issue’s importance to the public. According to one activist, “It is harder to organize people around deaths caused by drugs which do not exist and perhaps never will, but should” (Arno and Feiden 1992:232; Epstein 1996). In later years, disease advocacy organizations could follow the AIDS model and quickly organize people to lobby the NIH for more research.

These precedents and institutionalized systems for participation let later disease advocates participate without the same struggles. Fat-acceptance advocates used the AIDS model to “claim authority to intervene in medical debates,” and they got “a seat at the table at FDA and NIH meetings” (Saguy and Riley 2005:909). When Alzheimer’s advocates clamored for access to Tacrine, an experimental drug, the FDA allowed access using system it had developed under pressure from AIDS activists (Arno and Feiden 1992:239). Schizophrenia patients were similarly inspired by ACT UP to challenge pricing for a new antipsychotic drug in 1990 (Arno and Feiden 1992:244).

Disease advocates also used the success of AIDS advocacy as a rhetorical tool to increase the legitimacy of their claims. Breast cancer advocates cited the success of AIDS to argue that breast cancer deserved more federal funding (Klawiter 2008:285). Similarly, Chronic Fatigue Syndrome activists drew on AIDS’ legitimacy, calling their disease “AIDS junior” and “non-HIV positive AIDS,” and pushed to add “immune dysfunction” to the name to invoke “an association with AIDS” (Barrett 2004:160-1). Advocates for Parkinson’s disease, prostate cancer, and diabetes also cited the funding levels for AIDS and breast cancer in lobbying for their own earmarks (Dresser 1999; Johnson 1998).

Breast cancer advocates also dramatically increased the political legitimacy of disease advocacy. In the early years of the movement, grassroots breast cancer advocates struggled to get meetings with Congressional staffers—a far cry from the current situation, in which many representatives “are anxious to meet with them personally and seek opportunities to attend NBCC events” (Kedrowski and Sarow 2007:145). Corporate partners were also wary; when the Komen foundation asked bra manufacturers to help them promote mammograms, they refused, saying it would be “negative advertising” (Belkin 1996). Now, pink ribbons decorate everything from sneakers to buckets of fried chicken (Sulik 2011). When the movement secured funding increases for breast cancer research in 1992, they faced widespread criticism for promoting “junk science” in *Time*,

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30 AIDS patients were not the first to push the FDA for access to experimental drugs; they followed in the footsteps of cancer advocates in the 1970s (Carpenter 2010).
the *New York Times*, the *Washington Post*, and *Science* (Anglin 1997:1410). By the end of the 1990s, favorable coverage of breast cancer advocacy was plentiful (Sulik 2011).

These successes smoothed the way for later movements. Members of Congress sometimes added prostate cancer to breast cancer legislation (Kedrowski and Sarow 2007:160). Breast cancer proponents set a precedent for earmarking Department of Defense funds for breast cancer research. Once the program was in place, it was relatively easy to incrementally expand it, and advocates for other diseases successfully pushed for DOD funds for their diseases (Kedrowski and Sarow 2007:160).

Perhaps due to these pathways for access to policymakers, advocates for other diseases were less likely than AIDS advocates to rely on confrontation and disruption. One group of breast cancer activists seeking compassionate use access to an experimental drug used disruptive tactics to protest a drug company. They borrowed ACT UP’s strategy of phone “zaps” (tying up phone lines with a barrage of calls) and collaborated with AIDS activists to stage a “die-in” and blockade the company’s headquarters. But the breast cancer organization’s board said that the demonstrators had gone too far. Similarly, some Chronic Fatigue Syndrome advocates adopted ACT UP’s tactics (Barrett 2004:160), but the CFIDS Association seeks “mainstream respectability” and avoids “sit-ins or noisy street protests” (Foreman 1995:42-43). Thus, as the patient advocacy model expanded across diseases, later diseases tended to rein in disruptive strategies in favor of more mainstream lobbying. Advocates for these diseases may have faced fewer hurdles than AIDS activists due to lower levels of stigma. However, it is also possible that disruptive activism was less necessary, since the AIDS and breast cancer movements had forged pathways for more direct political influence.

My data on witness testimony reveal evidence of these increasingly well-trodden avenues for disease advocates’ political participation. With the emergence of the AIDS and breast cancer movements in the 1980s, the numbers of disease advocates testifying in Congress ballooned, and by the 1990s, single disease advocates were consistently between 10 and 15% of the witnesses at HHS appropriations hearings. These percentages are extraordinarily high, given that these hearings cover federal agencies from labor to education, and many types of health policy that are not disease-specific. Congressional testimony had become an institutionalized way for disease advocates to communicate with policymakers.

**Expertise, Strategies, and Symbols**

In addition to legitimacy, existing organizations can provide expertise, symbols, and strategies to new organizations (Freeman 1973; McAdam 1995; Meyer and Whittier 1994; Minkoff 1994, 1995; Taylor 1989; Walker 1983; Whittier 2004). For example, the civil rights movement’s tactics of sit-ins and passive resistance were adopted by the anti-war movement (McAdam 1988). Similarly, the peace movement adopted protest techniques from the women’s movement (Meyer and Whittier 1994).
Disease movements drew on the expertise of advocates from forerunner movements. For example, ACT UP activists taught Bay Area breast cancer activists “how various agencies worked and helped them organize a protest against Genentech” (Klawiter 2008:285). In turn, breast cancer advocates advised later movements. For instance, while forming the National Prostate Cancer Coalition, NPCC advocates invited a former vice president of NBCC to address and advise them (Kedrowski and Sarow 2007:32). The Arthritis Foundation supported the nascent fibromyalgia movement by sending speakers to meetings, offering self-help courses, and publishing books on the subject (Barrett 2004:154). This cooperation across diseases facilitated the expansion of the disease advocacy field.

As a groundbreaking disease movement, AIDS activists did significant cultural work in creating a symbol for the fight against AIDS. They experimented with several possibilities before settling on the red ribbon. At the 1991 Oscars, ACT UP Los Angeles passed out 1000 Silence=Death pins and only three celebrities wore them (Green 1992). Searching for a symbol that more people would adopt, activists turned to another type of awareness campaign:

The yellow ribbons from the Gulf War were still all around," said Patrick J. O'Connell, [ACT UP Los Angeles] director and one of the original ribbon makers. "We noticed that they could mean anything from 'I care about young people who have gone overseas' to 'I support Bush.' We wanted that kind of leeway, too, something that could mean 'I hate this Government' or just 'I care about people with AIDS.'"

(Green 1992)

These multiple possible meanings made the ribbon inoffensive, nonthreatening, and easier to wear. Activists distributed red ribbons at the 1991 Tonys and Emmys and the 1992 Grammys, where hundreds of celebrities wore them and some discussed them on the air (Green 1992). The AIDS activists’ creativity in transposing the ribbon symbol from support for the troops to a disease had paid off.

After the success of the red ribbon, it was an easy move to create ribbons for their diseases. The year after AIDS ribbons took off, breast cancer advocates began producing pink ribbons. Evelyn Lauder, founder of the Breast Cancer Research Foundation, recalls that “Alexandra [Penney] had the idea to take the loop pin, from AIDS, and to make it pink. I said, ‘We could give away these pink ribbons at all the Estee Lauder counters all over the country’” (quoted in Belkin 1996). 31 After the breast cancer movement adopted the pink ribbon, the numbers of colored disease ribbons took off rapidly. In a parallel to

31 Others attribute the pink ribbon to Charlotte Haley or to the Susan G. Komen Foundation (Kedrowski and Sarow 2007:59; McCormick 2009:44-5). The Komen Foundation states that they gave out pink ribbons to participants in the Race for the Cure in 1990, suggesting that they may have adopted the symbol before AIDS advocates (Sulik 2011:47).
the pink ribbon, prostate cancer advocates adopted a blue ribbon (Kedrowski and Sarow 2007:59). Now, hundreds of diseases use ribbon symbols (craftsncraps.com 2012). The ballooning numbers reflect the relative ease of transposing schemas across short distances. Since ribbons are widely understood as disease symbols, advocates for rarer diseases can adopt a ribbon and feel confident that the symbol will be intelligible, even without a major promotional campaign.

Another strategy that spilled over across diseases was the fundraising and awareness walk. The March of Dimes had run a charity walk since 1970, first called WalkAmerica and then the March for Babies, with proceeds funding research on birth defects. Organizers call it “the oldest walking event in the country” (Brenner 1999). In the 1980s, both AIDS and breast cancer advocates drew on the idea of a charity walk and launched high-profile walks to bring attention and funding to their diseases. The first American AIDS walk took place in Los Angeles in 1984, drawing 4,500 supporters and raising $673,000 (AIDS Walk Los Angeles 2012). Just as AIDS advocates experimented before settling on the ribbon design, the Susan G. Komen foundation used multiple fundraising events, including “lunches, races, polo matches, cocktail parties, dinner dances and other events” (Klemesrud 1985). The first Race for the Cure was held in Dallas in 1983, and it was the fundraising model that took off. The trademarked races now occur annually in 136 locations and draw 1.5 million participants (Sulik 2011:50).

Advocates for other diseases consciously adopted the form and borrowed its legitimacy. For instance, organizers of a prostate cancer walk hoped that it would succeed, “much like breast cancer has benefited from the Susan G. Kolman’s Race for a Cure [sic]” (quoted in Kedrowski and Sarow 2007:33). Like ribbons, fundraising walks have diffused widely, but remained tightly linked to diseases. In 2012, a website attempting to compile an exhaustive list of charitable walks listed events in 46 categories, 38 of which were diseases (charitywalksblog.com 2012). This proliferation of disease walks reveal the prominence and legitimacy of this fundraising strategy.

**Competition**

So far, I have focused on positive spillovers, in which initial disease organizations smoothed the way for later organizations. However, previous researchers emphasize that social movement organizations can also compete with each other for resources, personnel, members, and access to policymakers (Armstrong 2002; Koopmans 1993; Minkoff 1997; McCarthy and Zald 1977; Tarrow 1991), and that competition sometimes leads to the disbanding of SMOs (Gray and Lowery 1995). Density-dependence theory suggests that while initial increases in density promote organizational founding by increasing the legitimacy of an organizational form, further increases lead to competition, lowering founding and survival rates (Hannan and Carroll 1992). Minkoff (1995) found

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32 I also found media coverage of a lower-profile AIDS walkathon in Canada in 1983 (Globe and Mail 1983).
that among social movement organizations promoting the rights of women, African Americans, and other racial minorities, there was “a modeling or legitimation effect across group boundaries and competition within them” (Minkoff 1995:115).

My data are consistent with Minkoff’s (1995) finding that more similar organizations are likelier to compete. Model 1 (Table 2.2) shows that when more organizations targeting a particular disease already existed, fewer new ones were formed. While organizations targeting other diseases facilitated organizational founding, organizations targeting the same diseases do seem to compete with one another. My data on witnesses are also somewhat consistent with the competition argument. The increasing proportion of single disease advocates among HHS witnesses abruptly leveled off in the 1990s (see Figure 2.1). Secondary sources suggest that the number of disease advocates who wanted to participate continued to increase, but as their numbers expanded, the appropriations committee instituted a lottery system to determine which disease advocates would be allowed to testify (Stolberg 1999). However, the number of witnesses targeting a disease in the previous year is positively associated with the number of witnesses, suggesting that the general pattern was one in which early disease advocates created political opportunities for later ones.

Conclusion

The case of disease advocacy provides insights into how identities become politicized. Broader social changes make people more likely to identify with a category and mobilize around it. But to explain the expansion of a type of organizing, we need to consider the interactions between social movements.

The expansion of disease advocacy relied in part on changes in science, medicine, and the experience of disease. The germ theory made tuberculosis seem like a solvable problem, inspiring philanthropists to tackle it. The success of the polio vaccine created enormous faith in medical research, inspiring later disease movements. Chronic diseases replaced infectious diseases as the biggest killers, and overall levels of disease stigma declined; my data show that chronic and non-stigmatized diseases were more likely to organize. Medical screening may have made more people feel at risk, motivating advocacy for breast cancer and other diseases.

But to truly explain the rapid rise of disease advocacy, we need to understand spillovers and diffusion. The AIDS and breast cancer movements inherited resources, advocates, and models for organizing from the gay rights and women’s health movements. But there was significant cultural work involved in transposing ideas from these other identity categories onto diseases, and then spinning off diseases as their own movements. Other diseases quickly followed the examples of AIDS and breast cancer, with their quick multiplication showing the ease with which schemas can be transposed across short distances.
# Tables and Figures

**Table 2.1: Descriptive Statistics**

<table>
<thead>
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<th>Category</th>
<th>Mean / %</th>
<th>SD</th>
<th>Min.</th>
<th>Max.</th>
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<td>7.5</td>
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</tr>
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<td>.87</td>
<td>0</td>
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<td>.88</td>
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<td>5</td>
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<tr>
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<tr>
<td>Stigmatized disease</td>
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<tr>
<td></td>
<td>(1) Nonprofits Founded</td>
<td>(2) Congressional Witnesses</td>
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<td></td>
<td></td>
<td>(0.0021)</td>
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<tr>
<td>Mortality changes (previous year)</td>
<td>0.090***</td>
<td>0.015</td>
<td></td>
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<tr>
<td></td>
<td>(0.022)</td>
<td>(0.014)</td>
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<tr>
<td>Infectious disease</td>
<td>-64.1</td>
<td>-0.076*</td>
<td></td>
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<tr>
<td></td>
<td>(68.8)</td>
<td>(0.031)</td>
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<tr>
<td>Stigmatized disease</td>
<td>-46.8</td>
<td>-0.080*</td>
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<tr>
<td></td>
<td>(58.8)</td>
<td>(0.039)</td>
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<tr>
<td>Observations</td>
<td>488</td>
<td>644</td>
<td></td>
<td></td>
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<tr>
<td>R-squared</td>
<td>0.440</td>
<td>0.590</td>
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Unit of analysis is the disease.
Analyses exclude HIV/AIDS and breast cancer.
All independent variables lagged by one year.
Models include year fixed effects.
Robust cluster standard errors in parentheses.

*** p<0.001, ** p<0.01, * p<0.05
Figure 2.1: Growth of Single-Disease Advocacy
Figure 2.2: Increasing Representation of Patients Among Disease Advocates
Figure 2.3: AIDS and Breast Cancer Research Funding
Chapter 3

The Politicization of Disease and the Politics of Medical Research Funding: Advocacy’s Direct, Distributive, and Systemic Effects

Abstract:

This chapter explores the effects of disease advocacy on federal medical research policymaking. Previous studies of advocacy organizations’ political effects have focused narrowly on direct benefits for constituents. Using data on 53 diseases over 17 years, I show that in addition to securing direct benefits, advocacy organizations have aggregate effects and can systemically change the culture of policy arenas. Disease advocacy reshaped the funding distribution, changed the perceived beneficiaries of policies, promoted metrics for commensuration, and made cultural categories of worth newly relevant to policymaking.
As disease advocacy expanded, patients raised their voices in Congress to an unprecedented degree, organizing to demand funding for research into their conditions. This chapter tracks their influence on federal medical research priority-setting. While previous studies of the political effects of advocacy have focused narrowly on the achievement of benefits for constituents, I show that advocacy can produce two additional types of political outcomes, which I call distributive and systemic effects. Using data on 53 diseases over 17 years, I show that diseases with the most organized patients secured dramatic increases in research funding. I find suggestive evidence that diseases that affect primarily women and blacks tended to have lower levels of advocacy, so as disease advocacy became increasingly influential, the funding distribution shifted away from those diseases. Additionally, disease advocates made claims on the basis of dollars per death, encouraging policymakers to use mortality as a metric to commensurate diseases and creating political pressure to standardize the NIH budget. Finally, the rise of disease advocacy encouraged policymakers to think of research funding as a benefit given to patients with various diseases. Once patients were thought of as the beneficiaries of medical research funding, their perceived moral worthiness became increasingly relevant to funding decisions. These results bridge medical sociology and social movements research to demonstrate that advocacy organizations transform the categories and meanings that shape policymaking.

The Effects of Disease Advocacy

Scholars have argued that the rise of health advocacy transformed the social contract for science (Callon 2003; Guston 2000; see also Banaszak-Holl et al. 2010). Advocates challenged scientific autonomy (Guston 2000), changed how medical knowledge is produced and distributed (Clarke et al. 2003; Epstein 2007), and increased the prominence of lay expertise (Epstein 1996). However, we know relatively little about disease advocacy’s effects on the politics of medical research funding. Virtually all studies of disease advocacy focus on a single disease movement (for reviews, see Epstein 2008 and Hess et al. 2008). Single-disease studies can neither document advocacy’s effects by statistically comparing outcomes across diseases nor observe the overall effects of the increase in disease advocacy. The few cross-sectional surveys of existing patients’ organizations (Allsop, Jones, and Baggott 2004; Keller and Packel 2007; Wood 2000) can neither track the growth of disease advocacy over time nor conclusively document its effects on medical research policymaking. Simultaneously, a growing literature explores the determinants of NIH funding but does not measure the influence of advocacy (Gross et al. 1999; Hegde 2009).33

33 In one exception, Hegde and Sampat (unpublished) find that lobbying has positive effects on federal funding for rare diseases.
This study is the first to analyze longitudinal data on the emergence of disease movements and also the first to track their relationship to federal medical research funding priority-setting. Studying this dramatic change in health politics allows me to expand theories of the political effects of advocacy organizations.

**Political Outcomes of Advocacy Organizations**

I argue that advocacy organizations can produce three types of political outcomes: direct benefits, distributive changes, and systemic effects. Despite a growing body of research on the outcomes of advocacy (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998; Burstein 1999; Giugni 1999; Smith 1995), only direct benefits have been systematically studied empirically.

**Direct Benefits**

Most studies of the political outcomes of advocacy focus on what I call *direct benefits*: the extent to which movements secure gains for their constituents. Researchers have looked for “success” in relation to a movement’s stated goals (Burstein et al. 1995; Gamson 1990) or for the achievement of “collective goods [for the] intended beneficiary group” (Amenta and Young 1999:40). Studies have shown that advocacy organizations can move issues up the agenda (Burstein 1991; Cobb and Elder 1983; Johnson 2008; King et al. 2007) and influence policy content and passage (Andrews 2001; Baumgartner and Leech 1998; Skrentny 2006). Not all studies show political outcomes for movements, leading to some controversy over the extent to which movements influence policy (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998).

Studying multiple diseases over time provides an ideal test whether movements can secure direct benefits for their constituents. Previous longitudinal studies of social movement effects have focused on organizations within a single social movement industry (McAdam and Su 2002; Meyer and Minkoff 2004; Olzak and Ryo 2007; Olzak and Soule 2009) or a small number (Giugni 2004; Soule and King 2008). Sampling 53 diseases over 17 years gives my analyses more statistical power and allows for more conclusive tests of whether advocacy organizations obtain direct benefits. Additionally, some previous studies of social movement effects sample on the dependent variable, only studying issues with relatively high levels of mobilization. Sampling diseases instead of movements allows me to compare diseases that were and were not targeted by advocacy, enabling stronger conclusions about causality. I draw on these unique features of my data to test whether disease advocates secured increased medical research funding for their diseases. However, we cannot fully understand advocacy’s political outcomes without exploring aggregate effects. When advocates enter a political arena, how do the distribution of resources and the decision-making process change?
Distributive Changes

When advocacy organizations enter a political arena and begin receiving direct benefits, they shift the distribution of resources to favor the type of people who are most likely to organize. If traditionally excluded groups are more likely to mobilize for change, then advocacy will tend to diminish elites’ political advantages (Berry 1999; Dahl 1961; Lofland 1996; Loomis and Ciger 1995; McAdam 1982; Piven 2006; Radcliff and Saiz 1998; Vogel 1989). Alternatively, if socially advantaged people mobilize more, then advocacy organizations will tend to skew the distribution of benefits towards advantaged groups (Edwards and McCarthy 2004; Hacker and Pierson 2010; Schattschneider 1960; Schlozman et al. 2007). I use the term *distributive changes* to describe these aggregate consequences of multiple groups’ achievement of direct benefits. As disease advocacy expanded, some researchers hoped that it would challenge an inequitable funding distribution and direct resources towards minorities’ and women’s diseases (Callahan 2003), while others worried that it would draw funds away from minorities’ and women’s diseases (Dresser 1999).

Despite being the focus of extensive theoretical debates, distributive changes are rarely empirically observed, perhaps because researchers seeking to document distributive changes face methodological challenges. Many studies focus on a single social movement, making it impossible to observe the aggregate effects of advocacy. Other studies document biases in mobilization without analyzing their distributive effects on policy, in part because it is difficult to systematically classify policies by whom they benefit. Collecting data on multiple diseases over time allows me to track changes in the funding distribution. And since diseases can be classified by their patients’ race and gender, I can track whether the emergence of disease advocacy shifted funding to or from diseases that primarily affect minorities and women.

Systemic Effects

Direct benefits occur when advocacy organizations secure advantages for their constituents, and distributive changes are the aggregate results of these individual outcomes. *Systemic effects* occur when advocates go beyond achieving benefits for their own constituents and change the structures, systems, or schemas of political decision-making. Since most researchers focus on direct benefits, systemic effects are rarely discussed. When they are mentioned, systemic effects are generally presumed to be rare, intentional, and concrete. I argue that instead, they may be common, unintended, and cultural.

First, many scholars assume that “social movements rarely alter political institutions” and that they can do so only when crises make institutions vulnerable (Giugni 1999:xxix; Kriesi and Wisler 1999). Second, researchers focus on systemic effects that are intentionally sought. Giugni (1999) suggests that social movements “face a fundamental dilemma:” the choice between demanding “short-term policy changes” and “long-term
institutional changes” (Giugni 1999:xxix). Kitschelt (1986) views systemic effects as an alternative strategy for achieving direct benefits: when an advocacy group cannot achieve its goals in the current political system, it “will try to broaden its demands to include those for altering the existing political system fundamentally” (Kitschelt 1986:67). Third, existing studies focus on concrete changes in formal rules and systems of representation, such as the introduction of new parties (Kitschelt 1986), interest groups (Clemens 1997), government offices that serve as “institutional homes” for advocates (Bonastia 2000; Epstein 2007; Skrentny 2002), and direct legislation (Kriesi and Wisler 1999). While scholars recognize that social movements often have unintended consequences and cultural effects on society at large (Andrews 2002; della Porta 1999; Earl 2004; Giugni 1999; Haveman et al. 2007), these effects are rarely discussed in the political realm.

Growing literatures demonstrate, however, that policymaking has a strong cultural element (Berezin 1997; Campbell 2002; Skrentny 1996; Steensland 2009). Policies are profoundly affected by problem definitions (Guetskow 2010; Rochefort and Cobb 1993; Stone 1989), cognitive and normative ideas (Campbell 2002), and logics of action (Skrentny 1996). Scholars recognize that social movement framing seeks to change the ideas that shape policymaking, but they generally describe framing as a strategic process that helps individual organizations or movements achieve direct benefits (Benford and Snow 2000; Cress and Snow 2000; McAmmon et al. 2007; McVeigh et al. 2003). However, if advocacy organizations change the ideas that shape policymaking, the effects are likely to go beyond direct benefits for individual movements, changing the rules of the game for all participants (Armstrong and Bernstein 2008:76). Next, I discuss two systemic cultural effects of advocacy organizations: the introduction of new categories for comparison and changes in policies’ perceived target populations.

**Commensuration**

Political decision-making often requires comparing different entities on a single metric in a process called commensuration (Espeland and Stevens 1998; Timmermans and Epstein 2010). Advocacy organizations often promote metrics for comparison that favor their causes, and if an organization’s preferred metric is adopted by policymakers, there will likely be direct benefits to that group. But new metrics for commensuration can also have systemic effects on a policy arena, since the criteria for evaluating claims affect all participants, not just the ones who lobbied for the change. Below, I show that as some

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34 Clemens (1993) describes changes in the taken-for-granted rules for political action that are both cultural and material.

35 One exception is Pedriana and Stryker’s (1997) finding that supporters of affirmative action recast the meaning of equal employment opportunity. This reframing reshaped subsequent debates about civil rights law and legitimated future government enforcement strategies.
disease advocates promoted dollars per death as a way to commensurate diseases, NIH funding for all diseases drifted towards this standard.

Target Populations and Worthiness

Policies vary profoundly depending on their perceived beneficiaries or target populations—the groups to whom they distribute resources, whom they take resources from, or whose behavior they try to change. Beliefs about the worthiness of policy targets shape which policies seem appropriate or politically feasible, influence the available frames, and are institutionalized in programs that reinforce the categories (Steensland 2006:1276; see also Lieberman 2009; Skrentny 1996, 2002, 2006; Steinmetz 2007). Policies and laws tend to disadvantage, punish, or impose restrictions on stigmatized groups and/or distribute benefits to positively constructed groups (Gilens 1999; Schneider and Ingram 1993).

Most existing research treats target populations as a constant feature of policies, often coding the target population directly from the text of bills (Donovan 2001; Schroedel and Jordan 1998). In contrast, I argue that a policy’s perceived targets can change over time. These changes in perceived beneficiaries matter because they determine whether a particular beneficiary group’s worthiness is relevant to the policymaking process. This chapter shows that while Congress formerly thought of scientists and the public at large as the beneficiaries of medical research funding, disease advocates encouraged Congress to think of disease patients as beneficiaries. Once patients were thought of as the beneficiaries, their perceived moral worthiness was increasingly relevant to funding decision-making, disadvantaging stigmatized diseases.

Research on the political outcomes of advocacy has focused primarily on direct benefits. Distributive changes have rarely been explored empirically and systemic effects have

36 Some researchers recognize that policies’ perceived targets can vary over time or across institutional locations. Weir (1992) argues that during the 1960s, the media and politicians reframed the War on Poverty as primarily benefiting African Americans. Laumann and Knoke (1987) find that when considering capping hospital charges, actors from the health policy domain focused on impacts on patients and health care providers, while actors from the domestic economy domain focused on the overall economy and federal budget.

37 Skrentny (1996) also shows that the relevance of worthiness depends on the meanings attributed to a policy. The race riots of the late 1960s changed the rationale for affirmative action from justice to crisis management, making African-Americans’ perceived worthiness less relevant (Skrentny 1996:103). I argue that perceived beneficiaries are an aspect of policy meaning that is especially likely to change the relevance of worthiness.
been mostly ignored. The growth of disease advocacy provides an ideal opportunity to document the direct, distributive, and systemic effects of advocacy.

**Data and Methods**

**Variables**

My dependent variable is federal medical research funding from the National Institutes of Health (NIH) and the Department of Defense Congressionally Determined Medical Research Program (DOD-CDMRP). My key independent variables are three measures of the level of advocacy targeting a disease: the total number of organizations targeting the disease, their total lobbying expenditures in a given year, and the number of advocates testifying for each disease in congressional appropriations hearings. I also use variables for the mortality attributable to the disease and dummy variables equal to one if over 95% of fatalities are women (breast, cervical, ovarian, and uterine cancers; pelvic inflammatory disease) or blacks (sickle cell anemia). Table 3.1 provides descriptive statistics for the variables used in the analysis.

**Analysis**

I began by using absolute funding levels as the dependent variable and including a lagged measure of funding in the regression equation. Its coefficient was very close to one, indicating the presence of a unit root. Therefore, I first-differenced the dependent variable: all models now predict changes in NIH funding. I used the Cochrane-Orcutt transformation to correct for first-order autocorrelation. All independent variables are lagged by one year, and all models use robust standard errors to account for clustering by disease (Rogers 1993; Williams 2000). Results were extremely robust to model specification. 38 All figures show five-year moving averages.

My sample includes HIV/AIDS and breast cancer, which were targeted by unusually large and successful advocacy campaigns. When these outliers are included in the analyses, the effects of advocacy appear dramatically larger. Therefore, all models shown in tables exclude HIV/AIDS and breast cancer, with notes in the text explaining when their inclusion would change the results.

38 To test the robustness of the results, I ran the models in various ways: using the Prais-Winsten method instead of Cochrane-Orcutt; excluding DOD funding from the dependent variable; limiting the sample to fatal diseases; controlling for disability-adjusted life-years lost in addition to mortality; including HIV/AIDS and breast cancer in the analysis; and coding patients’ race and gender as a percentage instead of a dichotomous variable. The key findings were very similar in all models. Results are available from the author upon request.
I supplement the quantitative analyses with a qualitative analysis of testimony and secondary sources. I examined the congressional testimony of a representative sample of disease advocates. To document changes over time across thousands of pages of testimony, I also conducted an automated content analysis using WORDij software (Danowski 2009a, 2009b). I analyzed news coverage of NIH policymaking in newspapers (including *The Washington Post* and *The New York Times*) and scientific journals (*Science* and *The New England Journal of Medicine*). I also read congressionally mandated reports from the Congressional Research Service and the Institute of Medicine. The qualitative data and secondary sources help me document cultural changes in medical research politics.

I observe direct, distributive, and systemic effects in different ways. Direct benefits produce positive coefficients for the advocacy variables, indicating that diseases with more advocacy had bigger funding increases. Distributive changes create coefficients for blacks’ or women’s diseases that are mediated by advocacy, indicating that differential levels of mobilization are shifting the funding distribution across demographic groups. To document systemic effects, I begin by using graphical and qualitative data to show changes in policy meanings that are attributable to advocacy. Next, I look for funding effects of these changes that are not mediated by advocacy, indicating that the changed terms of the debate affected all diseases.

**Results**

**Direct Benefits**

Scholars have argued that disease advocates successfully pushed for research funding in the 1990s (Brown and Zavestoski 2004; Dresser 1999; Epstein 1996). To test this claim, Model 1 (Table 3.2) controls for changes in mortality and includes three measures of disease advocacy: the change in the number of nonprofits targeting a disease, their total lobbying expenditures, and the number of witnesses testifying on behalf of the disease.

The results reveal a strong relationship between advocacy and funding changes. Increases in the number of nonprofits and lobbying expenditures are both significantly associated with increases in research funding, with each $1,000 spent on lobbying associated with a $25,000 increase in research funds the following year. The coefficient for witnesses is

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39 I use the absolute number of witnesses and lobbying expenditures as independent variables (rather than changes in these numbers) because the modal value for these variables is zero. In many cases, the first-differenced versions of these variables would have negative values the year after a disease’s advocacy organizations lobbied or testified in Congress. These models would implicitly predict that a disease whose advocates had been active the previous year would do worse the following year than diseases with no advocacy.
also positive, but not statistically significant.\textsuperscript{40} These findings suggest that disease advocacy organizations secured direct benefits in the form of increased medical research funding.

**Distributive Changes**

Contemporary observers made competing predictions about how advocacy might affect the overall distribution of research funding. Some scholars and advocates argued that disease advocacy would correct inequities, shifting funds to diseases that disproportionately affect women and racial minorities. Others worried that disease advocacy would have the opposite effect, drawing money away from the diseases that affect disadvantaged groups (Callahan 2003:239-40; Dresser 1999:265-66).

My results support the latter prediction. In the aggregate, disease advocacy shifted money away from diseases that primarily affect women and blacks. Model 2 (Table 3.2) includes dummy variables indicating when at least 95% of a disease’s fatalities are female or black. Both coefficients are negative and statistically significant, suggesting that women’s and blacks’ diseases tended to receive smaller funding increases. To see whether these smaller increases are attributable to lower levels of advocacy, Model 3 (Table 3.2) controls for advocacy. The coefficients for women’s and blacks’ diseases decrease, indicating that low levels of advocacy explain some of the funding disparities.

However, these results should be interpreted cautiously for two reasons. First, the disadvantage for women’s diseases disappears when breast cancer is included in the analyses. Second, my sample only includes one black-dominated disease (sickle cell anemia) and only a few female-dominated diseases besides breast cancer (cervical, ovarian, and uterine cancers and pelvic inflammatory disease). The observed effects might be particular to these specific diseases and not general patterns based on patients’ demographics. To address this concern, I re-ran all models with an alternate specification of the race and gender variables: the percentage of women and blacks among each disease’s fatalities. The patterns are similar in these models, suggesting that the results are not particular to the small number of female- and black-dominated diseases, but the results are no longer statistically significant.\textsuperscript{41}

\textsuperscript{40} When HIV/AIDS and breast cancer are included, the coefficients for lobbying and witnesses increase dramatically.

\textsuperscript{41} Since they vary over time, these alternate measures allow me to ask whether the race and gender effects operate between or within diseases. When I include disease fixed effects, the race and gender coefficients are close to zero, indicating that within diseases, changes in patients’ demographics do not affect research funding. Perhaps short-term demographic changes do not lead to substantial changes in organizing or public perceptions of the disease. Rather, the race and gender effects are driven by diseases that are consistently “raced” or “gendered” in the public imagination.
Systemic Effects

Thus far, I have shown that disease advocates secured large funding increases, and that these successes may have created funding disparities on the basis of patients’ race and gender. Turning to systemic effects, I find that disease advocates changed the political meaning of medical research, with profound consequences for the distribution of research funds.

Mortality as a Metric for Commensuration

Seeking increased funding for their diseases, many advocates argued that the NIH funding was out of sync with the burden of disease. Mortality emerged as an influential metric for commensurating diseases and reshaped the funding distribution.

Following the successes of AIDS advocacy in the 1980s, AIDS received more research funding than any other disease. The high levels of AIDS funding meant that advocates for virtually every disease could use measures of dollars per death or per patient to claim that their disease was underfunded. For example, in 1984, breast cancer advocate Rose Kushner testified that the federal government was spending $11,000 for each new AIDS patient but only $400 per person diagnosed with breast cancer (U.S. House of Representatives 1984:49). In 1995, a representative of the American Heart Association noted that “in fiscal year 1993, HHS spent 36 times more on research funding per death of an AIDS victim than was spent per death of a heart disease victim” (U.S. House of Representatives 1995:129). While most advocates based their claims on mortality, advocates for non-fatal diseases based their claims on prevalence, comparing dollars per patient (Marshall 1997).

The mortality and prevalence metrics were attractive to policymakers because they came from official government statistics and provided a simple and seemingly rational way to compare funding across diseases (see Porter 1995). In the House, Representatives Istook (R-OK) and Nethercutt (R-WA) echoed advocates’ claims that some diseases were being underfunded compared to AIDS, a point Istook pushed in NIH appropriations subcommittee meetings (Dresser 1999; Istook 1997; Marshall 1997). Representative Bonilla (R-TX) also picked up the dollars-per-death frame to push for more money for diabetes research (Marshall 1997). All three representatives used the mortality metric to push for increased congressional intervention in the NIH budget.

These dollars-per-death claims created political pressure to standardize the NIH funding process. A Congressional Research Service report complained that advocates tended to choose the comparisons most favorable to their own diseases, offering up a “vast and sometimes confusing array of charts and tables comparing disease-specific research funding with statistics on morbidity, mortality, and health care costs” (Johnson 1998,
pages not numbered). In response to the advocates’ various metrics and standards, some members of Congress began requesting reports of NIH funding by death rates. In 1994, the Senate appropriations committee ordered the NIH to submit a report of funding by death rates, medical spending, and indirect economic costs of diseases (Agnew 1996).

That same year, the Congressional Research Service produced a report of NIH funding and mortality rates for the leading causes of death (Johnson 1994). In 1997, the Senate held a hearing examining NIH priority-setting.

The NIH resisted the push for standardization. At the Senate hearing, NIH director Harold Varmus rejected diseases as the appropriate categories for judging the funding distribution and opposed formal commensuration as a priority-setting tool. He testified that it would be foolhardy to set funding targets by diseases because medical advances often arise from non-disease-targeted basic research or spill over across diseases. He also argued against adopting standardized formulas for commensuration, saying that “numbers are suspect,” and “assessing or designing a research portfolio from numbers alone is a very tricky, indeed a hazardous enterprise” (U.S. Senate 1997:9,8). Varmus was supported by a group of representatives including John Porter (R-Ill), the chair of the NIH appropriations subcommittee, who sought to avoid earmarks and preserve NIH autonomy in setting funding priorities (Dresser 1999; Epstein 2007).

Faced with the conflict between scientific autonomy and advocates’ critiques, Congress stopped short of requiring standardization, but did push the NIH to formalize its decision-making process and allow for more public input. Congress requested a report from NIH on its priority-setting procedures and asked the Institute of Medicine (IoM) to issue recommendations on how to improve the process (Dresser 1999). This request for formalization and justification constituted a compromise, avoiding earmarks but also opening the black box of NIH decision-making. In the report, the NIH for the first time listed criteria for priority-setting between diseases. They provided five unranked criteria:

- public health needs,
- scientific quality of the research,
- potential for scientific progress (the existence of promising pathways and qualified investigators),
- portfolio diversification along the broad and expanding frontiers of research, and
- adequate support of infrastructure (human capital, equipment instrumentation, and facilities).

(Institute of Medicine 1998:4)

These criteria provide some information about NIH priority-setting while maintaining significant scientific autonomy over funding decisions. Congress followed the IoM’s advice to avoid explicitly standardizing the NIH budget. However, the series of reports and hearings made it clear that advocates and members of Congress would continue to question whether NIH funding lined up with mortality and other measures of the burden of disease.

Although Congress never required that the NIH use mortality as a metric, as the NIH was increasingly critiqued on the basis of dollars per death, mortality gradually became a better predictor of NIH funding. Model 4 (Table 3.2) includes the number of deaths
attributable to a disease during the previous year. The coefficient for mortality is positive and significant, showing that during the time period under study, “big killers” had larger increases in NIH funding. As the mortality metric became increasingly taken-for-granted, high-mortality diseases were at an advantage in the competition for funds.

Next, I ask whether the dollars-per-death frame advantaged all high-mortality diseases or only those whose advocates used the frame. Model 5 (Table 3.2) includes an interaction effect between witnesses and mortality. The positive interaction effect, showing that high-mortality diseases had a larger payoff from witness testimony, suggests that dollars-per-death claims helped witnesses secure funding increases for their diseases. Importantly, though, the main effect for mortality remains large and statistically significant, suggesting that the rise of mortality as a metric for commensuration advantaged high-mortality diseases even if their advocates had not testified. Thus, the dollars-per-death frame was more than a mechanism for witnesses to secure direct benefits for their own diseases; the introduction of the mortality metric systemically changed the terms of the debate over medical research funding.

Perceived Beneficiaries

Disease advocacy organizations encouraged Congress to think of patients with specific diseases as the beneficiaries of medical research funding. Throughout most of the 20th century, when fights broke out over the distribution of NIH funding, diseases were not generally the competitors. Midcentury congressional critiques of the NIH focused on whether money was being disbursed to unqualified researchers and whether NIH funding was “geographically elitist” (Guston 2000:74). Testifying in Congress in 1963, NIH Director Shannon argued that the large NIH budget was defensible because the scientists who received the money deserved it: “the national figures are very large… But when you go from a national picture to a State… and begin to recognize institutions and scientists,

42 This finding is separate from the pattern in which funding responds to changes in mortality, increasing as diseases become more prevalent. These adjustments are reflected in the positive coefficient for change in deaths, not for the absolute number of deaths.

43 Carpenter (2010) describes a similar case of a metric for evaluation changing the actions of a federal agency. In the 1970s, academics and advocates criticized the FDA for being too slow to approve new drugs. They evaluated the FDA based on the number of new chemical entities approved per year and the average lag between drug approvals in Europe and the United States. After facing public criticism on the basis of these metrics, the FDA began keeping data on them, discussing them in reports, and considering them when making decisions (Carpenter 2010:377-8).

44 Model 5 also controls for advocacy. Holding nonprofits, lobbying, and witnesses constant, we still see a large positive coefficient for mortality, indicating that the mortality effect is not an artifact of higher-mortality diseases being targeted by more advocacy.
you begin to understand the role they play in the community life” (U.S. House of Representatives 1963:30). While the Institutes’ overarching goal was to improve the nation’s health, this rhetoric constructed scientists as the beneficiaries of NIH funding.

This construction is reflected in the characteristics of witnesses at appropriations hearings. In the 1960s and 1970s, more than 15% of the witnesses testifying at the House Labor, Health, Education, and Welfare appropriations hearings represented health institutions like medical schools, research institutes, and hospitals (see Figure 3.1). As the groups most likely to receive money directly from the NIH, they were a natural constituency for NIH policy. Meanwhile, only 5-10% of the witnesses represented organizations targeting diseases. (See Figure 3.1).

Subsequent changes reflect the increasing prominence of disease patients in NIH policymaking. The proportion of witnesses representing health institutions dropped dramatically in the 1980s and 1990s, declining to under 7% of witnesses by 2004. They were replaced by disease advocates, who made up more than 20% of the witnesses by the 1990s. (See Figure 3.1.)45 This percentage is astonishingly high, given that the denominator includes witnesses testifying about the appropriations for all of HHS, Labor, and Education. Even though these disease advocacy organizations were not receiving money directly, they expressed an interest in the distribution of funding to diseases, and their presence as witnesses suggests that members of Congress viewed these claims as legitimate.

In their testimony, disease advocates portrayed patients as the beneficiaries of research funding. For instance, in 1992, one breast cancer advocate argued that “my daughter Jody, the women in this room, and women everywhere deserve no less” than increased funding for breast cancer research. Another asked, “Is this too much to ask for your wife, your sister, your mother?” (U.S. House of Representatives 1992:31,59). These advocates depict breast cancer patients, not scientists, as the beneficiaries of breast cancer research funding. While discussions of the distribution of funding among states and researchers did not disappear, they were now overshadowed by discussions of the distribution of funds to diseases.

In another indication of the shift to viewing patients as beneficiaries, witnesses were increasingly likely to mention patients when they discussed the NIH.46 In 1960,

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45 A similar change occurred at the Food and Drug Administration (FDA). In the 1960s, the FDA’s main external critics were scientists, industry, medical professionals, and Congress; this changed in the 1970s and 1980s cancer and AIDS patients began to challenge the FDA’s practices (Carpenter 2010:322, 395).

46 I tracked the frequency with which the names of NIH institutes were mentioned in close proximity to words referring to patients (patient, patients, sufferer, sufferers, survivor, survivors, affected, individuals, person, people, women, woman, men, and
approximately 40% of references to the NIH appeared in close proximity to references to patients; by 2010, this number had increased to over 70% (see Figure 3.2). This growing discursive link between the NIH and patients supports the claim that patients were increasingly thought of as the beneficiaries of medical research funding.

*The Relevance of Deservingness*

Once patients were viewed as the beneficiaries of NIH funding, moral judgments about their deservingness became increasingly relevant to funding deliberations. When scientists and the public at large were viewed as the beneficiaries of medical research funding, it would have made little sense to argue that patients of any particular disease “deserved” more research funds. But once patients were constructed as beneficiaries, some advocates began arguing that those suffering from their diseases were innocent victims, with the implication that other diseases merited less support. In a letter to Representative Porter, a Muscular Dystrophy advocate attacked funding for research on drug abuse and alcoholism, saying that “it is shocking that over $754 million is devoted to address the health problems of people whose irresponsible behavior causes those problems, while less than 1 percent of that sum helps children dying of Duchenne muscular dystrophy” (Havemann 1998:4). Such direct attacks were rare, but my analyses of Congressional transcripts reveal that advocates for stigmatized and non-stigmatized diseases made different types of claims.

Witnesses for non-stigmatized diseases tended to focus their testimony on their suffering and its effects on their families. For example, one mother spoke about her 13-year-old son, saying that “Michael is not comfortable as he sits here strapped to his wheelchair. If you look into his beautiful brown eyes, he has no vision… It is horrible what Batten’s disease does to a normal healthy child” (U.S. House of Representatives 1990:701). Another mother who lost a child to a genetic disease described her “agony [at] the thought that another child will die from this” (U.S. House of Representatives 1997:108). These witnesses also made claims on scientific and economic grounds, but their most common strategy was to evoke sympathy.

In contrast, witnesses with potentially stigmatized diseases spent their testimony attempting to manage the stigma. For example, one witness with liver disease emphasized that he did not drink or smoke, “never experimented with drugs,” and “had one sexual partner and continue to have one sexual partner in my whole life, my wife” (U.S. House of Representatives 1997:132). Some advocates strategically focused on the least stigmatized subgroups of their patient populations. Juvenile diabetes advocates emphasized the differences between their disease and Type 2 diabetes, which has more behavioral risk factors (Perez-Pena 2006). Lung cancer advocates focused public
awareness campaigns on types of lung cancer not caused by smoking (Griffith 2005). Additionally, witnesses for stigmatized diseases were more likely to justify funding on economic grounds. For example, a former drug user emphasized that research and treatment allowed her to go from “tax burden to tax payer” (U.S. House of Representatives 1997:318), and a spokesman for the American Lung Association noted that “lung diseases cost the U.S. economy an estimated $84.4 billion annually” (U.S. House of Representatives 1997:143). Perhaps less confident that their stories would evoke sympathy, these witnesses were disproportionately likely to rely on economic arguments to justify funding increases.

Next, I show that stigmatized diseases actually received less money in the new political climate by tracking funding for lung cancer and liver cancer. Both cancers have potentially stigmatized risk factors (smoking for lung cancer; hepatitis infection and alcohol consumption for liver cancer). Year after year, both diseases received smaller funding increases than would have been predicted based on mortality. To document this cumulative disadvantage, I summed each disease’s residuals from regression analyses over time (see Figure 3.3). The lower dots in the graph are the diseases’ cumulative residuals from Model 4 (Table 3.2), which controls for mortality. By 2006, lung cancer and liver cancer were receiving about $100 million and $35 million dollars less, respectively, than would have been expected based on how many people they killed.47 Controlling for advocacy does not move the residuals substantially closer to zero, indicating that lung and liver cancer’s disadvantages cannot be explained by lack of advocacy (see Figure 3.3, cumulative residuals from Model 5, Table 3.2). The increasingly negative residuals for lung cancer and liver cancer suggest that as patients were constructed as the beneficiaries of medical research funding, these stigmatized diseases were at an increasing disadvantage.

By constructing patients as the beneficiaries of medical research funding, disease advocates unintentionally increased the relevance of stigma to medical research priority-setting. But the history of AIDS activism reveals complexities in the relationship between disease advocacy and stigma. The fact that AIDS disproportionately affected stigmatized groups limited the initial public health response to the emerging epidemic. The AIDS movement emerged in response to the federal government’s inaction, and the movement was extremely successful in overcoming stigma and putting AIDS on the government agenda (Donovan 2001; Epstein 1996). As I showed in Chapter 2, subsequent campaigns targeting other diseases were inspired by the AIDS movement’s successes and adopted its symbols and strategies, including ribbons, fundraising walks, and federal advocacy (Anglin 1997; Dresser 2001; Klawiter 2008). My findings show that ironically, these movements inspired by AIDS advocacy actually expanded the influence of disease stigma on federal health policy.

47 These funding deficits are substantial, given that the total 2005 funding levels for lung cancer and liver cancer were $180 million and $50 million, respectively.
Discussion

The emergence of disease advocacy transformed the politics of medical research funding. By combining quantitative and qualitative data on 53 diseases over 17 years, I identified several previously overlooked effects of advocacy. In addition to securing direct benefits, disease advocacy organizations reshaped the funding distribution, introduced metrics for commensuration, changed the perceived beneficiaries of medical research, and made deservingness increasingly relevant to funding deliberations.

Regarding direct benefits, I found a very strong relationship between advocacy and increases in NIH funding to diseases. These results indicate that advocacy organizations can secure large benefits for their constituents. However, we should not expect equally large effects in every policy arena. First, medical research funding can be given out in small units, meaning that Congress can distribute resources widely to placate as many groups as possible (Lowi 1964). Advocacy’s effects might be smaller when organizations compete over legislation. Second, Congressional representatives tend to view disease advocates more favorably than other lobbyists, since the advocates do not directly profit from medical research expenditures (Cook-Degan and McGeary 2006:192). Less favorably-viewed advocates might be less successful. Finally, the large funding increases occurred in the context of an expanding NIH budget. Advocacy’s effects might be smaller during times of austerity.

With respect to distributive changes, I found that with the exception of breast cancer, there was less advocacy for women’s and blacks’ diseases. Therefore, as more and more disease advocates secured direct benefits, the funding distribution shifted away from women’s and blacks’ diseases.48 This pattern suggests that contemporary inequalities in mobilization may create health disparities for future generations. However, these results are based on a small number of women’s and blacks’ diseases and are changed by the inclusion of breast cancer in the analysis, so they should not be taken as definitive.

My findings concerning systemic effects reveal two processes related to categorization. Advocates first asserted that diseases were the relevant categories across which to judge the NIH funding distribution. Making these judgments then required classifying and comparing diseases through commensuration and cultural categories of worth (see Lamont and Molnar 2002).

In the first categorization process, social movements construct, maintain, or highlight group boundaries (Polletta and Jasper 2001) and then import these categories into

48 I focused on patients’ race and gender, but distributive changes may occur across any variable that is correlated with advocacy. Disease advocacy may have caused distributive changes based on other characteristics of patients or diseases, including patients’ social class or age and diseases’ causes or psychiatric nature.
political deliberations. In this case, advocates organized around disease categories and encouraged policymakers to judge the distribution of funding to diseases. But advocacy organizations do not create categories in a vacuum, and the move to hold the NIH accountable for funding to diseases reveals an unexpected relationship between disease advocacy and established disease categories. Patients mobilize around the disease definitions and diagnoses provided by healthcare systems (Brown et al. 2004; Rabinow 1992; see also Bowker and Star 2000; Rosenberg 2007). They then create political pressure for the NIH to target research funding to their diseases, despite NIH officials’ preference for funding research that might cross traditional disease boundaries. This pressure increases the likelihood that future scientific advances will fall within established disease categories. Thus, in challenging scientific authority over funding decisions at the NIH, disease advocacy may actually have reinforced the dominant disease classifications by diminishing scientists’ ability to conduct research across categories.\(^\text{49}\) In the same way that groups mobilize around categories encoded in policies (Pierson 1993; Skocpol 1992), advocacy develops around pre-existing disease categories and can reinforce those categories.

When advocates used the dollars-per-death frame to push for funding increases for their diseases, they created political pressure to standardize the NIH budget by mortality and formalize NIH priority-setting procedures. This finding confirms recent work on experts and standardization. Sociological theory often links the spread of standardization and expert authority (Weber 2003). However, my findings support recent observations that standardization often challenges the autonomy of experts (Espeland and Stevens 1998; Evans 2010; Guston 2000; Porter 1995; Timmermans and Epstein 2010). Porter (1995) notes that calls for public accountability force professions to justify their decisions on the basis of objective standards instead of expert judgment. In this case, the NIH managed to avoid explicitly standardizing its priority-setting process, but the funding distribution gradually approached the standard proposed by many advocates. This implicit compromise illustrates the strong but challenged professional authority of scientists and medical professionals in the contemporary United States (Epstein 1996; Guston 2000; Pescosolido 2006).

Advocates also encouraged policymakers to think of patients as the beneficiaries of medical research funding. This pattern reveals a rarely discussed pathway through which advocacy shapes policy: by changing the policy’s perceived beneficiaries. Political scientists have long recognized that policies vary dramatically based on whether the affected parties are attentive to and engaged in political debates (May 1991; Schattschneider 1960). But when disease advocates asserted their interest in the

\(^{49}\) Epstein (2007) describes another case in which advocates’ use of categories constrained scientific autonomy. Advocates assumed that race and gender would be meaningful biological categories for the conduct of scientific research. This successful “categorical alignment” resulted in mandates to include research subjects of varying races and genders and to analyze scientific results by race and gender.
distribution of medical research funding, they did more than awaken a predefined group of beneficiaries: they redefined who counted as a beneficiary, making a new set of interests relevant.  

Once patients were viewed as the beneficiaries of medical research funding, disease stigma became increasingly relevant to NIH priority setting. This finding suggests a new source of variation in the influence of deservingness on policy. Even if the symbolic construction of a group is constant—for example, if liver cancer patients face a consistent amount of stigma, or if welfare recipients are routinely disparaged—the extent to which stigma shapes policy depends on who is thought of as the policy’s beneficiaries. While the perceived worthiness of beneficiary groups tends to change slowly (Steensland 2006), the political relevance of worthiness can change quickly and dramatically depending on whether the group is considered a beneficiary. For advocates for stigmatized groups, this result could be construed as a rallying cry or a cautionary tale. Advocates could strategically redefine policy beneficiaries to decrease the relevance of stigma. However, the existence of advocacy may encourage politicians to view movement constituents as policy beneficiaries, calling attention to their moral characteristics.

The study of systemic effects reveals that political environments are not only a context for social movements; they are a field that social movements work to reshape. In promoting mortality as a metric for commensuration and framing deserving patients as beneficiaries, advocates changed the rules of the competition for medical research funds (see Armstrong and Bernstein 2008:84-5). These cultural changes had concrete effects on the funding distribution, shifting money towards high-mortality diseases and away from stigmatized diseases.

The field metaphor should not lead us to assume that all systemic effects are strategically sought. When disease advocates used the dollars-per-death frame to push for more funding for their diseases, the pressure to formalize NIH priority-setting and the increasing influence of mortality were side effects. Similarly, when disease advocates defined patients as the beneficiaries of medical research funding, they never intended to increase the relevance of stigma. These findings suggest a more subtle role for social movement framing, which researchers view primarily as a mediator for direct benefits (Amenta et al. 2010; Benford and Snow 2000; Burstein and Hirsh 2007; Cress and Snow 2000). Social movement frames can have unintended effects on metrics for commensuration, perceived beneficiaries, and cultural categories of worth in policy arenas. Since these changes affect all participants in political fields, outlast the advocates who introduced them, and contribute to institutional change (Clemens and Cook 1999), they may be the most sweeping and durable effects of advocacy.

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50 This process likely occurs in other realms as well, as when the crime victims’ movement asserted their interest in sentencing policy (Elias 1985).

51 Smith (1984) similarly argues that while policymakers’ values change slowly, their perceptions of which values are relevant to a particular policy are relatively fluid.
Advocates are not the only players in political fields. Social movements and the state often interpenetrate each other, with advocates collaborating with policymakers (Armstrong and Bernstein 2008; Epstein 2007; Goldstone 2003; Santoro and McGuire 1997; Skrentny 2002; Wolfson 2001). My data reveal advocates’, policymakers’, and NIH officials’ interwoven strategies. When advocates strategically adopted the mortality metric, some members of Congress joined them in arguing that the NIH budget did not line up well with the burden of disease. Other policymakers and NIH officials responded by defending scientific autonomy. The NIH ultimately provided some information about priority-setting procedures and shifted more funding to high-mortality diseases. These outcomes depended on the actions of advocates, policymakers, and government officials. In studying the political outcomes of advocacy, we should not ignore effects that depend on multiple actors; we can attribute causality to movements even when they do not function purely as exogenous shocks.

My analysis of the systemic political effects of advocacy parallels research on the societal effects of social movements. While scholars have generally assumed that systemic effects on policy are concrete and intentionally sought, studies of effects on society at large have discovered unintended consequences and cultural changes (Amenta et al. 2010; della Porta 1999; Earl 2004; Haveman et al. 2007). Focusing on systemic effects brings these insights to the political sphere and reminds us that culture is not an isolated realm of social life that can be separated from politics (Armstrong and Bernstein 2008). The political effects of politicization include changes in the categories and meanings that shape political decision-making.
Tables and Figures

**Table 3.1: Descriptive Statistics**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Min.</th>
<th>Max.</th>
</tr>
</thead>
<tbody>
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<td>178</td>
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<td>Change in number of nonprofits</td>
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<td>Total lobbying expenditures (thousands)</td>
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<tr>
<td>Number of witnesses testifying</td>
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<td>.77</td>
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<td>5</td>
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<tr>
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<td>Black fatalities</td>
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<td>15</td>
<td>.86%</td>
<td>98%</td>
</tr>
<tr>
<td>Female fatalities</td>
<td>56%</td>
<td>20</td>
<td>0%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Unit of analysis is the disease; variables describe the funding, advocacy, and mortality for each disease in each year. All financial data are in 1987 dollars.
<table>
<thead>
<tr>
<th></th>
<th>Column 1</th>
<th>Column 2</th>
<th>Column 3</th>
<th>Column 4</th>
<th>Column 5</th>
<th>Column 6</th>
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<td>0.26*</td>
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<td>(1.21)</td>
<td>(0.69)</td>
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<td>(0.0070)</td>
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<td>0.0094**</td>
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<td>Change in Deaths (thousands)</td>
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<td>0.70</td>
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<td>(0.39)</td>
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</tr>
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<td>Constant</td>
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<td>4.14***</td>
<td>2.76***</td>
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<td>1.86</td>
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</tbody>
</table>

Dependent variable is change in NIH and DOD funding to disease research in millions.
Analyses exclude HIV/AIDS and breast cancer.
All independent variables lagged by one year.
Robust cluster standard errors in parentheses.
*** p<0.001, ** p<0.01, * p<0.05
Figure 3.1: Witnesses at House Appropriations Hearings Representing Disease Organizations* and Health Institutions, 1965 to 2004

*Includes organizations targeting one or several diseases
Figure 3.2: References to Patients per 100 References to the NIH, 1960 to 2010
Figure 3.3: Lung Cancer and Liver Cancer’s Cumulative Residuals from Regressions of Funding Changes on Mortality and Advocacy, 1992 to 2006

<table>
<thead>
<tr>
<th>Cumulative Residuals from Model 4 (Mortality)</th>
<th>Cumulative Residuals from Model 5 (Mortality and Advocacy)</th>
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Chapter 4

The Interdependence of Social Movements:
Disease Advocacy as Zero-Sum Game or Synergy

Abstract:
Researchers seldom ask how social movements affect each other’s outcomes. This chapter examines movement interdependence for the case of disease advocacy. As health advocates increasingly targeted particular diseases, some critics worried that they would siphon funds from other diseases instead of creating increases in the NIH budget. Using data on 53 diseases over 17 years, this chapter shows the opposite to be true. Gains spilled over across diseases, with research funding to diseases increasing after advocacy targeted other diseases. An analysis of congressional debates suggests that particularistic politics led to increasing budgets by creating new constituencies and by expanding the boundaries of the competition for funds. These results demonstrate that to understand social movement outcomes, researchers must consider their interactions.
A growing research literature examines the political outcomes of social movements. However, these studies tend to examine social movement organizations (SMOs) or social movement industries (SMIs) in isolation from each other, asking how a movement’s resources, tactics, frames, and opportunities affect its likelihood of achieving benefits for its constituents (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998; Burstein 1999; Giugni 1999; Smith 1995). Similarly, in the previous chapter, I measured direct benefits at the level of the disease without asking whether diseases’ outcomes were correlated. But since movements may fight for space on the government agenda or create political opportunities for each other, their outcomes are unlikely to be independent. It remains unclear how social movements affect each other’s outcomes—whether the presence of other movements changes the likelihood that any one movement will be influential.

This chapter fills this gap by examining how movements targeting various diseases affected each other’s outcomes. I test two hypotheses arising from research on agenda-setting and identity politics. The first is that movements compete for government attention in a zero-sum game (Hilgartner and Bosk 1988; Kingdon 1984; McCombs 2004; Zhu 1992). In the case of disease advocacy, some critics worried that advocates would siphon funds away from other diseases. The second is that narrowly targeted movements might be unlikely to achieve broad goals (Collins 1991; Gamson 1995; Gitlin 1994, 1996). With the transformation of disease advocacy, critics argued that when advocates focused on particular diseases instead of lobbying for overall increases in medical research funding, the NIH budget would stagnate.

Using data on advocacy and federal research funding to 53 diseases over 17 years, I find that neither of these hypotheses is correct. Diseases tended to receive larger funding increases following lobbying targeting other diseases, and the NIH budget grew dramatically as single-disease advocacy expanded. Thus, disease advocacy was synergistic rather than a zero-sum game. Through an analysis of debates over medical research funding, I identify three factors that made disease advocacy synergistic: spillover effects within policy arenas, the introduction of politically attractive policy beneficiaries, and changed boundaries of the competition for funds. My findings demonstrate that movements shape each other’s outcomes through synergistic processes that are invisible in studies of individual movements.

**Density, Diversity, and the Outcomes of Advocacy**

Recent changes in the United States social movement sector highlight the importance of understanding the interdependence of social movement outcomes. Since the 1960s, social movement density—the number of active SMOs—has increased dramatically as existing movements expand and new ones begin (Andrews and Edwards 2004; Berry 1997; Schlozman and Tierney 1986; Walker 1983). At the same time, movements have become
more diverse and specialized. “New social movements” target an expanding array of lifestyle-related concerns (Bernstein 2005; Pichardo 1997), and existing movements have broadened their range of issues, as when the environmental movement began focusing on health effects in addition to conservation (Johnson 2008; McLaughlin and Khawaja 2000). With the emergence of “identity politics” came the growth of groups focused on the concerns of particular races, ethnicities, genders, and other groups (Bernstein 2005). As growing numbers of social movements target an increasingly diverse array of issues, some researchers argue that “more is better:” more social movements targeting more issues will lead to better political outcomes (Minkoff et al. 2008:525; Berry 1999; Minkoff 1995, 1997a). However, to know whether more social movements translate into expanded political effects, we need to know how social movements’ outcomes interact. Do movements compete for outcomes in a zero-sum game, fighting for space on a finite political agenda? Conversely, do they create opportunities for each other, operating synergistically?

Despite a growing body of research on social movement outcomes, we have very little information about how they interact. When predicting movement influence, most studies focus on variables associated with individual movements (e.g., resources, tactics, and frames) or with the political system (e.g., political opportunities) (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998; Burstein 1999; Giugni 1999; Smith 1995). Researchers rarely look for explanatory variables at an intermediate level of analysis, asking how movements affect each other’s outcomes. One reason for this lacuna is that analyses of the interaction of movement effects require longitudinal data on multiple movements, and such data are rarely collected.

While scholars have not systematically examined the interaction of social movement outcomes, several research literatures suggest hypotheses about these interactions. In the following sections, I review research on social movement density and diversity that raises competing predictions about how social movement outcomes will interact.

Social Movement Competition

Several lines of research ask how social movements affect each other, yielding mixed predictions about how density would shape social movement outcomes. Some researchers have found that density has positive effects on SMOs’ founding, survival, and strategies. Existing organizations can provide resources, networks, personnel, and legitimacy to help new ones get off the ground (Freeman 1973; McAdam 1995; McLaughlin and Khawaja

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52 One exception is research on the interactions of movements and countermovements (e.g., Andrews 2002).
53 A few researchers have used longitudinal data to look at social movement effects, but they have generally studied organizations within a single SMI (McAdam and Su 2002; Meyer and Minkoff 2004; Olzak and Ryo 2007; Olzak and Soule 2009) or a small number (Giugni 2004; Soule and King 2008).
Ideas and tactics sometimes spill over from one movement to another (Armstrong 2002; Lounsbury et al. 2003; Meyer and Whittier 1994). Additionally, competition among organizations can encourage strategic innovation, specialization, and a greater diversity of tactics and goals (Koopmans 1993; Meyer 1993; Meyer and Imig 1993; Olzak and Ryō 2007; Soule and King 2008; Stepan-Norris and Southworth 2010; Tarrow 1991). While these studies do not measure social movement outcomes, they suggest that density might make social movements more influential by encouraging organizational founding and inspiring innovative strategies.

However, density can also have negative effects on movements. Density can create competition for resources, personnel, and members (Armstrong 2002; Koopmans 1993; Minkoff 1997b; McCarthy and Zald 1977; Tarrow 1991), sometimes leading to the disbanding of SMOs (Gray and Lowery 1995). Additionally, advocates may compete for political outcomes in a zero-sum game (Hilgartner and Bosk 1988; McCombs 2004). In the case of policymaking, Congress’s “carrying capacity” limits the number of issues that can be on the agenda in any given year, meaning that if a social movement pushes a problem onto the Congressional agenda, another problem might be pushed off (Hilgartner and Bosk 1988; Kingdon 1984). The competition may be especially acute in struggles over budget allocation, which, according to one scholar, “by its definition is a zero-sum game” (Zhu 1992:829). Some studies of budgetary priority-setting have found that various segments of the federal budget are negatively correlated, indicating zero-sum tradeoffs (Domke et al. 1983; Kamlet and Mowery 1987; Nicholson-Crotty et al. 2006). If advocates are competing in a zero-sum game, any positive effects of density on organizational founding and strategies would not translate into improved outcomes. As some social movements became more influential, their gains would come at the expense of other organizations. Increased numbers and improved strategies would be a form of inflation, with more and more members and innovations required to achieve the same political outcomes.

However, the competition for funding and space on the policy agenda may not be rigidly zero-sum. Spending increases can be funded by increased revenues or deficits, meaning that they do not always involve zero-sum tradeoffs with other policy arenas (Gifford 2006; Hicks and Misra 1993; Huber et al. 1993). The level of gridlock in Congress varies over time (Binder 1999), and the size of the congressional agenda may increase during reform-minded eras or during a Presidential administration’s “honeymoon period” (Kingdon 1984). Moreover, policy action on one issue may spill over onto related issues (Hilgartner and Bosk 1988; Kingdon 1984; Skrentny 2006). Movement competition will not be invariably zero-sum; we need to know when advocates compete for outcomes and when they are able to expand the agenda.

54 Density-dependence theory suggests that initial increases in the number of organizations will have positive effects on organizational founding, but as competition becomes more extreme, founding and survival rates decrease (Hannan and Carroll 1992).
Submovements, Schisms, and Specialization

Previous research also raises competing predictions about how specialization affects social movement outcomes. When large movements split into smaller, specialized, or identity-based movements, are they less likely to achieve broad goals? Some scholars have argued that diversity can restrain social movements. The pursuit of divergent goals may waste resources, decrease cooperation, and diminish organizational strength (Armstrong 2002; McAdam 1982). Infighting and schism can lead to the collapse of movements (Gamson 1990; McAdam 1982; Mushaben 1989). Moreover, critics of identity politics argue that the splintering of interests prevents the formation of coalitions to pursue larger agendas (Gamson 1995; Gitlin 1994, 1996; Hobsbawm 1996; Kaufman 1990; Piore 1995; Turner 1999). They contend that the focus on particular identities displaces a politics based on class (Gitlin 1996; Piore 1995; Rorty 1999; Waters 1994; Weakliem 1997) and that identity-based movements fail to challenge broader systems of domination and exclusion (Collins 1991; Gamson 1995; hooks 1989). The underlying assumption of these critiques is that splintered movements will be less likely than united movements to achieve broad goals.

However, movements may also capitalize on diversity and difference. The environmental movement achieved more legislative victories as it expanded the range of issues it addressed (Johnson 2008). Activists report that heterogeneous organizations effectively fill specialized niches (Levitsky 2007). Diversity and dissent may or may not be divisive, depending on how movements frame and organize difference: the gay rights movement’s strategic embrace of identity politics allowed diversity to strengthen the movement and helped it survive the decline of the New Left (Armstrong 2002; Ghaziani and Baldassarri 2011). Identifying with a smaller group does not necessarily preclude commitments to larger goals (Bickford 1997), and claims for recognition are often connected to material concerns, meaning that identity-based movements do not always neglect class issues (Bernstein 1997; 2005; Polletta 1994). These studies demonstrate that movements can sometimes integrate multiple views into coherent agendas. However, they do not demonstrate whether coherent agendas facilitate social movement outcomes, or whether groups of smaller, diverse movements are less likely to achieve broad goals.

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55 Researchers tend to describe factions and schisms as divisions within a single social movement. However, once schisms occur, factions can be viewed as related movements pursuing different goals. If we view factions as independent but related SMIs, the question is no longer whether a single SMI needs to be coherent, but whether multiple small movements are less likely to achieve broad goals than a single large movement.

56 Like researchers, activists themselves may disagree about whether coherence is necessary and whether inclusive or identity-based movements are more influential. Armstrong (2002) argues that the gay rights movement was at times organized around an interest group political logic that assumed that movements are most successful when a
Concerns About Disease Advocacy

Thus, previous research leaves open two questions about movements’ interdependence. First, are movements’ political achievements positively or negatively correlated, zero-sum or synergistic? Second, can advocacy on behalf of subgroups lead to broader gains? This chapter answers these questions through an analysis of the increasingly dense and diverse field of disease advocacy.

When disease advocacy took off in the 1980s and 1990s, critics worried that advocacy was a zero-sum game and that splintered movements would not achieve broader goals. The few disease advocates who testified before the mid-1980s had "generally avoided open competition among themselves" (Dresser 1999:260; Kolker 2004). In the 1990s, a growing chorus of critics protested that disease advocates were engaged in a zero-sum competition that limited the growth of the NIH budget (Agnew 1996; Ferraro 1993; Institute of Medicine 1998; Johnson 1998; Marshall 1997; Stapleton 1998). In a Congressional Research Service report, Johnson (1998) noted that disease lobbying “appear[ed] to have succeeded in gaining large increases for certain diseases (e.g., AIDS and breast cancer) at the expense of others” (Johnson 1998, pages not numbered). Others worried that specialized disease advocacy would not lead to overall increases in the NIH budget. Stapleton (1998) declared that “competition between disease-interest groups has always diluted the research community’s ability to ‘move the needle’ when it comes to funding” (quoted in Dresser 1999:267). Similarly, an NIH official suggested that “when you start getting jockeying for more money by constituencies of a certain disease, that, in the long run, doesn't help,” whereas “everybody benefits” from overall increases in the NIH budget (NIAID Director Anthony Fauci, quoted in Cohen 1997). This chapter empirically tests these claims for the first time and shows that in fact, disease advocacy was synergistic and expanded the NIH budget. I then explore mechanisms that prevented disease advocacy from becoming a zero-sum game.

Methods

I combine quantitative and qualitative data to analyze the outcomes and interactions of disease advocacy organizations. To gauge the influence of advocacy on funding levels, I use dynamic autoregressive models with changes in NIH and DOD funding to diseases as the dependent variable. I used the Cochrane-Orcutt transformation to correct for first-

single umbrella organization makes coherent claims, and at other times embraced an identity political logic that assumed that a diverse set of organizations can be as effective. Additionally, during the gay rights movement’s encounter with the New Left, some activists sought to combine the cause of gay liberation with a broader social justice movement, while others preferred to limit the movement’s focus to sexuality concerns.
order autocorrelation. All independent variables are lagged by one year, and all models use robust standard errors to account for clustering by disease (Rogers 1993; Williams 2000). To observe the extent to which disease-specific advocacy is independent, competitive, or synergistic, I include variables for the advocacy targeting each disease and the advocacy targeting all other diseases. Table 4.1 provides descriptive statistics for all variables used in the analysis.

I supplement these statistical models with a qualitative analysis of testimony and secondary sources. I analyzed the congressional testimony of disease advocates, focusing on the extent to which they frame their diseases as being in competition with other diseases or with other parts of the federal budget. I also draw on journalistic and academic accounts of NIH politics. These qualitative data and secondary sources help me identify mechanisms that prevented disease advocacy from becoming a zero-sum game.

**Results**

**Synergistic Advocacy**

As I discussed in Chapter 3, disease advocates were extremely successful in attracting research funding. Model 1 (Table 4.2) replicates Model 1 from Chapter 3 (Table 3.2), showing the direct benefits accrued by disease advocates. Lobbying expenditures and increases in the number of nonprofits targeting a disease were both positively associated with funding increases. The number of witnesses testifying about a disease in Congress was also positively associated with funding increases, but this relationship was not statistically significant.

To determine whether disease advocacy was competitive, independent, or synergistic, I ask whether diseases secured smaller or larger funding increases following advocacy for other diseases. Model 2 (Table 4.2) adds variables related to advocacy for other diseases. For instance, for heart disease, the first set of variables measure the previous year’s change in the number of heart disease nonprofits, lobbying expenditures for heart disease, and witnesses testifying about heart disease, whereas the second set of variables measures the previous year’s change in the number of nonprofits targeting all other diseases, lobbying expenditures for all other diseases, and witnesses representing all other diseases. If disease advocates are competing in a zero-sum game, the coefficients for other diseases’ advocacy would be negative. If disease funding streams are independent, these coefficients would be zero. Finally, if disease advocacy is synergistic, the coefficients would be positive. Model 2 demonstrates that for the most part, disease advocacy was synergistic. Funding to a disease tended to increase the year after witnesses testified for other diseases, even when controlling for a disease’s own level of advocacy. When disease advocates targeted Congress directly, benefits spilled over onto other diseases.

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57 I run all models with and without HIV/AIDS and breast cancer, which are outliers in terms of their huge and successful advocacy campaigns.
An Expanding Pie

Some critics assumed that if disease advocates did not explicitly request overall increases in medical research funding, the NIH budget would stagnate. In fact, the opposite occurred: the expansion of competitive disease advocacy was accompanied by a dramatic increase in the NIH budget. During the expansion of single-disease nonprofits and the growth of competitive claims in Congress, the NIH budget tripled in inflation-adjusted dollars (see Figure 4.1). While this pattern does not prove that disease advocacy caused the increase, it demonstrates that advocacy for single diseases did not prevent overall funding increases.

Instead of distracting Congress from increasing the NIH budget, the competition among disease advocates may have motivated the increase. One Congressional staffer told researchers that Congress’s 1998 law calling for doubling the NIH budget within five years “was predicated on the hope that this policy would eliminate some of the intense competition for funds among advocates for particular diseases (Kedrowski and Sarow 2007:208). Overall funding increases at the NIH may have been the easiest way for Congress to respond to demands for more funding for particular diseases, given that lawmakers have traditionally been reluctant to include earmarks in NIH funding bills (Casamayou 2001:145). Increasing the entire NIH budget provided a ready response to disease advocates, demonstrating Congress’s support for medical research without compromising the NIH’s autonomy in funding decisions.

In addition to providing a motivation to increase the NIH budget, disease advocacy may have made it more politically profitable to do so. In Chapter 3, I argued that throughout much of the 20th century, discussions of NIH funding focused on science and scientists. While the Institutes’ overarching goal was to improve the nation’s health, patients were not viewed as the direct beneficiaries of NIH funding. When disease advocates appeared on the scene, they provided a newly visible constituency and encouraged Congress to think of medical research funding as a benefit to particular groups of patients. The shift to viewing patients as beneficiaries may have made research funding more politically attractive. According to the chair of an Institute of Medicine panel on medical research funding, “the American public is not terribly sympathetic to the cause of science for its own sake. The only really feasible way to get large infusions of new money for research is to tie it to a specific disease” (quoted in Johnson 1996:45). Since “no one ever died of microbiology,” focusing on patients as the beneficiaries of medical research funding may have made it easier for members of Congress to lobby for funding increases (Rettig 2005:12).
**Broadening the Boundaries of the Competition**

Next, I analyze congressional testimony to show how advocates and policymakers prevented disease competition from becoming a zero-sum game. Zero-sum models of social movement competition assume that the size of the “pie” is fixed and competitors can only fight for bigger slices. However, the very definition of the pie—the agreed-upon pool of resources to be competed over—depends on laws, political institutions, and policymakers’ strategic actions. In pushing for increases in the NIH budget, advocates and policymakers explicitly struggled over the boundaries of the competition for funds, with two competing models of funding competition. Some advocates and Republican members of Congress framed the competition as being between diseases, while other advocates and Democratic members of Congress framed the competition as being between medical research funding and defense spending. These frames inspired competing funding strategies.

In congressional testimony, some advocates’ rhetoric implied a competition between diseases. For example, one prostate cancer advocate noted high levels of breast cancer research funding, saying that “if we look at the $80,000,000 they have for that disease, there is only $13,000,000 being spent for prostate cancer at the National Cancer Institute" (U.S. House of Representatives 1991b:616). Other advocates compared mortality rates between their diseases and those that received more research funding, saying that “each year diabetes and its complications contribute to the death of 170,000 Americans, more than die of AIDS and breast cancer combined” (U.S. House of Representatives 1997:705), and that “Hepatitis B kills more people worldwide in one day than AIDS does in one year” (U.S. House of Representatives 1992b:148). These claims resonated with Representative Ernest Istook Jr. (R-OK), who published an op-ed in the *Journal of NIH Research* arguing that AIDS was overfunded compared to heart disease, stroke, diabetes, and cancer (Istook 1997). In these claims, the presumed competition is among diseases, and the easiest way to equalize funding would be to transfer money from AIDS and breast cancer research to other diseases. These frames were accompanied by explicit efforts by the Republican leadership to transfer research funds from AIDS to other diseases (Cohen 1997; Kedrowski and Sarow 2007:141). In the previous chapter, I argued that these claims created political pressure for the NIH to standardize its funding distribution on the basis of mortality.

Seeking to avoid competition among diseases, other advocates and members of Congress set up a different rhetorical competition: between disease research funding and defense spending. This frame drew on a long-standing symbolic competition between the defense budget and cancer research. In the early 1970s, Ann Landers orchestrated a letter-writing campaign arguing that cancer research funding should be prioritized over defense spending (Casamayou 2001:42). As the breast cancer movement gained strength in the 1990s, advocates consistently argued for research funds by drawing comparisons to defense spending (Kolker 2004). Breast cancer surgeon and advocate Dr. Susan Love told Congress that “we want less money for defending our country and more for defending our lives” (U.S. House of Representatives 1992a:18). Members of Congress also used the
war analogy to push for more breast cancer research funding. Representative Ted Weiss (D-NY) noted that “we spent $67 million for breast cancer research grants in 1990. However, we will spend 45 times that much for the B-2 bomber in the coming year, even though that program was recently canceled” (U.S. House of Representatives 1991a:2). Similarly, Representative Mary Rose Oakar (D-OH) testified, “I see budgets where we have requests for a billion dollars more in Star Wars research. If I asked my constituents: Would you rather have more research in breast cancer and other related diseases than Star Wars? I've got to tell you, they'd say: Please find a cure for breast cancer; it has devastated my family.” (U.S. House of Representatives 1990:115).

Kedrowski and Sarow (2007) argue that these comparisons to defense spending were merely symbolic, “only deal[ing] with funding priorities in a most general way and fail[ing] to engage in a discussion about how research funds should be allocated among diseases” (Kedrowski and Sarow 2007:171). This critique assumes that the real funding competition takes place among diseases for a fixed medical research budget. In fact, the symbolic weighing of defense spending against medical research funding had concrete effects on the funding distribution. In the early 1990s, Senator Tom Harkin (D-IA) proposed taking $200 million from the DOD and using it to fund breast cancer research through the NIH. His proposal faced a hurdle in the Budget Enforcement Act of 1990, which had set up “fire walls” between defense, international, and domestic spending, mandating that money could not be transferred from one category to another (Franklin 1993). The Act stipulated that all domestic spending priorities would compete only with each other, setting up a zero-sum competition between domestic spending priorities. Unable to transfer money out of the DOD to pay for breast cancer research, Harkin introduced an amendment to the 1993 defense appropriations bill earmarking $210 million for breast cancer research within the DOD (Casamayou 2001:148; Johnson 1996). Despite protests from the director of the Office of Management and Budget and the New York Times, which called it “an openly cynical maneuver,” (Casamayou 2001; New York Times 1992), the amendment passed the Senate and the House and created the Department of Defense Congressionally Directed Medical Research Program (DOD-CDMRP). This funding strategy prevented disease advocacy from becoming a zero-sum game by broadening the boundaries of the funding competition to include the Defense budget.

Discussion

Critics predicted that disease advocates would engage in zero-sum competition, moving funds from one disease to another instead of attracting more funds for medical research. However, I found that advocacy’s effects spilled over across diseases: advocacy for particular diseases increased the likelihood that other diseases would see funding increases. Moreover, while critics predicted that disease competition would lead to a stagnant research budget, I found that disease advocacy coincided with an expansion of the NIH budget and the creation of a new research program at the DOD. Thus, the splintering of medical research advocacy into disease categories did not limit the growth
of the NIH budget. These results demonstrate that to understand social movement outcomes, researchers must consider their interactions.

My findings suggest three ways that dense and diverse advocacy can become synergistic. First, the effects of advocacy can spill over, benefiting other groups within the same policy arena (Kingdon 1984:200). Most advocates for single diseases requested funding for their own diseases and did not explicitly request overall medical research funding increases. However, their increasing prominence attracted congressional attention to medical research funding, increasing the likelihood of NIH funding increases. This finding shows that advocates do not always compete in a zero-sum game.

Second, by focusing on particular beneficiaries and constituencies, identity politics can provide compelling funding rationales for policymakers. Disease advocacy shifted the focus of funding debates to patients, a sympathetic beneficiary group, making it easier to justify increases in medical research funding. Counter-intuitively, particularistic politics can lead to growing pies, since they create more constituencies that politicians may try to placate and provide concrete examples of the types of people a policy helps.

Third, institutions, laws, and strategic action determine the level at which the competition between funding priorities is zero-sum. During the fiscal year, disease competition is zero-sum within the NIH budget, with grants competing for funding within a pre-set budget, but at appropriations time, the NIH budget can increase or decrease, changing the size of the pie. The Budget Enforcement Act sought to ensure that NIH funding would compete with other domestic spending priorities in a zero-sum game. However, as the creation of the DOD-CDMRP shows, policy entrepreneurs can maneuver within these rules, choosing to expand the boundaries of the competition to benefit a favored cause. Whether advocacy becomes a zero-sum game depends on how social movement actors and policymakers construct the boundaries of the competition.
# Tables and Figures

**Table 4.1: Descriptive Statistics**

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Min.</th>
<th>Max.</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH and DOD Funding (Millions)</td>
<td>97</td>
<td>168</td>
<td>0</td>
<td>1326</td>
</tr>
<tr>
<td>Change in NIH and DOD funding</td>
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<td>16</td>
<td>-90</td>
<td>134</td>
</tr>
<tr>
<td>Advocacy for the Disease</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># Nonprofits</td>
<td>24</td>
<td>39</td>
<td>0</td>
<td>211</td>
</tr>
<tr>
<td>Change in # Nonprofits</td>
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<td>4.3</td>
<td>-54</td>
<td>29</td>
</tr>
<tr>
<td>Lobbying (Thousands)</td>
<td>25</td>
<td>80</td>
<td>0</td>
<td>567</td>
</tr>
<tr>
<td># Witnesses</td>
<td>0.43</td>
<td>0.81</td>
<td>0</td>
<td>5</td>
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<tr>
<td>Advocacy for all other diseases</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td># Nonprofits (Hundreds)</td>
<td>51</td>
<td>6.9</td>
<td>40</td>
<td>65</td>
</tr>
<tr>
<td>Change in # Nonprofits (Hundreds)</td>
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<td>1.9</td>
<td>-1.62</td>
<td>7.7</td>
</tr>
<tr>
<td>Lobbying (Millions)</td>
<td>5.7</td>
<td>2.4</td>
<td>1.4</td>
<td>9.7</td>
</tr>
<tr>
<td># Witnesses</td>
<td>56</td>
<td>13</td>
<td>34</td>
<td>81</td>
</tr>
<tr>
<td>Mortality</td>
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<td></td>
</tr>
<tr>
<td>Deaths (Thousands)</td>
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<td>107</td>
<td>0</td>
<td>743</td>
</tr>
<tr>
<td>Change in mortality (Thousands)</td>
<td>0.21</td>
<td>2.4</td>
<td>-28</td>
<td>26</td>
</tr>
</tbody>
</table>

Note: N=654 for all variables
Longitudinal data with disease as the unit of analysis
All financial variables are in 1989 dollars
**Table 4.2: Estimated Effects of Advocacy on Changes in Medical Research Funding**

<table>
<thead>
<tr>
<th></th>
<th>(1)</th>
<th>(2)</th>
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</thead>
<tbody>
<tr>
<td>Change in own organizations</td>
<td>0.24*</td>
<td>0.16</td>
</tr>
<tr>
<td></td>
<td>(0.10)</td>
<td>(0.099)</td>
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<tr>
<td>Own lobbying (thousands)</td>
<td>0.025**</td>
<td>0.027***</td>
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<tr>
<td></td>
<td>(0.0076)</td>
<td>(0.0075)</td>
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<tr>
<td>Own witnesses</td>
<td>0.22</td>
<td>0.091</td>
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<tr>
<td></td>
<td>(0.93)</td>
<td>(0.92)</td>
</tr>
<tr>
<td>Change in others' organizations (hundreds)</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.066)</td>
</tr>
<tr>
<td>Others' lobbying (millions)</td>
<td>-0.065</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.26)</td>
<td></td>
</tr>
<tr>
<td>Others' witnesses</td>
<td>0.16**</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.054)</td>
<td></td>
</tr>
<tr>
<td>Change in mortality (thousands)</td>
<td>0.70</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td>(0.40)</td>
<td>(0.40)</td>
</tr>
<tr>
<td>Constant</td>
<td>3.78***</td>
<td>0.33</td>
</tr>
<tr>
<td></td>
<td>(0.89)</td>
<td>(2.12)</td>
</tr>
<tr>
<td>Observations</td>
<td>682</td>
<td>682</td>
</tr>
<tr>
<td>R-squared</td>
<td>0.047</td>
<td>0.071</td>
</tr>
</tbody>
</table>

All independent variables lagged one year
Dependent variable is changes in NIH and DOD funding in millions of 1989 dollars
Robust standard errors in parentheses

*** p<0.001, ** p<0.01, * p<0.05
Figure 4.1: Total Funding Increased as Advocates Targeted Diseases
Chapter 5

Conclusion
This dissertation has documented a dramatic change in American politics: the emergence and expansion of disease patients’ interest groups. In the 1980s, AIDS and breast cancer advocates institutionalized a new model for patient-centered advocacy. This form diffused widely, and advocates for patients with dozens of diseases founded hundreds of nonprofits and lobbied Congress to an unprecedented degree. The new disease advocacy changed how the federal government distributes research funding. Disease advocates were incredibly successful at securing funding increases for their diseases. In the aggregate, these increases changed the funding distribution to the detriment of diseases that primarily kill blacks and women (with the exception of breast cancer). It is important to note, though, diseases did not compete in a zero-sum game; instead, disease advocacy attracted unprecedented levels of public funding to medical research. Disease advocates also had significant cultural effects on medical research politics. They framed mortality as the most legitimate way commensurate diseases, creating pressure on the NIH to shift funds towards high-mortality diseases. They also encouraged policymakers to think of patients as the beneficiaries of medical research funding. This change in perceived beneficiaries made stigma increasingly relevant to funding deliberations. These findings show that advocacy’s political effects are cultural as well as concrete, including changes in how policymakers evaluate policies and judge competing claims.

Cultural understandings and objective conditions interact to shape politics and policy. On the one hand, my findings demonstrate that objective conditions are filtered through cultural understandings. The level of breast cancer organizing depended on perceived interests and risks, not solely on objective conditions. Budget rules that prohibited the transfer of funds from defense to medical research were overcome by political entrepreneurs who creatively redefined the budget categories. On the other hand, my findings also show that frames and cultural categories are neither freely chosen nor universally influential. Advocates’ frames were limited by the biological features of their diseases: lung cancer advocates were less able to present their patients as deserving. Cultural categories of worth were not always relevant to policy decision-making, depending on the policy’s perceived beneficiaries. Calling disease competition a zero-sum game didn’t make it so. Thus, the effects of objective conditions depend on how they are perceived, but actors are not entirely free to create new perceptions.

This study also demonstrates the importance of looking at interactions between social movements. The diffusion of templates for organizing was a crucial factor in the growth of the field of disease advocacy. Advocates had systemic effects on medical research policymaking, changing the rules of the game for each other. And disease advocacy organizations had synergistic outcomes, with benefits spilling over across diseases. These findings demonstrate the importance of studying entire fields of advocacy, since such interactions are invisible in studies of single movements.

My findings also shed light on the complicated relationship between advocacy and expert autonomy. The second half of the twentieth century saw increasing demands for public
control over and participation in science (Bucchi and Neresini 2008; Guston 2000; Hess 2006; Moore 2006). But public faith in science remains high, and the public tends to “alternate between mythologizing and demonizing scientists” (Epstein 1996:6; Pescosolido 2006). The emergence of disease advocacy highlights both trends. Disease advocates challenged the authority of experts to make subjective funding decisions, introducing metrics for commensurating diseases that created pressure to standardize the budget. However, the advocates’ focus on the NIH budget reflects their faith in science’s power to cure disease and their commitment to spending public money on research. Their advocacy also provided new, politically attractive constituencies for NIH funding, attracting increased funds and influence to the NIH.

The emergence of disease advocacy signals the growing prominence of diseases in American politics and culture. Disease patients have become powerful interest groups, claiming a larger share of the federal budget for medical research and redefining the political meaning of that research. Outside the political sphere, disease advocacy is even more prominent: ribbons and bracelets symbolize diseases, athletic events raise money to fight diseases, and a growing share of the charitable and nonprofit sector targets diseases. In one light, the emergence of disease advocacy is an uplifting story about people coming together to lengthen and improve their lives. But the very universality of this goal allows diseases to overshadow other social problems, raising concerns about their growing prominence.

Medical research is an almost uniquely politically popular government program. Other health policy proposals, such as national health insurance, are more controversial, split along party lines, and opposed by powerful interest groups including the American Medical Association (Quadagno 2005). Medical research, on the other hand, directly benefits scientific researchers, universities, and the pharmaceutical industry without attracting sustained opposition from other groups (Cook-Degan and McGeary 2006; Sampat 2009; Strickland 1972). Medical research is also less redistributive than health care provision, benefiting the rich as much as or more than the poor. This pattern may contribute to its near-universal appeal. In the 1980s, the NIH was so politically popular that when the conservative Heritage Foundation suggested cuts to the federal government, they “identified NIH as virtually the only domestic agency of government whose work was so important, so efficiently carried out, and of such high benefit-to-cost ratio, that no cuts should be made in it” (Strickland 1988:90). The unusual political status of medical research as a culturally valorized goal and a non-controversial policy helps explain the extraordinary successes of advocates pushing for more research on deadly diseases: they are interest groups with few or no enemies.

The political popularity of medical research and the valorization of disease advocates have contributed to our sky-high expenditures of public funds for medical research. We spend much more on medical research than any other country—five times as much as the entire European Union (Murphy and Topel 2003:2). Meanwhile, unlike other industrialized democracies, we have no national health insurance. We should not assume that there is a fixed health budget, with research and care competing in a zero-sum game.
But if we inflate the least controversial areas of the federal budget, we may end up with non-redistributive policies that favor the interest of corporations and industries. No one could be against curing diseases. But by defining our interests around disease categories, we may be overlooking other threats to our health and wellbeing.
Works Cited


Appendix: Codebooks

Coding Instructions for Witness Affiliations

What part of the listing should you code?

* Base your codes on the **organization** the witness is representing.
  Exceptions:
  o Code any congressperson as 15, even if an organization is listed.
  o In hearing parts that have only one or a few witnesses per panel, the vast majority of the witnesses are federal officials. (In the 1990 hearings, this is everything except House parts 8 and 9 and Senate parts 3s, 4s). In these parts, assume that acronyms refer to federal agencies and code witnesses as federal officials unless some other organization is listed.

* If they are representing more than one organization, code the **first** one listed

* If they’re not listed as “representing” anything, code the organization they work for. If they have multiple jobs, code the first one.

* If the affiliation is listed below several witnesses, apply the affiliation to all the witnesses. (E.g., after the third witness in a list, "all representing the AHA")

* If the witness is testifying “on behalf of” someone else, code the second person’s affiliation, if provided.

* If a witness is “accompanied by” others who are not given their own lines in the witness list, code only the original witness.

* If the witness is listed as “also representing _____,” code whatever organization comes before the word also.
  - Example: GLICKMAN, Robert M., Dr., President, American Gastroenterological Association; also representing National Digestive Diseases Advisory Board. The “also” implies that he was “representing” the American Gastroenterological Association. Code American Gastroenterological Association.
  - Exception: if the “also” refers to the fact that this witness is representing the same organization as the previous witness. Example: PURPURA, Dominick P., Dr., representing Society for Neuroscience and NCR, p. 204-237. MUNSAT, Theodore L., Dr., past President, American Academy of Neurology; also representing NCR. Here, the “also” refers to the fact that Munsat is representing the same organization as Purpura. Code NCR.)

(See next page for codes)
<table>
<thead>
<tr>
<th>Witness codes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>?</strong></td>
<td>If there is no information provided, code 16 (can’t tell).</td>
</tr>
<tr>
<td><strong>Reps</strong></td>
<td>Is the witness a congressperson (identified as Rep, Sen, or Del)? If yes, code 15. (Code 15 even if the congressperson is also representing an organization).</td>
</tr>
<tr>
<td><strong>Is the witness’s organization health-related?</strong> (Includes physical health, mental health, substance abuse, disabilities, and reproductive health. Excludes violence. Includes “aging” but not “aged”).</td>
<td></td>
</tr>
<tr>
<td><strong>Health-related</strong></td>
<td>Not health related</td>
</tr>
<tr>
<td><strong>Is the witness a federal health official?</strong> (Health-related and in an official part of a hearing or “accompanied by staff officials.” See note on previous page.) If yes, code 3. <strong>Examples:</strong> An NIH institute (a &quot;national institute of...&quot;), the CDC, National Mine Safety and Health Commission, ADAMHA, Health and Human Services.</td>
<td><strong>Is the witness a non-health-related federal official?</strong> (Not health-related and in an official part of a hearing or “accompanied by staff officials.” See note on previous page.) If yes, code 10. (Note: Congresspeople are coded as 15). Examples: DOL, BLS.</td>
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<tr>
<td><strong>Professional associations</strong></td>
<td><strong>Places and programs</strong></td>
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<tr>
<td>Is the witness representing a health-related professional association? (Represents people who work in the health care or health research field. Includes a reference to an occupation, field of study, or job task). (Research doesn’t count as a job task). If yes, code 4. <strong>Examples:</strong> American Dental Hygienists’ Association, American Psychiatric Association, American Medical Association, American Academy of Neurology, American Society for Gastrointestinal Endoscopy</td>
<td>Is the witness representing one or more medical research centers, medical schools, hospitals, clinics, health centers, medical museums, or medical libraries? (One or more physical places devoted to medical research, training, or care. Includes schools serving people with disabilities or disorders). If yes, code 5. <strong>Examples:</strong> Association of American Cancer Institutes, National Council of Community Mental Health Centers,</td>
</tr>
<tr>
<td><strong>Federal officials</strong></td>
<td></td>
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<tr>
<td>Local government</td>
<td>Is the witness representing a <strong>health-related state or local government office or state or local government officers</strong>? (Mentions a state or locality, or specifies that it’s for state or local officials). If yes, code 6. <strong>Examples:</strong> Missouri Department of Mental Health</td>
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<td>Is the witness representing a health-related <strong>private company</strong>? (e.g., pharmaceutical company, insurance company, biotech. Excludes non-profits and foundations). If yes, code 7. <strong>Examples:</strong> Blue Cross and Blue Shield</td>
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<td></td>
<td>Does the witness have no organizational affiliation listed, AND is identified as a <strong>patient</strong>, a caregiver or a patient’s family member? If yes, code 2 and enter the disease in column H. <strong>Examples:</strong> Arthritis patient</td>
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<td></td>
<td>If you have not coded 2-7, code the witness as a <strong>health advocate</strong>: code 1 and enter the organization name in column G. Always code 1 if the key piece of information in the organization name is a disease or body part. <strong>Examples:</strong> American Foundation for AIDS Research; American Heart Association; National Mental Health Association</td>
</tr>
</tbody>
</table>

Coding Instructions for Witness Testimony

Code the oral portion of the witness’s testimony (not the “prepared remarks”). Do not include answers to questions from members of Congress. Feel free to code multiple categories per sentence.

Overall testimony (0=no, 1=yes):

**Testimony:** (0= the witness does not make a statement or speaks for less than half a page; 1=the witness makes a statement of at least half a page)

**Research:** (Code 1 if the witness mentions medical research, medical researchers, the NIH, or an NIH institute at least once. Does *not* include medical treatment).

Who are they (0=no / not mentioned, 1=yes, X=explicitly denied – e.g., “I’m not a scientist, but…”)

**Patient/caregiver/family member:** Witness specifies that they or a family member or someone they’ve provided care for has or had the disease/condition.

**Doctor/scientist/researcher:** Witness states that he or she is a doctor, scientist, researcher, or medical professional and/or is referred to as “Dr.,” “M.D.,” “Ph.D.,” “R.N.,” etc.

**Celebrity:** Witness is a professional athlete, professional entertainer, well-known author, or otherwise famous.

**Child:** Witness states that he or she is a child, is under 18, and/or is a student (high school or below)

**Gender** (0=don’t know, 1=male, 2=female)

Bad behavior (0=not mentioned, 1=mentioned as a cause, X=denied as a cause):

**Sex:** Witness specifies that sex causes or might cause the disease.

**Smoking:** Witness specifies that cigarette smoking causes or might cause the disease.

**Drugs:** Witness specifies that drug use, not including tobacco, causes or might cause the disease. (Note: if the condition is drug abuse, do not code drug use as a cause)

**Alcohol:** Witness specifies that alcohol use causes or might cause the disease. (Note: if the condition is alcohol abuse, do not code alcohol use as a cause)
**Importance** (0=not mentioned, 1=mentioned, X=died (e.g., “this disease doesn’t affect many people”)):

- **Many affected**: Witness states that lots of people get or die from the disease. Includes statements about people affected in the past, present, and future. Statistics can be for the whole population or for a subgroup.

- **Money and economy**: Witness refers to the economic impact of the disease. Includes statements about public or private medical costs. Includes economic harms (e.g., lost productivity, lost tax revenues, lost wages). Includes individuals missing or doing worse at work or school. Also code 1 for statements that research could decrease or has already decreased these costs.

- **Potential**: Witness states that scientific progress on their disease is close at hand; that scientific discoveries about their disease are likely to happen soon. Includes predictions about the discovery of new or improved tests, treatments or cures. (e.g., “If more research is done, we’re likely to find a cure;” “Because we’ve just learned a lot about the disease, we’re close to developing treatments”). Does **not** include predictions about future access to existing treatments (code zero for “we will be able to save a lot of lives by distributing drugs to more people”).

**Competitions** (0=not mentioned, 1=mentioned, X=explicitly say they’re NOT making the comparison)

- **Disease competition**: Witness compares importance (e.g., number affected, severity, costs, etc), reasons for funding or levels of funding/attention for their disease to another disease or other diseases. (e.g., “lung cancer kills more women than breast cancer;” “the NIH spends a lot on AIDS and only a little on diabetes,” “diabetes is underfunded compared to other diseases,” “arthritis affects more people than any other chronic disease”). (Code zero for “this disease is the leading cause of death” because the comparison to all other diseases is too vague).

- **NIH competition**: Witness compares importance, reasons for funding, or levels of funding/attention for a disease or NIH institute to other NIH institutes or to the size of the entire NIH budget. (e.g., “The NCI only gets a small portion of the NIH budget;” “The NHLBI gets less money than the NCI,” “prostate cancer gets only a small portion of the NCI budget,” “Even though the NIH budget increased a lot, my disease didn’t get any extra money”)

- **War competition**: Witness compares importance, reasons for funding, or levels of funding/attention for their disease to war or to defense spending. (e.g., “We spend more to build a single fighter jet than we do on researching breast cancer;” “More people die of cancer each year than died in the Gulf War”).