Whose Deaths Matter?
Mortality, Advocacy, and Attention to Disease in the Mass Media

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Abstract

Diseases capture public attention in varied ways and to varying degrees. In this paper, we use a unique dataset that we have collected about print and broadcast media attention to seven diseases across nineteen years in order to address two questions. First, how (if at all) is mortality related to attention? Second, how (if at all) is advocacy, in the form of organized interest group activity, related to media attention? Our analysis of the cross-disease and cross-temporal variation in media attention suggests that who suffers from a disease as well as how many suffer are critical factors in explaining why some diseases get more attention than others. In particular, our data reveal that both the print and the broadcast media tend to be much less attentive to diseases that disproportionately burden blacks relative to whites. We also find a positive link between the size of organizational communities that take an interest in disease and media attention, though this finding depends on the characteristics of those communities. Finally, this study also reveals the limitations of relying on single-disease case studies—and particulary HIV/AIDS—to understand how and why disease captures public attention. Many previous inferences about media attention that have been drawn from the case of AIDS are not reflective of the attention allocated to other diseases.

Introduction

Even in today's world of global terrorism, economic crisis and political impasse, the news is often about one of the oldest of humankind's problems, that of disease. Headlines about disease regularly appear on the front pages and throughout major newspapers. Both newspapers and television news programs rely on reporters who cover "the health beat," and many news venues have dedicated health or science sections, providing regular coverage of diseases. Moreover, organized interest groups such as ACT-UP, the American Lung Association, and the National Breast Cancer Coalition are a ubiquitous presence in public policy debates. Hollywood celebrities and members of Congress frequently become "sponsors" of various diseases, with their involvement sparking even greater public attention. Indeed, disease captivates the interest of newsmakers, of the public at large, and of policymakers and other political actors.

Most social science research on the process of allocating attention to disease has focused on a single disease at a particular point in time. In this paper, we use a unique dataset that we have collected about print and broadcast media attention to seven diseases across nineteen years in order to address two questions about media attention to disease. First, how (if at all) is the social burden of a disease related to attention? Second, how (if at all) do organized interest groups affect attention? To be sure, many scholars have taken an interest in how the epidemiology and politics of particular diseases—usually examined in case study form—affect attention from the media. But our project has two unique features. First, the inferences we draw about the impact of social burden and interest groups on media attention to disease are based on a direct comparison of burden, groups, and attention across different diseases. This direct comparison of burden across different "problems" has been difficult for researchers to undertake because most problems lack a common metric for comparison. But we can approximate the

social burden of a disease with the number of deaths it causes in order to examine directly the relationship between the social burden a problem inflicts and the attention it receives from the media. Second, given that much research about media attention to disease has been dominated by studies of single, high profile diseases such as breast cancer and AIDS, we examine directly whether the process of allocating attention to one of those diseases -- HIV/AIDS -- is illustrative of the attention generating process characterizing diseases in general, or whether the attention process to AIDS is distinct from that of the other diseases.

Moreover, studying these seven diseases enables us to escape the constraints of a strict constructionist perspective on the news—that is, that the mass media "create" social problems via their attention to them. Although we are not able to address the content of media attention or the framing of these seven diseases as social problems in this analysis, we are able to examine rigorously and empirically the relationship between "the underlying reality" of a social problem (in this case, a particular disease) and attention to that problem in the public arena. Our analysis of the cross-disease and cross-temporal variation in media attention suggests that who suffers from a disease as well as how many suffer are critical factors in explaining why some diseases get more attention than others. For example, our data illustrate that both the print and broadcast media tend to be much *less* attentive to diseases that burden blacks more than whites, a result that is robust across the full sample of diseases we study. However, a number of our inferences about media attention are sensitive to the inclusion or exclusion of AIDS observations from the sample, suggesting that scholars should be cautious about generalizing from the AIDS case to the attention process more broadly. We argue that only through a study of why the media allocate different amounts of attention to different diseases at different points in time is it possible to

separate the anomalous aspects of AIDS from those aspects that reflect general tendencies of attention allocation by the media.

Variation in Media Attention to Disease

Our interest in the correlates of media attention derives from the observation that while public attention to disease in general is expanding over time, different diseases capture that attention in varied ways and to varying degrees. Some diseases, such as HIV/AIDS, dominate public discourse, while other diseases, such as pneumonia (which is among the ten leading causes of death in the U.S.), receive only glancing attention, if any at all. Figure 1 demonstrates this variation for the period 1980 through 1998 among the set of seven diseases we study, all of which are leading causes of mortality in the United States: heart disease, lung cancer, cerebrovascular disease, chronic obstructive pulmonary disease (COPD), diabetes, HIV/AIDS and Alzheimer's disease. The first row of bars depicts the total number of deaths attributed to each disease over this time period, ranging from 14.2 million for heart disease, to 236,000 for Alzheimer's disease.[1] The second row depicts the total number of stories on each disease appearing in the *New York Times* and the *Washington Post* combined; the third row shows the total number of stories appearing on the major television networks' evening news programs (ABC, CBS and NBC).

[Figure 1 here]

Figure 1 illustrates that some diseases get a lot of attention across both print and broadcast venues—most notably, HIV/AIDS, but also heart disease—whereas diabetes, for example, attracts substantial newspaper attention, but almost no attention from the television news. In addition, these data show that at least one measure of social burden—mortality—is not

a consistent predictor of media attention to that disease: diseases that cause more deaths do not necessarily get more attention. HIV/AIDS is the clear outlier here, though note as well that while COPD causes almost seven times as many deaths as Alzheimer's, newspaper stories on Alzheimer's outnumber stories on COPD by about two to one.[2]

Although Figure 1 relies on aggregate data for the time period, attention to disease varies over time as well, as shown in Figure 2, which depicts the total number of stories devoted to each disease in each year between 1980 and 1998 appearing in the *New York Times* and the *Washington Post*. Again, we can see the unequal levels of attention to these diseases, as well as differences in the extent to which that attention varies over time. In the case of AIDS, Figure 2 shows a gradual increase in media attention throughout the early years of the disease, up until attention peaks in the late 1980s. Although media attention to AIDS subsequently begins to decline, the level of attention it commands remains relatively high through the 1990s. The peaks and valleys in attention to the six remaining diseases are much less pronounced. Thus, these diseases are allocated less attention by newspapers than is AIDS, and the annual variation in attention to them is not nearly as dramatic. Figure 2 also illustrates the tremendous growth of annual total stories devoted to disease overall, from fewer than 100 stories in 1980 to about 350 stories in 1998, down from a peak of about 800 stories in 1987 when news writers and producers were giving extensive coverage to the relatively new disease called AIDS.[3]

[Figure 2 here]

That disease garners public attention, then, is indisputable. But *how* and *why* do some diseases get more attention from the media than others? Disease itself, as a category of news story, fulfills most of the criteria scholars have associated with newsworthiness. "Newsworthy"

problems have been characterized as those that are "new" or current; that affect the general population, or threaten to do so; that are easily described, typically through the use of a "hook" or "human interest" angle; and that can be readily linked to authoritative sources, such as public health officials, scientists or physicians (Gans 1979, Tuchman 1978, Schudson 1978). Diseases in and of themselves typically bear all of these characteristics. Moreover, diseases frequently attract the attention of celebrity advocates, and may be associated with notable people (e.g., sufferers who are known by the general public) and "trigger events" (e.g., a breakthrough in treatment or diagnosis) that researchers have argued are essential for attracting attention to problems (Corbett and Mori 1999; Dearing and Rogers 1996; Elliott 2002; Kurtz 2000). Yet acknowledging that disease is newsworthy – either inherently or by association with newsworthy individuals or events – does not help us understand the dramatic variation in attention over time, across diseases, and across venues that we observe in Figures 1 and 2. What propels one newsworthy disease to receive more attention than another newsworthy disease, and what drives these observed shifts in attention levels?[4]

Extant research does not directly answer either of these questions. Because most social problems lack a common metric for comparison, researchers have had difficulty sorting out precisely why some problems attract more attention than others. Several studies have described or characterized how variables including interest group involvement, "windows of opportunity," shifts in decision making venues, easily accessible sources of expertise, affected target populations, and definitions or images rooted in appealing symbols contribute to the ebb and flow in public attention to particular issues and problems (Baumgartner and Jones 1993; Best 1990; Blumer 1971; Cobb and Elder 1983; Cobb and Ross 1997; Cook 1998; Downs 1972; Edelman 1971, 1988; Elder and Cobb 1983; Epstein 1996; Gusfield 1981; Hilgartner and Bosk

1988; Kingdon 1995; Kitsuse and Spector 1973; Schneider and Ingram 1993; Spector and Kitsuse 1973; Terkildsen, Schnell, and Ling 1998). But with no basis for comparing problems, what we know about the correlates of attention to issues and problems is drawn from studies that observe attention to individual problems. In this way, it is only through implicit comparison that we come to understand why attention is allocated to some problems more often than others. For example, many researchers claim that empirical indicators of severity are unrelated to the attention a problem receives (Blumer 1971). As evidence for the "relative unimportance" of "real-world indicators," Dearing and Rogers (1996) mention Kerr's (1986) story showing that attention to the war on drugs peaked in response to the death of a young basketball star and Nancy Reagan's "Just Say No" campaign, both of which happened while the number of drug-related deaths declined. Similarly, media attention to environmental issues was shown to increase as pollution decreased (Ader 1993 cited in Dearing and Rogers 1996), lending support to the idea that attention to a problem is uncorrelated or negatively correlated with objective indicators of its severity or that there is a lag between the manifestation of a problem and its recognition in the mass media. But because these studies focus on one social problem at a time, they do not indicate whether variation in the societal burden of drug deaths relative to the societal burden of pollution help to explain differences in attention to drugs relative to environmental issues; the burden of drug deaths cannot validly be compared with the burden of pollution.

Like these studies, much of what is known about how health problems and diseases capture public attention is drawn from studies of a single disease, particularly AIDS or breast cancer, at a specific point in time (Casamayou 2001; Colby and Cook 1991; Epstein 1996; Lantz and Booth 1998; Lerner 2001). Yet Figures 1 and 2 suggest that generalizing about how and

why diseases capture attention based on any single case—and particularly on AIDS—could be problematic. Because AIDS generated intense media, scientific and academic attention in the early years of the epidemic, it lent itself to the case study approach. Yet, AIDS is hardly a "typical" disease. Not only does AIDS command a relatively large amount of public attention and cause far fewer deaths in aggregate than many other diseases, it also is associated with a relatively sizable set of organized groups that advocate on behalf of individuals who suffer from the disease. Moreover, while AIDS mortality may be lower in aggregate than that caused by other diseases, AIDS has powerful cultural associations with death because of its nearly 100 percent case-fatality rate and because it strikes most often in the prime of life. AIDS also enjoys the advantage of a keen news hook via its connection to sex. In addition, as an emerging disease—never seen before—AIDS was both new and "news" in a way that other diseases are not. Yet because scholars have generalized from AIDS, the conventional understanding of how *any disease* gets attention has come to be that the number of deaths associated with it is less important in drawing public attention than is having organized and politically active advocates who work to increase research funding for and public attention to that disease.

But with no basis of comparison, whether these two explanations—organized disease advocates and the burden of a disease—appropriately characterize attention given by the media to other diseases and help to explain variation in attention to different diseases is unclear. Moreover, because the amount of attention paid to individual diseases varies considerably over time, it is important to consider whether these and/or other explanations of attention explain adequately the temporal fluctuations in attention we observe (see Figure 2). In a departure from previous research, our data allow us to capture the temporal dimensions of attention patterns, and

they also enable us to model the extent to which attention differs among diseases as a function of disease burden and the efforts of organized activist communities associated with disease.

Disease Burden and Media Attention

From the common cold to AIDS, diseases exact a toll on society as well as on individuals. We believe the burden a disease imposes on the population as a whole, and on specific groups within the population, shapes attention. In other words, diseases garner attention in the public arena precisely because they have *real consequences* for individuals and for society as a whole. However, the burden of a disease is typically distributed unequally across society. This uneven distribution of burden means that diseases have varying degrees of *salience* in the public arena, and this variation in salience may manifest in differential attention from the media.

There are at least two fundamental dimensions of burden that we argue may affect the salience of a disease and thus the attention allocation process. First, the nature of the burden itself, whether in the form of morbidity or mortality, impact on quality or length of life, or such direct costs to the health care system as treatment, hospitalization, or pharmaceuticals, may draw the media's attention. Diseases make people sick; morbidity in turn affects the quality of life, labor force productivity, and the care burden that falls on family members or society. Thus, it is important to know how many people suffer from a particular disease, as well as something about the cost of that suffering to them as individuals and to society as a whole; how many and what kinds of societal and health care resources are allocated to the disease? For our purposes, this information is most readily identifiable in data on disease incidence and mortality, hospitalizations, outpatient visits, and drug utilization, though such data do not begin to capture

the complete burden of disease. The point is that diseases do exact some burdens that are measurable, even if the true cost of a particular disease to society is itself immeasurable.[5]

Second, we expect the salience of a disease (and subsequent media attention given to a disease) to depend on *who* in society suffers these burdens as described above. At the most basic level, the characteristics of the people who suffer or die from a particular disease are important. Are they young or old, male or female, black or white, rich or poor? Few diseases affect all sectors of the population equally. Demographic characteristics of groups on whom the burden of disease falls differentially vary across disease. For example, black mortality from diabetes is significantly higher than white mortality; whereas the reverse is true for mortality from COPD. Men suffer higher death rates from heart disease than women, while women suffer higher death rates from cerebrovascular disease. Thus, the disease burden, reflected in terms of mortality, falls differentially across different population groups and we believe that not only the numbers of people burdened by a particular disease, but also the demographic characteristics of those people (i.e., race, sex and age) affects the salience of a disease in the public eye.

These two dimensions of burden – its degree and who endures it – map onto distinct ways in which it may affect media attention. First, the overall numbers of those affected (either in terms of deaths, incidence, cost, etc.) by a particular disease may create or shape attention to that disease. Although some research suggests that attention levels do not reflect trends in burden as measured by death (Colby and Cook 1991: 222-223), a relatively recent study finds that newspaper coverage of disease *is* responsive to trends in disease mortality (Adelman and Verbrugge 2000). But Adelman and Verbrugge include obituaries and paid death notices in their measure of newspaper coverage, all but ensuring that coverage will map closely with rates of death (indeed, they find that trends in coverage do not correspond to trends in prevalence or

incidence of a disease). Thus, the link between attention and burden remains empirically unfounded.

Second, we expect that changes in the burden of a particular disease—either in the form of increases or decreases over time—may affect levels of attention to that disease. This idea is consistent with Adelman and Verbrugge's (2000) suggestion that the newsworthiness of a decline in cancer deaths may explain why they observe no decrease in news coverage of cancer even as the death rate from cancer decreases, a pattern that is at odds with their central finding that death rates and coverage are linked.

Third, we expect that the groups in society who bear the burden of a disease are likely to have an impact on the amount of attention that is given to a disease. For instance, diseases that affect minority groups may draw less attention than heart disease or other diseases that afflict white males at a greater rate than the general population precisely because "minority" diseases may be regarded as less salient. Diseases affecting minority groups may be perceived as meriting less attention because they pose less of a threat to the general population; less attention to these diseases also may result from the news selection strategies of (predominantly) white broadcast and print media executives who are attentive to problems affecting their own families and friends (Cohen 1999). Editors may also select stories about particular diseases in order to draw readers of a particular social group; diseases that impose a greater burden on women than men may be given more attention as news producers make efforts to attract a female audience. In addition, diseases that are especially burdensome to younger rather than older groups in the population may attract relatively more public attention precisely because the death or illness is premature. Moreover, diseases that affect "sympathetic" social groups such as children, even in a relatively limited way, may garner more attention because of the group affected (Vallabhan

1997). Our analysis, then, examines not only whether death matters in the attention process, but more precisely, *whose* deaths matter.

It is possible that the media respond not to "real" burden but to the perceived burden of a disease. Researchers have demonstrated time and again that the mass media often "get the facts wrong" in portraying social problems (Hubbard et al. 1975) as diverse as child abduction (Best 1990), environmental degradation (Mazur and Lee 1993), and school shootings (Newman 2004). Surely, advocates associated with social problems contribute to these misperceptions. For example, breast cancer is far more likely to strike and kill older women than younger women. But because advocacy groups often emphasize breast cancer deaths among young women, especially young mothers, the public actually misunderstands the epidemiology of the disease (Lantz and Booth 1998). Relatedly, recent public awareness campaigns about heart disease among women have been initiated (at least in part) to clear up the misperception that breast cancer causes more deaths among women than does heart disease. The tendency of politicians and some organizations to link AIDS with children also illustrates how misperceptions can occur. Thus, it is possible that attention is driven not by actual mortality but by a misperception or mischaracterization of that rate. Mistaken portrayals or perceptions of burden could explain why mortality has been observed to be an inconsistent predictor of attention to disease.

Organized Advocacy and Media Attention

This phenomenon of identifying certain diseases with particular population groups is reflected as well in the politics of disease. There has been tremendous attention focused on the politics and politicization of disease, particularly around HIV/AIDS and breast cancer. Researchers and journalists have documented the social movements that emerged to seek more

research funding for HIV/AIDS and breast cancer, along with enhanced social service support for those suffering from the disease, and greater access to drugs and other medical treatments (Epstein 1996; Shilts 1987). Of course, organizations advocating on behalf of victims of disease are not new. Groups such as the March of Dimes, American Lung Association, and American Cancer Society have been around for well over seventy years and have frequently been credited with drawing public and governmental attention to health-related issues (Lerner 2001, Proctor 1995). However, in recent years, organized disease advocates have become a primary focus of those who have sought to understand both the increases in funding for HIV/AIDS and breast cancer research and the substantial public attention paid to these diseases. Casamayou (2001), for example, gives nearly sole credit to the National Breast Cancer Coalition, founded in 1991, for increasing federal funding for breast cancer. Epstein (1996) argues that the demographics of those most directly affected by HIV/AIDS (i.e., politically efficacious, white, middle-class men) made possible a movement of "activist experts" rather than of victims. These individuals established themselves as a credible source of knowledge apart from the medical establishment, allowing them to affect policy decisions made about AIDS treatment. More generally, others argue that AIDS advocacy was made relatively easy by the presence of politically active organizations in the gay community that existed prior to the epidemic (Cohen 1999).

Of course, disease sufferers and their advocates are not alone in their interest in drawing public attention to a disease. Physicians, research scientists, fund raisers, representatives of specialty care centers, and public health officials, among others, have a considerable stake in attracting public attention to particular diseases. Like disease sufferers, specialty associations of physicians and other professionals realize that decisions to allocate resources to a disease may flow from increased public attention. At the same time, reporters and other members of the

media most certainly are aware of and attentive to these "authoritative sources" populating many disease communities. Although it is unlikely that these professional associations and institutional interests are distributed evenly across the organizational communities associated with different diseases, they share the incentives of citizen advocates to draw public and governmental attention to health-related issues.[6]

The importance of organized advocates and social movements in drawing public and governmental attention to disease receives support in the broader literature on movements and groups (Best 1990; Cress and Snow 2000; Kitsuse and Spector 1973; Kollman 1998; Wright 1996). Indeed, any social problem that emerges or is recognized as such has associated with it a set of interest groups whose explicit aim it is to draw attention to *their* problem (Best 1990; Kitsuse and Spector 1973). However, the means through which these entities are most successful in drawing attention to their concerns – a strong organization, large numbers, an ability to provide information, protests, headline-grabbing advocacy tactics – is subject to debate (Gamson 1990; Gandy 1982; Montgomery 1989; Piven and Cloward 1977). One way through which organized interests secure attention to particular problems is by acting as noisemakers, communicating to policy makers and members of the media the salience of an issue. Relatively large and proactive organizational communities – like those associated with AIDS and breast cancer – can draw attention to specific issues by communicating, through their claimsmaking and general advocacy activity, a capacity to stir up public attention and interest, thereby signaling that a problem is salient and of concern to a large (or especially influential) segment of the public (Caldeira and Wright 1988; Kollman 1998; Spector and Kitsuse 1973). Similarly, communities that can give an impression that they will turn out large numbers of voters in response to a

particular issue on Election Day are likely to attract attention and agenda space (Donovan 2001; Wright 1996).

Another way in which organized interests can draw attention to problems is by providing information to subsidize the costs of search for those who control access to attention – that is, reporters and government decision makers (Berry 1999; Gandy 1982; Hall 2000). Members of the media operate under tight time schedules. As a result, the expertise, data, and intelligence available from organizations can both fulfill an important need for reporters and make it easier for them to be attentive to groups' concerns. Indeed, just as members of Congress grant access to organized interests who have an information provision advantage relative to their competitors (Hansen 1991), organizations may serve as "authoritative sources" about issues, enhancing the likelihood that "their" problems and concerns become part of the media agenda (Colby and Cook 1991; Cook 1998; Gans 1979). The movement of AIDS activist experts described by Epstein (1996) is especially illustrative of this information subsidy. Politically active groups may be especially valuable information sources since they are able to gather information and convey it to actors in both media outlets and government. Importantly, the ability of different communities of organizations to communicate effectively their concerns will depend on the skills and resources of individual organizations, and whether their message is one that resonates with mainstream public discourse (Barker-Plummer 1995; Gitlin 1980).

Data

In order to investigate how disease burden and organized disease advocates affect media attention to disease we have collected data about seven diseases for each of nineteen years.[7] We have deliberately included diseases that are leading causes of death for the U.S. population as a

whole, as well as for different age, gender and race/ethnicity groups. We examine both chronic and infectious diseases, diseases with low mortality but high morbidity, such as Alzheimer's disease and asthma, diseases that are media-prominent, and diseases that much less often appear in the headlines. Data about media attention to each disease, the organizations with an interest in each disease, and the social burden of each disease have been collected for each year from 1980 to 1998.

Media Attention to Disease. Our analysis rests upon five indicators of the attention allocated to each disease by the broadcast and print media. Broadcast media attention is captured by the number of disease-related stories featured on each of the ABC, CBS, and NBC early evening news broadcasts each week. These data were obtained from the *Vanderbilt Television News Abstracts and Indices* using the key words listed in Table 1. These search terms include words used by laypersons as well as medical professionals. For example, we not only searched for mentions of "heart disease" and but also for mentions of "myocardial infarction."

[Table 1 here]

Attention from the print media is measured by the weekly count of disease-related stories appearing in *The New York Times* and in *The Washington Post*.[8] The print data were gathered using the key words shown in Table 1 through Lexis-Nexis. We examined each of the broadcast story abstracts and print stories that were located through our search in order to determine whether the story was actually related to the relevant disease. We omitted from our attention counts any stories that were not primarily about the disease in question. For example, our search for HIV/AIDS brought up stories that described efforts to gain support for a housing program that happened to serve individuals with the disease. When those stories focused primarily on the program and only in passing mentioned the clientele served, the stories were not included in our

counts. However, if the story dealt with the myriad difficulties faced by HIV/AIDS sufferers, particularly as the disease was emerging, it was included in our counts. In general, when the disease in question was central to the story – either on its own or in conjunction with other topics – only then was that story included in our counts. Although this approach was more time consuming than relying on simple counts of the stories retrieved with each search term, it provides us with a measure that more truly reflects the concept of media attention to a particular disease.

We excluded obituaries and paid death notices from our counts to avoid conflating rising mortality from a particular disease with a genuine increase in attention to that disease outside of the obituaries.[9] Given that we have collected print and broadcast news stories for each week over nineteen years, we have 991 weeks of broadcast abstract counts and print story counts for each disease. Across our seven diseases, then, we have 6,937 weeks of data available for analysis (with each unit representing a broadcast or print story count for a given week of a given year for a given disease).[10]

Disease Burden. In this paper, we focus on mortality as one of the most fundamental measures of the social burden of disease. Death, after all, is the ultimate burden that a disease inflicts on the dead, as well as on the rest of us. We recognize that mortality is *not* the sum-total of social burden, nor is it even an appropriate measure for many diseases that cause sickness, but rarely death—the common cold, for example, is estimated to cause 189 million missed school days a year, along with 126 million missed work days and costs the U.S. economy close to $40 billion annually, a sizable burden that cannot be captured in mortality statistics (Fendrick et al. 2003). However, using mortality as our initial measure of the burden of disease has among its virtues that we can very precisely identify deaths from these diseases, using national vital

statistics. Since deaths are coded by the National Center for Health Statistics using the International Classification of Diseases (ICD-9) codes, we can accurately match deaths to the seven diseases in our sample for the entire time series and for specific population groups.[11]

Specifically, for each disease we have obtained annual, non-age-adjusted mortality rates that are designed to reflect the likelihood of dying from a disease in a given year for the general population. We use rates that are not age-adjusted because we believe that crude death rates capture more fully how death "appears" in the eyes of the general public. In other words, if deaths from Alzheimer's disease are increasing either because the population is aging, or because the underlying incidence of the disease is rising, we believe it is important to take into account this apparent increase, even if it is one that demographers or epidemiologists would discount through age adjustment.

In addition to measuring the overall mortality rate for a disease, we also expect that the media may be attentive to how death rates change over time, and to how different population subgroups bear the burden of disease. Thus, we include in our analysis an indicator of the absolute value of annual changes in the overall mortality rate for each disease, as well as several measures that reflect the differential burden a disease imposed on different subgroups. Specifically, we include an indicator of how each disease affected blacks relative to whites (expressed as the ratio of black mortality to white mortality), and the differential burden each disease imposed on females relative to males (the ratio of female mortality to male mortality). We use ratios rather than including separately the mortality rates for each of these subgroups because we are interested in how attention is affected by the *relative* impact of a disease on particular groups, rather than in how the mortality of individual subgroups affects attention. In other words, in addition to the overall burden inflicted by a disease, we are interested in how

attention from the media is shaped by the extent to which a disease affects and comes to be associated with one particular group, to the exclusion of other groups.

The seven diseases that we examine exhibit markedly different patterns of mortality change over the time period and across population subgroups. Figure 3 shows the mortality rates for each disease across the nineteen years of our series. (Because these death rates are not age-adjusted, changes in the rates may reflect changes in the underlying incidence of the disease, changes in the age structure of the population, or changes in medical treatment.) Mortality from heart disease and cerebrovascular disease dropped precipitously from 1980 to 1998, while deaths from lung cancer, COPD, diabetes and Alzheimer's disease rose. HIV/AIDS once again exhibits a unique pattern, with mortality rates rising in the first decade and a half of the epidemic and then declining rapidly from 1996 on, due in part to a leveling off in the spread of the disease and in larger part to the success of anti-retroviral treatment at prolonging life. The astronomical rate of increase in Alzheimer's disease is largely an artifact of the growing propensity over time to make this clinical diagnosis, as well as the aging of the population, rather than a true explosion of cases (Ewbank 1999).

[Figure 3 here]

Moreover, these diseases exhibit very different demographic patterns, as summarized in Table 2. Heart disease affects men more than women (although by 1998 crude death rates are roughly equivalent between men and women) and whites more than blacks. Lung cancer also kills more men than women, though the gap is narrowing over time. Cerebrovascular disease, in contrast, causes higher mortality among women and is also more likely to strike whites than blacks. COPD is initially a "male disease," but by 1998, women have caught up and mortality rates are fairly equal by sex. COPD also causes more deaths among whites than blacks.

Diabetes shows far greater differences in race than in sex, with blacks much more likely to die of diabetes than whites are. This difference reflects both the higher prevalence of diabetes in the black population, as well as worse care. Alzheimer's disease mortality is higher among women, in part because women are more likely than men to survive to older age. Deaths from Alzheimer's disease are also higher among whites than among blacks. The patterns of HIV/AIDS mortality are much more difficult to summarize. It is well-known that the demography of the AIDS epidemic has shifted dramatically, from a disease of gay, primarily white, men, to a disease of minorities that hits women particularly hard.

[Table 2 here]

Communities of Organized Interests. In order to examine the impact of organized interests on media attention to disease, we needed to identify the organizations that are part of each disease community as well as some of their relevant characteristics. In order to identify organizations in each community, we searched the text of national organization entries in the *Associations Unlimited (AU)* database (using the keywords shown in Table 1). Relevant organizations could include those that had a direct interest in some aspect of a given disease (e.g., as treatment providers, patient advocates, or seekers of research funding), as well as those with interests that were orthogonal to their primary organizational objectives (e.g., an organization that advocated a particular approach to treating disease that took an interest in cancer patients). The measure we use here focuses solely on the organizations that had a primary interest in a particular disease, a relatively conservative measure of the size of the interested organizational communities. The information about the individual groups was aggregated to obtain counts of the number of organizations expressing some interest in each disease in each year from 1980 to 1998.[12]

Once the relevant organizations associated with each disease community were identified, we also gathered information about some of their characteristics from *Washington Representatives* (2004). For present purposes, we need an indicator of a disease community's capacity for providing expertise and information about a disease to the media or others. Our measure of that capacity is the percentage of groups in each community that registered to lobby Congress as of 2002. Although organized interests may have information to provide to the media even if they do not lobby Congress (Wallack, et al. 1993), we believe that politically active organizations are especially likely to work proactively in this way. Because of their political involvement, they would be in a position both to gather information about government activity related to disease, and to obtain information about the priorities and activities of other interested organizations (Heinz, et al. 1993). Moreover, because registered groups are engaged in efforts to pursue their policy goals, they would likely be interested in getting attention to their issues on both the political agenda and media agenda.[13]

In Figures 4 and 5 we present information about the seven disease communities we have identified across the 1980 to 1998 time period. Not surprisingly, as Figure 4 illustrates, the growth in groups with a primary interest in AIDS has been most pronounced, increasing from two groups in 1982 to more than 40 national organizations in 1998. While the numbers of organizations with a primary interest in heart disease is large and has grown, this community has not experienced the degree of expansion that occurred among AIDS organizations during the same period. The communities for the remaining five diseases are much smaller, and have experienced little, if any, change over time. However, relative to most other diseases, it appears that many of the groups that take an interest in AIDS are not among the set that register to lobby. As shown in Figures 4 and 5, as the community of AIDS groups grows, the newer groups tend to

be those that do not lobby Congress (e.g., social service providers, various caregivers, foundations). In contrast, the proportion of registered groups is fairly high in the relatively smaller organizational communities associated with the remaining six diseases. This is most obvious in the case of the lung cancer community where one of the two organizations with a primary interest in lung cancer is engaged in legislative advocacy. Thus, lung cancer is a disease with a very small community of interested organizations but it is not an insignificant community from the standpoint of political advocacy given the interests of the American Lung Association.

[Figure 4 here]

[Figure 5 here]

Control Variables. In addition to the variables that are central to the hypotheses we test, each equation for media attention that we estimate contains some common control variables. To account for secular trends in coverage, we include simple trend variables, namely the year in question and the week of the year. These trend variables are important to include because coverage of health and disease has increased over the time period of our study (see Figure 2). We also include dichotomous variables for summer (Memorial Day to Labor Day), and for the first and last weeks of every year (winter vacation) to account for what are commonly considered low periods of readership and viewership. Additional time dependence is taken into account through the inclusion of a lagged dependent variable. The lagged term, which represents the number of stories in the previous week that were broadcast or written by a particular news outlet about a specific disease, allows us to account for patterns of attention continuity over time. In addition, because newspaper reporters and editors as well as television news producers may be responsive to scientific or medical news about disease (Bartlett, et al. 2002), we include a measure of the weekly scientific/medical coverage given to each disease, which is simply the average number of

articles about each disease that appeared each week in the *New England Journal of Medicine* (*NEJM*), the *Journal of the American Medical Association* (*JAMA*), the *Annals of Internal Medicine* (*AIM*), and *Science* combined (see Armstrong, et al. 2005 for more detail on the relationship between medical research and broadcast and print attention to disease).[14] To proxy for technological change, we also include an indicator of the aggregate number of disease-specific drugs that were approved by the FDA in each week of each year in our study. Newspapers and broadcast media alike often carry news of new FDA drug and device approvals. The approvals data allow us to account for the attention to a disease that is given by the media when the government sanctions a new drug treatment.[15]

Analytic Approach

Because our data are structured as a time-series cross-section (TSCS), it is difficult to assume that the errors in our equations satisfy the criteria necessary for estimation by ordinary least squares (OLS) to be appropriate. Like most TSCS models, the error variance may not be constant across diseases, there may be contemporaneous correlation in the errors across diseases, and the errors may be serially correlated within a disease. If this error structure characterizes our data, estimation either with OLS or certain generalized least squares (GLS) alternatives may produce standard errors that are biased downward (Beck and Katz 1995). Thus, based on the suggestions of Beck and Katz (1995), we estimate our five equations for media attention with Prais-Winsten regression and panel-corrected standard errors (the use of Prais-Winsten rather than OLS allows us to account for possible first-order correlation in the errors for a given disease).

The Question of Attention Endogeneity. In each print and broadcast equation, media coverage is estimated as a function of our interest group and burden variables as well as the control variables described above, but *not as a function of media coverage by other networks or newspapers*. In other words, we model NBC news coverage of disease as a function of mortality and interest groups, but *not* as a function of ABC news coverage and CBS news coverage, and not as a function of *New York Times* or *Washington Post* coverage. This might seem an odd choice, given that an important *New York Times* or *Washington Post* story is likely to be taken up by at least one if not all three of the broadcast television networks. So too, a story on the evening news concerning "disease X" may occasion similar coverage of "disease X" on other networks. By excluding such variables, our regression equations may be misspecified and bias and inconsistency may plague our coefficient estimates.

But for us to deal with the high endogeneity of one form of coverage to another requires finding network- and newspaper-specific instruments that would allow us to properly identify a system of equations. Locating appropriate instruments would be very difficult.[16] Moreover, if we attended to the endogeneity of coverage, our results would be highly sensitive to proper specification and we would likely need to ignore the TSCS structure of our data. In the absence of a sound set of exogenous regressors, estimation of a full system of equations is relatively less reliable than estimating a set of media attention equations in which the endogenous coverage variables are excluded from the right-hand side of our equations.

The Question of Outliers. Because AIDS is an outlier in terms of coverage (see Figures 1 and 2), organizational community size (see Figure 4), and in terms of the rate and change in mortality (see Figure 3) over the past two decades, we estimate each equation upon a full sample

of all seven diseases and then replicate the results with the AIDS observations excluded. As will be clear, this often changes our results appreciably.

Results

We have posed two main questions in this paper. We ask, first, how does the social burden of a disease affect attention levels in the mass media; second, how do organized groups affect attention? We present two sets of results in Tables 3 through 7. The first set of estimations is based on a full sample of all seven diseases, including AIDS, and the second set of estimations is based on a restricted sample, excluding AIDS. As the tables demonstrate, many of our findings change depending on whether AIDS is included or excluded.

[Tables 3-7 here]

We consider first the effect of social burden, specifically mortality, on attention. When we include AIDS, the total mortality rate has a negative and statistically significant effect on coverage levels in both newspapers and all three television news networks. In other words, the higher the mortality, the less coverage of that disease. Changes in mortality, whether increases or decreases, have no significant effect on attention in the full sample. However, when we exclude AIDS from our estimations, we find very different results: total mortality is again a statistically significant predictor of coverage across all five media outlets, but the sign has shifted from negative to positive, meaning that more deaths generate more attention. In addition, evidence of a positive and significant effect of change in mortality appears for NBC and CBS news stories, but not for the other media outlets. In sum, our results suggest that the relationship between death and news coverage is more complicated than prior research has demonstrated (e.g. Adelman and Verbrugge 2000). If AIDS is included in the estimation sample, it is not true that

more deaths mean more news; rather, the opposite hypothesis receives support. Yet when AIDS is excluded, we observe a positive relationship between aggregate burden and attention.

In addition to the overall impact of mortality on attention, our results reveal that the relative burden of a disease on different population subgroups also shapes media attention. One of the more consistent findings to emerge from our analyses is that the ratio of black mortality to white mortality tends to be negatively associated with news coverage, a finding that holds true for both the full and the restricted samples.[17] In other words, the greater the burden of disease for blacks relative to whites, the less the attention allocated to that disease. This result is particularly significant in light of how race differentials in media attention have previously been described. For instance, Cohen (1999) has described how infrequently the nightly news coverage of AIDS through 1993 focused on African-Americans. But our results suggest that this bias in media attention may be even broader: not only are blacks largely absent from the content of coverage of a disease that greatly burdened them, other diseases such as heart disease, stroke and diabetes that also disproportionately affect blacks are given less attention by television and print news media. The significant race gap in media attention to disease that we observe both reflects and contributes to existing health inequities in the U.S.

In contrast to our strong and consistent findings with respect to racial burden and attention, we find considerably more mixed evidence with respect to sex differentials in mortality. In the full samples including AIDS, a greater female burden (as measured by the female/male mortality ratio) is associated with less coverage, but in the restricted sample excluding AIDS, the coefficient for the female/male mortality ratio is positive and statistically significant. The direction of the effect, then, is highly sensitive to the presence of the AIDS data in the models, suggesting that the unique trajectory of AIDS is tilting what otherwise is a

positive relationship between female burden and media attention. Coverage of AIDS overall began to decline just as the epidemic was beginning to cause proportionally more female deaths. Thus, the drop-off in attention to AIDS coupled with rising AIDS deaths among women is confounding the relationship between female mortality and attention levels. While this hypothesis clearly deserves investigation in a larger sample, the idea of a positive relationship between relative female burden and media coverage has some plausibility. The cases of breast cancer and hormone replacement therapy, both of which receive extensive media coverage, attest to the power of (certain) women's health issues to command public attention.

To summarize our findings with respect to mortality and attention: the social burden that a disease exacts does affect news coverage. Indeed, it is not enough merely to ask *whether* death matters in the attention process; we must also ask *whose* deaths matter. Most clearly, diseases that claim proportionately more black lives than white lives receive less attention in the mass media. Beyond this observation, our conclusions are complicated by the abundant evidence that the attention process with respect to AIDS differs in significant ways from the attention process with respect to other diseases. Whether AIDS is included in the models or not yields diametrically opposed findings regarding the effect of total mortality on coverage, as well as how gender differentials in burden shape attention.

Our next set of results concerns our second question about the effect of organized interest groups on media attention. We expected to find a positive relationship between the presence of organized interest groups and news coverage of a disease, a hypothesis for which we find mixed support. Here again it is the presence or absence of AIDS in our models that proves crucial to our findings. In the full sample including AIDS, we find that the number of groups with a primary interest in each disease has a very consistent, statistically significant, positive effect on

attention. Organized interest groups increase both print and broadcast attention to disease. Yet once we exclude AIDS from the estimation samples, these effects drop to zero for the NBC and CBS equations, but remain positive and statistically significant for the ABC and newspaper equations.[18]

Additional purchase on the nature of the relationship between organizational activity and attention is apparent through our measure of the community's capacity for expertise, the proportion of primary groups registered to lobby by disease-year. Organizational communities in which a greater proportion of groups are registered to lobby, tend to attract relatively more attention to "their" diseases than do organizational communities with smaller proportions of politically-oriented groups; the effect of this variable is consistently positive in the samples excluding AIDS. When we include AIDS in the model estimation, the impact of the group variables reflects the unique patterns of organizational activity around AIDS. As shown in Figures 4 and 5, the community of organizations interested in AIDS is the only one in our sample that has increased appreciably over time. Yet, relative to other diseases, far fewer AIDS groups are registered to lobby. This lower proportion reflects the preponderance of AIDS groups devoted to providing direct services to AIDS patients, education about HIV, and fundraising for the disease, among other activities. In sum, the size of the organized interest group community dedicated to a disease appears to increase levels of media coverage of that disease, although the type of organizations in that community may affect the relationship we observe.

Finally, we note the effects of our control variables. When we include AIDS in our estimation of the models, the lagged measure of attention is positive and statistically significant such that stories about a particular disease in one week are likely to continue into the following week. (The extent of continuity is especially strong for stories appearing in the *Post* or the

Times.) Relative to diseases that are not covered in a given week, those that do receive attention are more likely to be reported on in a subsequent week. All else being equal, the volume of stories will decline over time, but attention to the disease will persist in the relevant media outlet. This pattern of persistence in coverage also is evident when we exclude AIDS from our estimation sample. However, the magnitude of the effect is considerably smaller and evident only for the two newspapers and ABC news.

Scientific attention, in the form of peer-reviewed scientific journal articles, has a positive and statistically significant effect on media coverage. As other researchers before us have demonstrated (Bartlett, et al. 2002), the mass media are responsive to scientific/medical attention to a disease, an effect we explore further elsewhere (Armstrong, et al. 2005). However, FDA attention in the form of new molecular approvals for drugs to treat our sample diseases does not have any effect on media attention.

The results we present here are relatively robust regardless of how we measure the burden of a disease. The first alternative replaces overall mortality with an indicator of "premature mortality," defined as the death rate among individuals under 55 years of age from a disease. This measure is intended to capture one dimension of the social salience of a disease, namely that which results from a disease's association with untimely deaths. The idea here is that the more deaths that occur among the relatively young from a particular disease, the more likely it is that the public is aware of, and interested in a particular disease. These mortality data are from National Vital Statistics Reports.

Second, we consider a measure of burden that reflects the time and monetary costs associated with a disease. Specifically, we count the annual average length of a hospital stay for each disease. This measure allows us to consider whether the media are attentive to diseases that

cause individuals to lose work or leisure time to relatively long hospital stays, and that are relatively more costly to treat from the standpoint of individuals, hospitals, and insurance companies. We consider the overall "days of care" burden associated with a disease, as well as how that burden is borne by females relative to males, and blacks relative to whites (expressed as the ratio of the annual average length of a hospital stay for females/blacks to the annual average length of a hospital stay for males/whites, respectively). The days of care data are from the National Hospital Discharge Survey.

Regardless of the measure of burden that we use, our central findings remain unchanged. First, the negative effect of burden on attention is apparent in the results from estimations that include the AIDS observations and the positive effect of burden on attention is evident when the AIDS observations are excluded. Second, we find that the black/white hospital days ratio is negatively associated with coverage regardless of whether the AIDS observations are included. The full set of these results are available from the authors.[19]

Conclusion

The mass media play an influential role in the process of agenda setting, by providing one of the primary attention arenas in the public domain, by calling attention to certain problems, and by framing what are seen as the causes of and solutions to those problems. In this paper we have demonstrated that newspapers and the nightly network news programs bring certain diseases into public view, while keeping others out of public sight. Our analysis of the cross-disease and cross-temporal variation in media attention suggests that *who* dies from a disease, as well as *how many* die, are critical factors in explaining why some diseases get more attention than others. Most significantly, our data illustrate that both the print and the broadcast media tend to be much

less attentive to diseases that burden blacks more than whites, a result that is robust across all of our model specifications. It appears that the news media diminish the agenda space granted to diseases that affect blacks more than whites, thereby curtailing public attention to such diseases. Our data cannot tell us why this pattern of coverage occurs. It may result from the efforts of the predominantly white management of the newspapers and broadcast outlets we study to cater to their predominantly white readers and viewers. But it is also possible that news outlets are reflective of their sources of information. That is, interest organizations and other information providers may not emphasize the diseases and concerns of underrepresented groups.

Our study is unique in that we compare directly the attention allocated to seven diseases across nineteen years as a function of the variation in both the social burden these diseases impose, and the interest groups they attract. As a result, we can make inferences about the attention allocation process characterizing diseases in general, as well as to gain leverage on how this process compares to that which characterizes attention to HIV/AIDS.

The results of our investigation underscore the fact that it is problematic to generalize about why disease captures public attention based on any single case, particularly HIV/AIDS. AIDS has a relatively high rate of fatality, there have been dramatic shifts in its incidence and mortality over the past twenty years, and it is a highly stigmatized and moralized disease. Moreover, within our sample, AIDS is the only infectious disease and even more significantly, it is the only disease to come into existence during the time period we study. The latter fact alone almost guarantees that the attention process to AIDS will be distinct. There is also the tendency of AIDS to kill not only in large numbers, but to kill at young ages. Among the seven diseases that we study here, AIDS is the only one to cause significant levels of premature mortality: over 90 percent of all deaths from AIDS occurred among people under age 55, compared with about

11 percent in the case of diabetes, the next highest.[20] Extreme premature mortality, then, may be one characteristic distinguishing AIDS from other diseases and shaping its distinctive attention process.

Although scholars who focus on AIDS have not explicitly argued that it is representative of other diseases, ideas about why the media pay attention to different diseases often emerge out of studies of AIDS because it has been the focus of so much research. In this regard, the status of AIDS is paradoxical: in terms of the media attention it receives, AIDS is recognized as being distinctly different from other diseases, while at the same time it often serves as a model for understanding the attention allocation process. This dual perception of AIDS has important implications for understanding (and misunderstanding) how and why diseases get attention from the media. Indeed, a number of our inferences about media attention are dependent on the inclusion or exclusion of AIDS observations from the model. We summarize our results in Table 8, which reports the main findings for the five media outlets, for both the models on the full set of seven diseases (upper left corner of each cell) and with AIDS excluded (lower right corner of each cell.) Cells that are shaded indicate changes in the direction of the effect and/or the statistical significance of the effect when AIDS is excluded.

[Table 8 about here]

Specifically, an analysis based on the full sample of seven diseases reveals a *negative* relationship between the number of individuals who suffer from a disease and media attention, and diseases that have a greater impact on women relative to men and attention. A *positive* link between the size of the organizational communities that take an interest in the disease and media attention also is apparent but there is also some evidence that the media give less attention to diseases that are of interest to more politically active organizational communities. When AIDS

is excluded from our sample, we observe a *positive* relationship between the number of individuals who die from a disease and media attention, and diseases that have a greater impact on women relative to men and attention, along with the persistent negative relationship between the burden of disease among blacks and attention. Diseases that are associated with more politically active organizational communities also appear to command more attention; the positive impact of the number of interest organizations on attention observed for the full sample is restricted to attention from the print media when the observations related to AIDS are excluded. The distinct features of AIDS appear to distort the mechanisms that affect the attention process; thus, we argue that our models that exclude AIDS provide a clearer reflection of the mass media attention process to disease.

More broadly, our research helps to illustrate the limitations of focusing on simplistic notions of disease burden and organized disease advocates to explain media attention. First, our data reveal attention allocation patterns that are unlikely to be explained solely by burden of disease and/or the activities of organized advocates. We observe both considerable temporal variation in media attention *within* each of our disease panels, and many weeks with no attention whatsoever. As shown in Table 9, the within-disease variance of our five media attention indicators is always higher than the between-diseases variance, often two times as high. It is therefore essential in future research that the determinants of the temporal variability in media coverage of disease are identified. Variables such as mortality and organized disease advocates, which are relatively stable over time, give us little purchase on the type of variation we see at the weekly level in media coverage of disease.

[Table 9 here]

Second, much greater statistical explanatory power is observed when simple aggregates of mortality and political organization are jettisoned in favor of more complex relationships. For example, the influence of organized advocacy is better specified not simply as a matter of numbers but as a matter of *group form*. When a disease is represented not by more groups, but by more groups that are registered to lobby, its expected media coverage will be higher. Future studies of the impact of organizational advocates on attention should consider how other characteristics of the organizational communities may affect attention, such as the extent to which the community is dominated by professional organizations or institutions as opposed to organizations represented by disease sufferers or their families.

Table 9 also shows the percentage of weeks in which there is some media coverage of disease. For more than nine out of ten weeks, there is no attention paid by the three networks to the seven diseases we study. A somewhat less stark pattern emerges for the major newspapers we study, but even for the *New York Times* and the *Washington Post*, there are more weeks in which no attention is paid to these diseases than there are ones in which there is coverage of one or more of them. The prevalence of no attention suggests that the attention allocation process may consist of punctuations, much as Baumgartner and Jones (1993) and Jones, et al. (2003) indicate. Attention cannot be allocated in incremental amounts, due in part to the demands of writing a story, and also to the dynamics of attention. These dynamics are evident in the positive relationships we observe between current and lagged levels of attention: one story on a disease is likely to beget other stories on the same disease (and hence push the coverage for other diseases closer and closer to zero).

This autocorrelation of attention varies across diseases and across media outlets in interesting ways. One easy conclusion from our analyses is that the autocorrelation of attention

is much greater for HIV/AIDS than for other diseases, insofar as exclusion of AIDS from the models always yields much smaller parameter estimates on the one-week lagged dependent variable (Tables 3-7). More interesting, perhaps, is that in the AIDS-exclusive samples, we observe attention auto-correlation in both newspapers (Tables 6-7), but in only one of three broadcast networks (ABC; Table 3). This may be consistent with the idea that the tighter attention budgets of broadcast media organizations allow less "room" for autocorrelation; a story must make its appearance and then must disappear unless its latent "newsworthiness" is extremely high (as may have been the case for AIDS). Both of these results raise questions that can fruitfully be explored further. Are some diseases more subject to "attention begetting more attention" than others? Are some media venues more subject to autocorrelation? We can in fact decompose our data to examine this array of questions more specifically.

In addition, the temporal variation in, and frequent absence of attention suggest that to explain better the attention-generating process, it is useful to break that process down into the forces that contribute to getting any attention (crossing the threshold from no attention to some attention) and the forces that lead to longer spells of attention once attention is given (i.e., to maintaining coverage once it is obtained). As part of an ongoing and broader project, we are investigating these and other more complex aspects of the attention-generating process.[21] Specifically, we expand our sample to a total of forty diseases, including all major categories of cancer; the top ten causes of death; diseases that cause high morbidity, but not many deaths; and diseases that are infectious, among other characteristics. For each of these diseases, we are collecting not only the data analyzed in this paper, but also indicators of congressional attention (in House and Senate hearings), and executive and administrative attention (in presidential statements and the Federal Register). We are also collecting data about regional newspaper

coverage of diseases. As part of this more comprehensive project, we plan to use our cross-disease data to clarify the consequences that attention by the media to one disease is likely to have on attention to other diseases, as well as its connections to political attention, public agendas, and policy generation. Our future work also allows us to move from an exclusive focus on the amount of attention given to a disease to an investigation of the content of that attention.

In the mass media, the decision of whether to give attention to a particular problem is a key determinant of what makes it onto the public agenda. Attention allocation reflects the distribution of scarce seconds of news coverage or columns of newspaper space to some problem at the expense of others. In this paper, we have demonstrated that certain characteristics associated with problems – namely the segment of society they most burden, and the activity of interested advocacy groups – affect systematically this process of attention allocation, bringing certain diseases into public view, while keeping others out of sight.

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Figure 1: Total deaths and media attention, 1980-1998

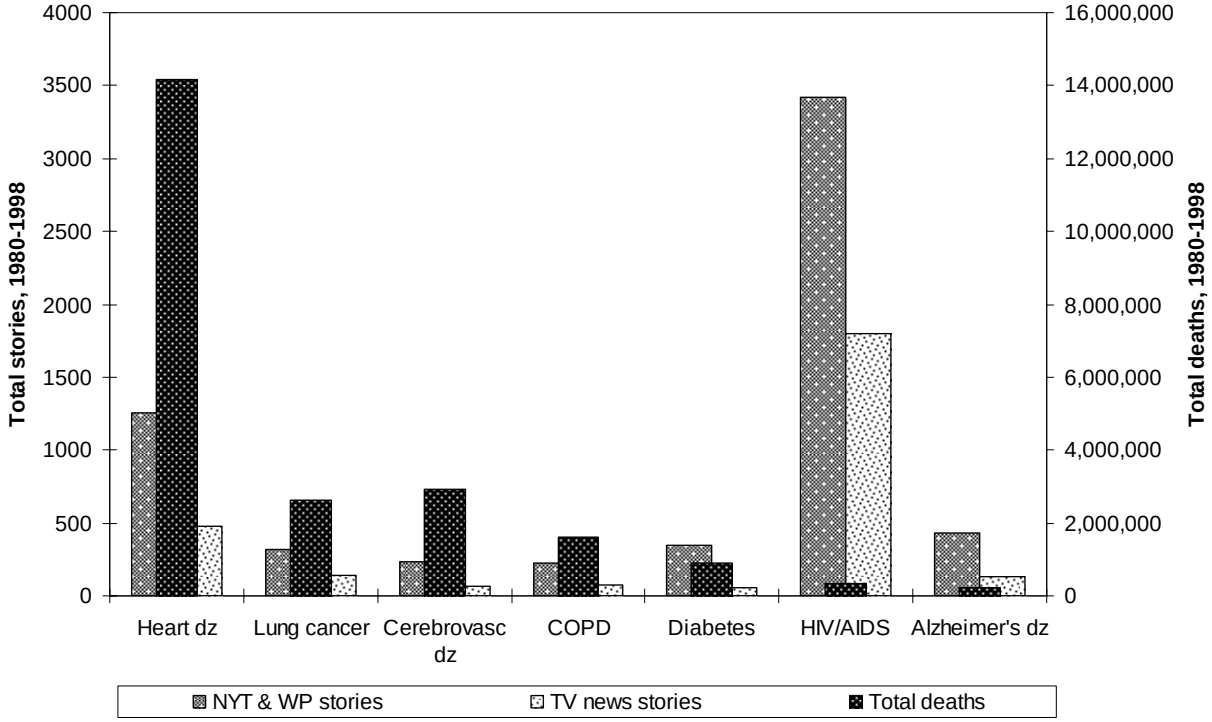

Figure 2: Annual newspaper stories, 1980-1998

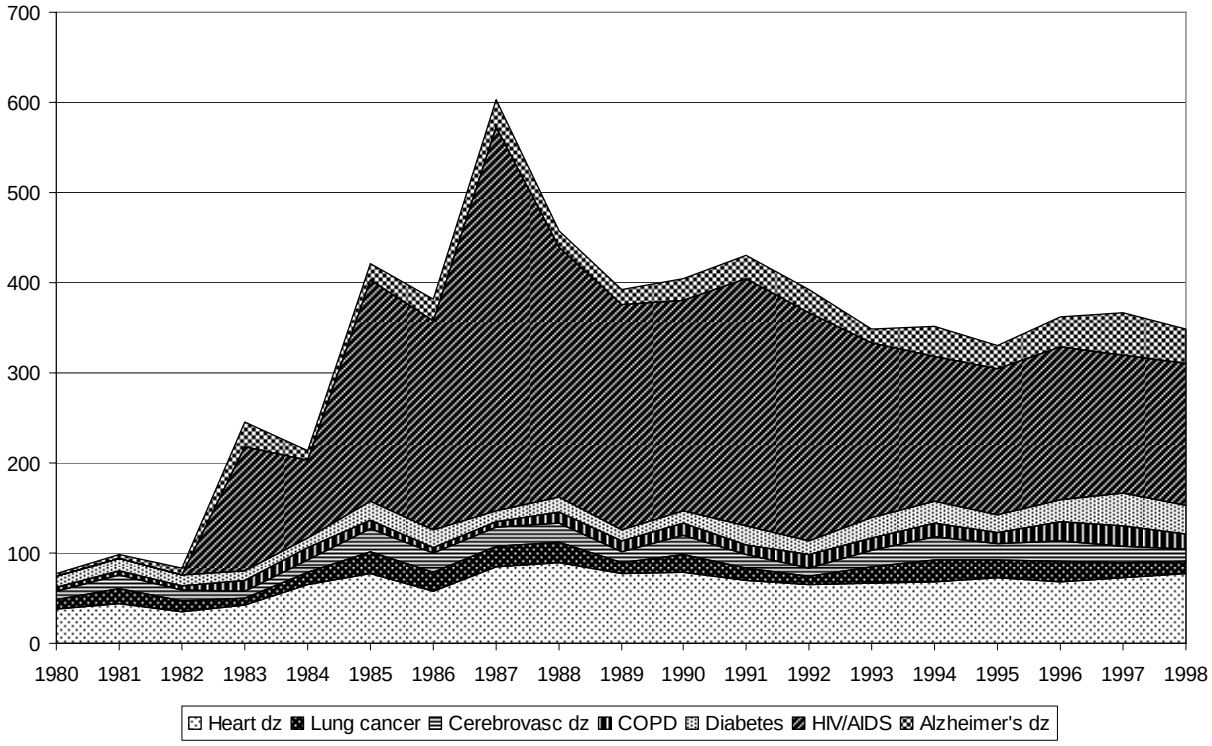

Figure 3: Mortality trends, 1980-1998

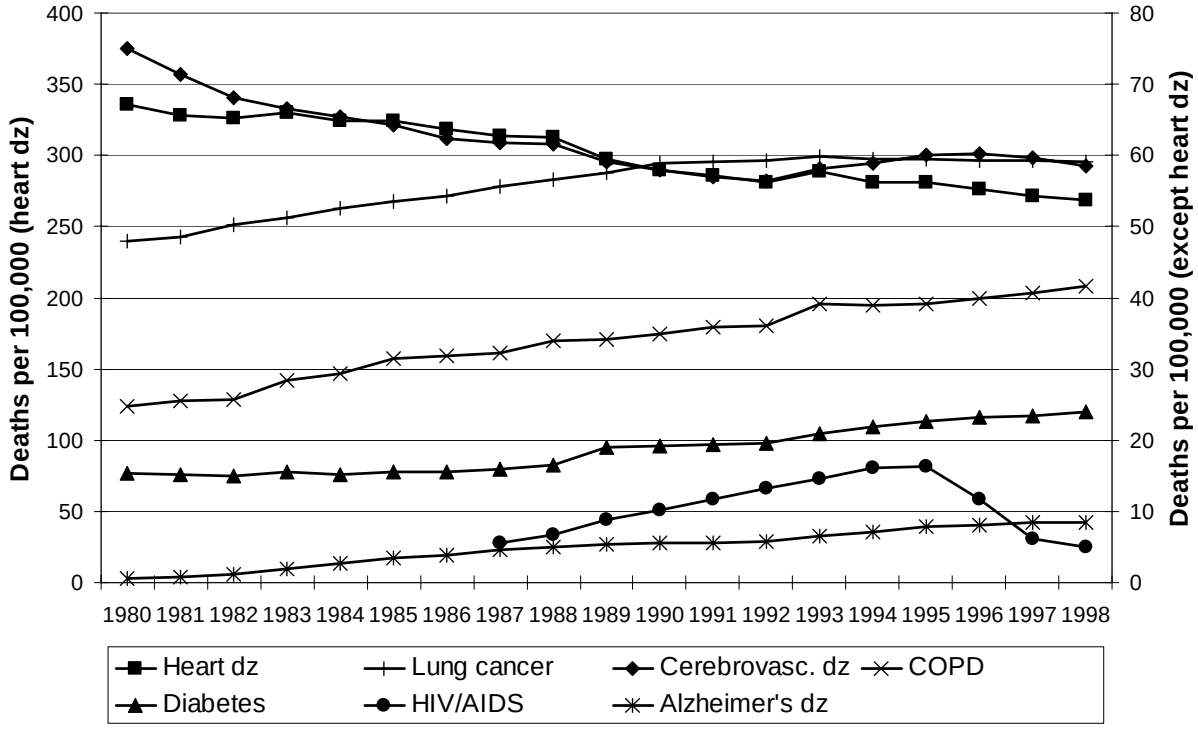

Figure 4: Number of organizations with a primary interest in each dz

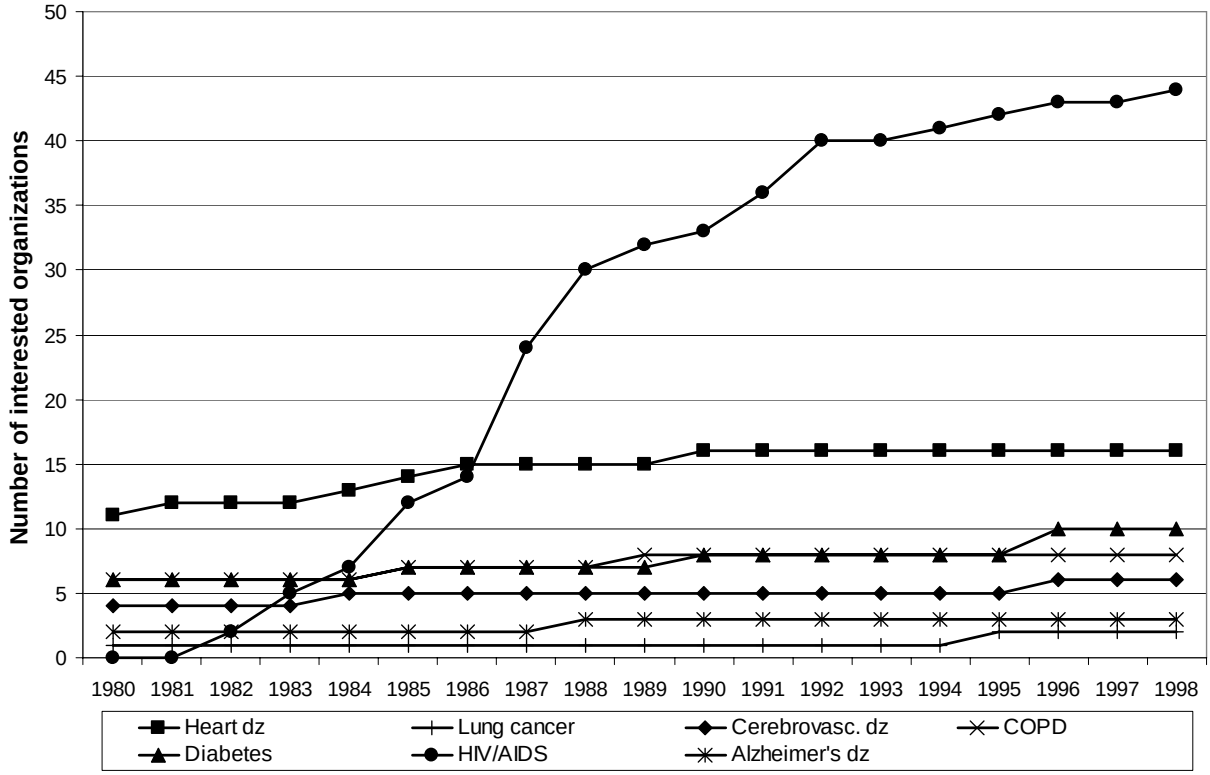

Figure 5: Percent of organizations with primary interest that are registered to lobby

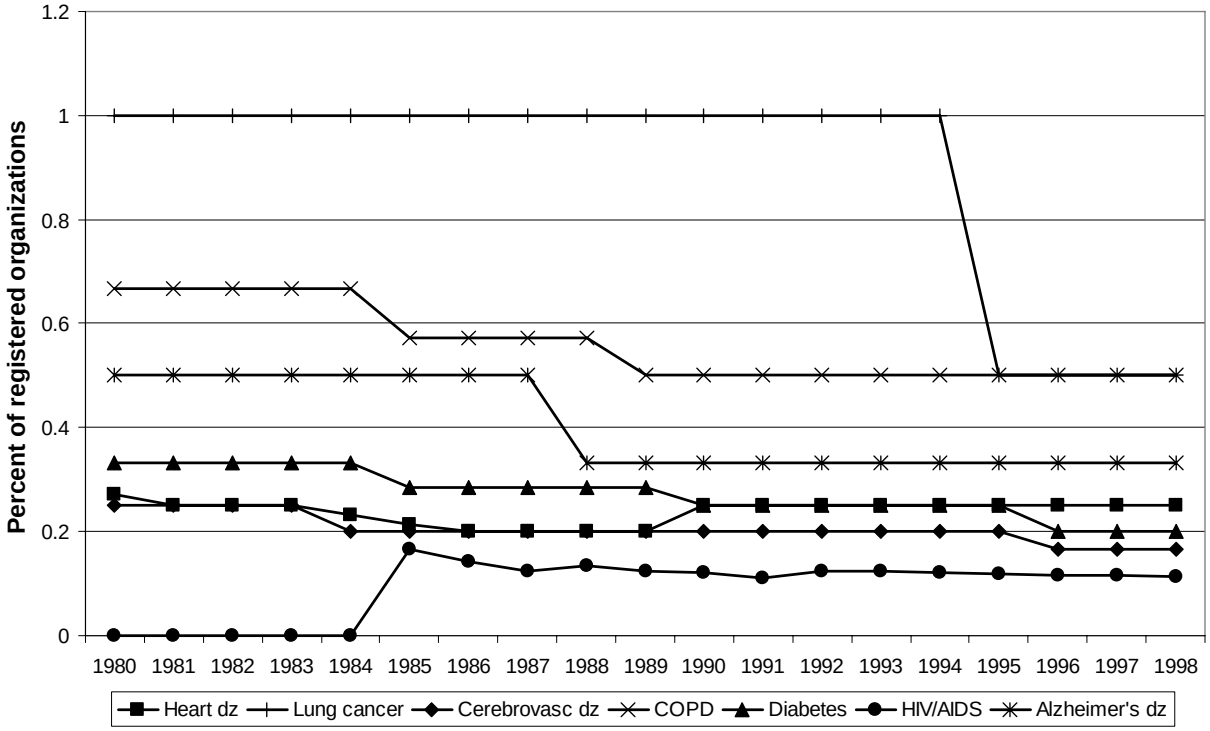

Table 1: Key Word Search Terms	
Disease	Search Terms
Diseases of the heart	diseases of the heart; cardiovascular disease; ischemic heart disease; heart attack; myocardial infarction; heart transplant; heart disease; angina; arrhythmia; hypertension; high cholesterol
Lung cancer	lung cancer
Cerebrovascular disease	cerebrovascular disease*; stroke; transient ischemic attack; thrombosis
Chronic obstructive pulmonary diseases (COPD)	chronic obstructive pulmonary disease*; bronchitis; emphysema; asthma
Diabetes	diabet*
HIV/AIDS	HIV; AIDS; acquired immune deficiency; acquired immunodeficiency syndrome
Alzheimer's disease	Alzheim*

Table 2: Crude Mortality Rates per 100,000 Population, 1980 and 1998										
	Total		Male		Female		Black		White	
	1980	1998	1980	1998	1980	1998	1980	1998	1980	1998
Heart disease	336.0	268.2	368.6	268.0	305.1	268.3	274.0	227.4	350.8	285.0
Lung cancer	47.9	59.1	71.9	72.1	25.2	46.6	43.6	49.2	49.4	62.9
Cerebrovascular disease	75.1	58.6	63.6	46.3	86.1	70.4	75.6	53.0	76.3	61.4
COPD	24.7	41.7	35.1	43.2	15.0	40.2	12.7	20.9	26.9	46.7
Diabetes	15.4	24.0	13.0	22.4	17.6	25.4	20.8	33.0	14.8	23.2
Alzheimer's disease	0.6	8.4	0.6	5.3	0.6	11.3	0.2	3.5	0.6	9.6
HIV/AIDS	1987	1998	1987	1998	1987	1998	1987	1998	1987	1998
	5.6	5.0	10.2	7.8	1.1	2.3	13.8	20.9	4.6	2.7

Table 3: Covariates of Weekly ABC Stories of Disease Coverage [Panel-Corrected Standard Errors]						
	Sample Including AIDS			Sample Excluding AIDS		
ABC stories	Coef.	S.E.	t	Coef.	S.E.	t
Burden:						
Mortality rate	-0.0006	0.0001	-6.02	0.0003	0.0001	4.25
Absolute annual change in mort rate	0.0001	0.0001	0.63	0.0002	0.0001	1.58
Black-white mortality ratio	-0.0434	0.0172	-2.52	-0.0144	0.0065	-2.21
Female-male mortality ratio	-0.0537	0.0231	-2.32	0.0461	0.0138	3.34
Organized interests:						
Number of "primary" groups by disease-year	0.01405	0.0023	6.07	0.0034	0.0016	2.11
Percent of primary groups registered to lobby by disease-year	-0.0001	0.0418	-0.02	0.0960	0.0277	3.46
Control Variables:						
Scientific coverage	0.0264	0.0047	5.63	0.0050	0.0029	1.74
Year	-0.0005	0.0007	-0.82	0.0024	0.0005	4.49
Week	0.0002	0.0003	0.74	0.0001	0.0002	0.70
Winter vacation	-0.0249	0.0255	-0.98	-0.0167	0.0159	-1.05
Summer	0.0076	0.0109	0.69	-0.0105	0.0070	-1.51
FDA molecular approvals	-0.0072	0.0289	-0.25	0.0115	0.0231	0.50
Lagged Dependent Variable:						
ABC stories[*t*-1]	0.2204	0.0279	7.89	0.0651	0.0190	3.42
Constant	1.1434	1.3501	0.85	-4.9454	1.0855	-4.56
Rho (errors, AR(1))	-0.0515			-0.0148		
N	6456			5883		
R^2	0.2402			0.0440		
Wald(k) [Pr]	421.46 (13) [0.00]			133.29 (13) [0.00]		

Table 4: Covariates of Weekly NBC Stories of Disease Coverage [Panel-Corrected Standard Errors]						
	Sample Including AIDS			Sample Excluding AIDS		
NBC stories	Coef.	S.E.	T	Coef.	S.E.	t
Burden:						
Mortality rate	-0.0008	0.0001	-7.68	0.0004	0.0001	5.46
Absolute annual change in mort rate	0.0002	0.0002	1.52	0.0003	0.0001	2.34
Black-white mortality ratio	-0.0634	0.0164	-3.87	-0.0173	0.0065	-2.67
Female-male mortality ratio	-0.0415	0.0224	-1.85	0.0435	0.0143	3.03
Organized Interests:						
Number of "primary" groups by disease-year	0.0164	0.0022	7.49	0.0007	0.0016	0.45
Percent of primary groups registered to lobby by disease-year	0.0428	0.0406	1.05	0.0920	0.0287	3.21
Control Variables:						
Scientific coverage	0.0335	0.0042	7.98	0.0079	0.0026	3.07
Year	-0.0012	0.0007	-1.77	0.0020	0.0006	3.64
Week	-0.0002	0.0003	-0.74	0.0001	0.0002	0.39
Winter vacation	-0.0303	0.0246	-1.23	-0.272	0.0155	-1.75
Summer	0.0044	0.0108	0.41	-0.0098	0.0069	-1.41
FDA molecular approvals	0.0102	0.0257	0.40	-0.0056	0.0205	-0.27
Lagged Dependent Variable:						
NBC stories[*t*-1]	0.0593	0.0273	2.17	-0.0216	0.0179	-1.20
Constant	2.4745	1.3834	1.79	-4.0979	1.1072	-3.70
Rho (errors, AR(1))	0.01872			0.01994		
N	6456			5883		
R^2	0.1840			0.0371		
Wald(k) [Pr]	333.23 (13) [0.00]			136.78 (13) [0.00]		

Table 5: Covariates of Weekly CBS Stories of Disease Coverage [Panel-Corrected Standard Errors]						
	Sample Including AIDS			Sample Excluding AIDS		
CBS stories	Coef.	S.E.	T	Coef.	S.E.	t
Burden:						
Mortality rate	-0.0004	0.0001	-4.20	0.0005	0.0001	5.79
Absolute annual change in mort rate	0.0004	0.0002	2.14	0.0005	0.0002	3.01
Black-white mortality ratio	-0.0321	0.0168	-1.91	-0.268	0.0076	-3.55
Female-male mortality ratio	0.0005	0.0248	0.02	0.0495	0.0174	2.85
Organized Interests:						
Number of "primary" groups by disease-year	0.0143	0.0023	6.16	0.0019	0.0019	0.97
Percent of primary groups registered to lobby by disease-year	0.0953	0.0446	2.14	0.0940	0.0345	2.73
Control Variables:						
Scientific coverage	0.0298	0.0045	6.60	0.0079	0.0032	2.47
Year	0.0004	0.0008	0.52	0.0029	0.0007	4.46
Week	0.0002	0.0003	0.60	-0.0000	0.0002	-0.14
Winter vacation	-0.0058	0.0267	-0.22	0.0014	0.0187	0.07
Summer	0.0137	0.0115	1.18	-0.0058	0.0083	-0.70
FDA molecular Approvals-0.0017	-0.0017	0.0285	-0.06	0.0055	0.0254	0.22
Lagged Dependent Variable:						
CBS stories[*t*-1]	0.1388	0.0253	5.47	0.0032	0.0182	0.18
Constant	-0.8480	1.5065	-0.56	-5.930	1.3171	-4.50
Rho (errors, AR(1))	-0.0280			0.0145		
N	6456			5883		
R^2	0.1767			0.0464		
Wald(k) [Pr]	356.69 (13) [0.00]			155.94 (13) [0.00]		

Table 6: Covariates of Weekly *Washington Post* Stories of Disease Coverage [Panel-Corrected Standard Errors]						
	Sample Including AIDS			Sample Excluding AIDS		
Post stories	Coef.	S.E.	t	Coef.	S.E.	t
Burden:						
Mortality rate	-0.0009	0.0002	-5.45	0.0008	0.0001	6.18
Absolute annual change in mort rate	0.0000	0.0002	0.05	0.0002	0.0002	0.84
Black-white mortality ratio	-0.0735	0.0254	-2.89	-0.0249	0.0145	-1.72
Female-male mortality ratio	-0.0284	0.0374	-0.76	0.1628	0.0269	6.04
Organized Interests:						
Number of "primary" groups by disease-year	0.0367	0.0037	9.98	0.0221	0.0029	7.51
Percent of primary groups registered to lobby by disease-year	0.0839	0.0676	1.24	0.2851	0.0514	5.55
Control Variables:						
Scientific coverage	0.0409	0.0072	5.69	0.0100	0.0050	2.00
Year	-0.0003	0.0012	-0.24	0.0055	0.0010	5.30
Week	-0.0005	0.0005	-0.92	0.0001	0.0004	0.29
Winter vacation	0.0029	0.0423	0.07	-0.0017	0.0299	-0.06
Summer	-0.0011	0.0179	-0.06	-0.0255	0.0130	-1.80
FDA molecular Approvals	-0.0744	0.0471	-1.58	-0.0757	0.0400	-1.89
Lagged Dependent Variable:						
Post stories[*t*-1]	0.2554	0.0043	10.52	0.0428	0.0169	2.53
Constant	0.5459	2.318	0.24	-11.3372	2.0837	-5.44
Rho (errors, AR(1))	-0.0783			-0.0102		
N	6454			5881		
R^2	0.4080			0.1239		
Wald(k) [Pr]	1111.41 (13) [0.00]			396.32 (13) [0.00]		

Table 7: Covariates of Weekly *New York Times* Stories of Disease Coverage [Panel-Corrected Standard Errors]						
	Sample Including AIDS			Sample Excluding AIDS		
Times stories	Coef.	S.E.	t	Coef.	S.E.	t
Burden:						
Mortality rate	-0.0009	0.0002	-5.22	0.0015	0.0002	9.30
Absolute annual change in mort rate	0.0001	0.0004	0.21	0.0004	0.0004	0.93
Black-white mortality ratio	-0.0942	0.0282	-3.34	-0.0215	0.0213	-1.01
Female-male mortality ratio	0.0003	0.0459	0.01	0.2955	0.0405	7.30
Organized Interests:						
Number of "primary" groups by disease-year	0.0444	0.0041	10.77	0.0196	0.0040	4.93
Percent of primary groups registered to lobby by disease-year	0.2076	0.0825	2.52	0.5325	0.0767	6.94
Control Variables:						
Scientific coverage	0.0640	0.0080	8.00	0.0252	0.0063	4.02
Year	-0.0031	0.0016	-1.99	0.0049	0.0015	3.34
Week	-0.0004	0.0006	-0.67	0.0001	0.0005	0.23
Winter vacation	-0.0643	0.0494	-1.30	-0.0746	0.0395	-1.89
Summer	-0.0505	0.0214	-2.37	-0.0725	0.0174	-4.17
FDA molecular Approvals	-0.0823	0.0568	-1.45	-0.0803	0.0493	-1.63
Lagged Dependent Variable:						
Times stories[*t*-1]	0.2336	0.0204	11.47	0.0384	0.0156	2.46
Constant	6.1179	3.0983	1.97	-10.1921	2.9051	-3.51
Rho (errors, AR(1))	-0.0508			0.0062		
N	6344			5773		
R^2	0.3909			0.1247		
Wald(k) [Pr]	1266.64 (13) [0.00]			458.02 (13) [0.00]		

Table 8: Summary of Results for All Media
Models including AIDS in upper left corner
Models excluding AIDS in lower right corner

	ABC stories	NBC stories	CBS stories	*W Post* stories	*NY Times* stories
Total mortality rate	- / +	- / +	- / +	- / +	- / +
Abs. ann. change in mortality		/ +	+ / +		
Black-white mortality ratio	- / -	- / -	/ -	- /	- /
Female-male mortality ratio	- / +	- / +	/ +	/ +	/ +
# of primary groups by yr.	+ / +	+ /	+ /	+ / +	+ / +
% of groups reg. to lobby by yr.	/ +	/ +	+ / +	/ +	+ / +

Note: The sign of the statistically significant coefficients is reported in each cell of the table. The models with the full sample including AIDS are reported in the upper left section of each cell; the models excluding AIDS are reported in the lower right section. Cells that are shaded indicate changes in direction of effect and/or statistical significance when AIDS is excluded. If the coefficient is not statistically significant, the cell is blank.

Table 9: Descriptive Statistics for Measures of Attention					
Variable	Variance Decomposition	Mean	Std. Dev.	Percentage of Weeks with at Least One Story	Observations
Number of ABC stories	Overall	**.129**	**.514**	8.8%	6937
	Between		.217		7
	Within		.473		991
Number of CBS stories	Overall	**.140**	**.513**	9.8	6937
	Between		.210		7
	Within		.475		991
Number of NBC stories	Overall	**.127**	**.493**	8.7	6937
	Between		.215		7
	Within		.475		991
Number of *NY Times* stories	Overall	**.552**	**1.140**	32.2	6786
	Between		.703		7
	Within		.941		991
Number of *Washington Post* stories	Overall	**.358**	**.883**	21.7	6936
	Between		.500		7
	Within		.752		991

*The *New York Times* data were not available through Lexis-Nexis for the first 21 weeks of 1980.

Endnotes

[1] This number may in fact be an underestimate of deaths attributable to Alzheimer's disease, which appears to be underreported as a cause of death on death certificates (Ewbank 1999).

[2] Similar trends are apparent when we examine attention to disease by Congress and the president. Variation in attention to disease by government decision makers is part of our broader research on agenda setting and attention to disease.

[3] We recognize that these data severely underestimate the total growth in coverage of disease over this time period, since they represent only a small subset of all diseases.

[4] There are two other elements that are significant in shaping the attention process to any social issue, particularly in the mass media. The first of these are "news shocks"—unanticipated, often calamitous events that dominate the news agenda when they happen, such as Hurricane Katrina in late summer 2005, the terrorist attacks of September 11, 2001, or the When such events occur, they crowd other issues off the agenda. The second element is known as "killer issues"—stories that routinely (and somewhat predictably) dominate the news agenda. Examples include both ongoing issues such as the state of the economy and periodic ones, such as taxation, which routinely overshadows news coverage around April 15th every year. In this paper, we are able to account for neither news shocks nor killer issues, though we acknowledge their role in helping to shape the attention cycle to disease.

[5] Estimating the burden that any given disease imposes on society and on individuals has long been regarded as a difficult endeavor. There are multiple dimensions of burden -- morbidity, mortality, direct costs to the health care system in terms of treatment, indirect costs in terms of lost productivity, quality of life, and so on – and, there is no consensus in the literature about how to measure these dimensions of burden. Commonly used multidimensional measures include quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs), both of which attempt to balance morbidity and mortality in the calculus of burden. Although we agree that burden is a complex concept, our point is simply that it is possible to identify, albeit incompletely, some aspect of the social burden of a disease.

[6] Readers may wonder whether organization is a simple reflection of burden. Certainly, the burden of a disease and organized interest group attention to that disease *may* be correlated. Diseases that exact large burdens on society may be more likely to have active groups associated with them precisely because of how widespread (or how deep) that burden is. Cancer is an example of the former, AIDS an example of the latter. Yet there are plenty of counter-examples as well: the common cold costs billions every year, is experienced by virtually everyone, yet there are no interest groups for this disease. Breast cancer attracts much more organized interest group attention and activity than does heart disease among women, despite the fact that the latter causes many more deaths than the former. Burden, then, is not the only determinant of interest group presence and activity.

[7] As part of our ongoing research, we are collecting data about thirty-three additional diseases: breast cancer, prostate cancer, colon cancer, cervical cancer, ovarian cancer, melanoma, non-

Hodgkin's lymphoma, leukemia, bladder cancer, cancer of the esophagus, cancer of the lip, oral cavity and pharynx, pancreatic cancer, stomach cancer, depression, arthritis, tuberculosis, lupus, multiple sclerosis, mosquito-borne viral encephalitis (e.g. West Nile virus), sickle cell disease, asthma, pneumonia and influenza, liver disease, septicemia, arteriosclerosis, meningitis, viral hepatitis, nephritis, benign neoplasms, alcoholism, obesity and hypertension.

[8] We recognize that our measures of media attention are not necessarily representative of the full array of news people read or see. Nightly news viewership has declined over the period of our study. However, for the better part of our time series, we have in effect sampled the entire universe of nightly network news, since we include NBC, ABC and CBS. Towards the later years in our time period, cable news begins to play a much greater role. In addition, although our indicators of print coverage come from only two sources, these two newspapers have widespread national distribution and are regarded as "papers of record" by many policymakers. In part, the enormous data collection requirements of this project dictated that we confine our initial analysis to these two newspapers, and to network news. We are currently collecting data on a much broader range of newspapers (approximately 12 regional papers and *USA Today*), and on cable news coverage in order to expand our sampling frame.

[9] There is one important way in which obituaries may yield information about trends in media coverage of disease. It is well-known that naming the cause of death in an obituary reflects the social acceptance of the disease. For decades, deaths from the dreaded disease cancer were noted in obituaries with the phrase "died after a long illness." When AIDS first emerged in the

early 1980s, its victims were subject to the same euphemisms once used to avoid public mention of cancer. Today, both HIV/AIDS and cancer are mentioned openly in obituaries.

[10] The *New York Times* data were not available through Lexis-Nexis for the first 21 weeks of 1980.

[11] Of course, these national vital statistics are accurate only to the extent that cause of death is correctly reported on death certificates. For a discussion of the accuracy of death certificate reporting, see Smith-Sehdev and Hutchins (2001), Nielsen et al. (1991), and Maudsley and Williams (1996). Although errors certainly do occur on death certificates (as well as arbitrary assignment of cause of death), we believe this misreporting does not affect our results in any particular direction.

[12] We recognize that these data about groups from published sources may not provide perfectly accurate information about the composition and character of the organizational communities in each year of our series. For example, when organizations express an interest in disease in 2004, we cannot in all cases determine when they first became interested in that disease. For some organizations such as the American Heart Association, it is clear that they have been interested in a disease since their founding. But for organizations such as the ACLU or the National Association of Black County Officials, it is unlikely that formation dates are equivalent to dates of initial interest in a disease. Although this problem exists for a number of organizations in the disease communities we have identified so far, it is especially problematic in the case of HIV/AIDS because many of the organizations that express an interest in AIDS existed long

before the virus was identified. Thus, our count of the number of organizations in the AIDS community over time reflects only those organizations that came into being in 1982 or later. Similarly, because we identified disease-related groups in 2004, we cannot account for organizations that existed earlier in our series but have since ceased to exist.

[13] As with the counts of organizations, we cannot know for certain if an organization that registered to lobby in 2002 was politically active in any or all previous years of its existence. (Assessing past political activity also is made difficult by the fact that organizations were not required to register to lobby until 1995.) However, we have no reason to expect that organizations in any disease community were systematically more or less likely to become politically active over the course of our time series.

[14] We have minimal concerns about treating scientific attention as exogenous to print and broadcast attention. Scientific and medical research is conducted over a relatively long period of time, and scientific and medical journals usually queue articles months in advance of their actual publication. If the *JAMA* publishes an important study about Alzheimer's disease, it can take just one day (or less) for a *New York Times* or NBC reporter to write up a story on the article. If, however, a team of medical researchers becomes more interested in Alzheimer's because Alzheimer's is making the nightly news, it will probably take years at a minimum for any findings resulting from their research to be published. Hence we expect no contemporaneous endogeneity (or week-to-week endogeneity) to hold for print and broadcast attention, and scientific or medical attention.

[15]Certainly it is possible that other indicators, such as the extent of research funding for a disease, the occurrence of scientific conferences relevant to a disease, and efforts by drug companies to publicize their disease-related drug treatments, may have an impact on the attention given by the media to a particular disease. However, many of these indicators of scientific or medical attentiveness to a disease are picked up through two of our control variables – number of FDA drug approvals and the number of articles in scientific journals about a disease. Indeed, it is reasonable to expect that research effort is evident through the reporting of research results in scientific journals, and that private (and public) investment in disease treatment is at least partially reflected through the successful research and development investments by firms as evident in FDA drug approvals. Moreover, since many dimensions of scientific or medical attention are difficult to observe empirically (e.g., it is not possible to obtain data about the amount of dollars spent by the government or private entities on research for particular diseases), it is more appropriate that we approximate the impact of these relatively specific variables through our general indicators than it is to ignore their impact because we lack more precise measures.

[16]Indeed, it is difficult to envision, for each equation in the endogenous system, an exogenous covariate – i.e., a variable correlated with the attention given to disease by media outlet X but uncorrelated with the attention to disease of media outlet Y, except through the effect of outlet X's attention on the attention of outlet Y.

[17]This result holds when we use seconds of television news and words in newspaper stories as our dependent variables. It also holds for simple fixed-effects models in which the covariance matrix is not adjusted as it is in the models we show here.

[17] We also considered the aggregate membership of organizations interested in each disease as an indicator of the size of each community of organizational advocates. If we focus on estimation based on the sample that excludes the AIDS observations, the replacement of number of groups with size of membership strengthens our results. Specifically, when the observations for AIDS are excluded from the estimation, we find that membership has a positive and statistically significant impact on both print and broadcast attention. However, the estimation based on the full sample reveals a consistently negative relationship between cumulative membership size and attention, exactly opposite the result we uncovered with the number of groups variable. Although we are uncertain about why this sign change occurs, we have reservations about what the membership variable is tapping. This is because organizations define "members" in very different ways. Some organizations use the approach of the American Diabetes Association and count their contributors and supporters as members. Other organizations with affiliated individuals (or groups) consider themselves non-membership groups. The Alzheimer's Association is one such organization. The Alzheimer's Association is identified as a non-membership group even though it has thousands of "volunteers" who support the organization and work on its behalf.

[19] In addition, we ran models that aggregated our dependent variables to the annual level. We were concerned about potential misspecification of our standard errors because our dependent

variables and independent variables are measured in different metrics; that is, our outcome variables are measured at the weekly level, whereas our predictor variables are measured at the annual level. Although there is no reason to expect dramatic shifts in either mortality from a disease or the presence of organized interest groups at the weekly level, indeed, our results confirmed this. Our results are the same whether the media attention variables are specified as weekly or annual counts of attention.

[20] In a set of models not reported here, we included a variable that measured the percent of deaths that occurred to people under age 55. Since AIDS is the only disease in our sample that causes significant levels of premature mortality, in effect, this variable functioned as a proxy for AIDS.

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