Transformations in Health Policy: An Analysis of Alzheimer's Disease Testing, Medicaid Enrollment, and Insurance Market Concentration

Citation	Wikler, Elizabeth McCarthy. 2013. Transformations in Health Policy: An Analysis of Alzheimer's Disease Testing, Medicaid Enrollment, and Insurance Market Concentration. Doctoral dissertation, Harvard University.
Accessed	April 17, 2018 4:03:22 PM EDT
Citable Link	http://nrs.harvard.edu/urn-3:HUL.InstRepos:11125997
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Transformations in Health Policy: An Analysis of Alzheimer's Disease Testing, Medicaid Enrollment, and Insurance Market Concentration

A dissertation presented

by

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to

The Committee on Higher Degrees in Health Policy

in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

in the subject of

Health Policy

Harvard University

Cambridge, Massachusetts

May 2013

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Abstract

This dissertation consists of three quantitative papers addressing contemporary issues in health policy. The first paper draws on a survey of 2,678 adults from the United States and four European countries to assess demand for a hypothetical early medical test for Alzheimer's disease (AD). Overall, 67% of respondents reported that they would be "very" or "somewhat" likely to get the test if it were available. Through logistic regression analysis, we find that interest was higher among those worried about developing AD, with an immediate blood relative with AD, and who have provided care for AD patients. Knowing that AD is fatal did not influence demand, except among those with an affected blood relative. We expect that a test becoming available could precipitate the creation of a large constituency of asymptomatic, diagnosed adults, affecting a range of health policy decisions.

The second paper utilizes Current Population Survey data to explore state-level Medicaid enrollment rates among eligible parents between 2003 and 2010, focusing on the interaction of race and ethnicity and political ideology. Using logistic regression analysis, we find that average take-up for Hispanics in conservative states was 23%, whereas take-up was 38% for both whites and blacks in those states, adjusting for state and individual demographics. These differences abated in liberal and moderate states. Among eligible Hispanics, enrollment rates were less than half as high in conservative states than in liberal states (23% versus 61%). Adjusting for differences in state Medicaid policies narrowed these disparities significantly, highlighting the importance of new provisions aimed at streamlining enrollment procedures across all states.

The last paper draws on public and private data from 2007 to 2010 to analyze how administrative spending by health insurers and providers varied across states with different levels of insurance and hospital market concentration. Using regression analysis, we find that in provider offices, high levels of insurance concentration were associated with lower administrative costs. If all states were as concentrated as the most concentrated state in our sample, we would expect nationwide savings of $3.6 billion in administrative expenses. However, market concentration did not reduce administrative spending by insurers or hospitals.

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Acknowledgements

First and foremost, I would like to thank my dissertation committee.

When I was a senior at Harvard College, Richard Frank dined with me at a student faculty dinner in Quincy house. Although I felt awkward and nervous at the time, Richard was gracious, inquisitive, and generous with his advice on life and research. He's been the same ever since. Over the past three years, I've shown him countless columns of data, and he's provided thoughtful feedback on each one. My modeling, my data skills, and this dissertation are much stronger analytically because of his feedback. And his commitment to public service is something I hope to emulate in my own career.

I met David Cutler as a college junior, when I took his health economics course. At time, I was fascinated by his ideas and intimidated by his brilliance. Neither feeling has entirely abated. Years later, however, I was lucky enough to serve as a teaching assistant for him in the same course, which led to a job as a research assistant on a project evaluating administrative costs. Over time, I came to consider him a mentor and a friend. As busy as he must have been, David always made me feel that my work was worth his time; he always responded quickly and perceptively to my round-the-clock emails, he always challenged me to think harder and probe data more deeply, and he always warmly supported my growth both as a student and as a wife and mother.

Robert Blendon was the chair of my committee. More than that: he was the reason I entered this field in the first place, the reason I returned to Harvard for graduate school, and now, in no small part, the reason I'm graduating. My first experience in health policy (aside from dinner-table discussions growing up) was as a sophomore taking Bob's Kennedy School class. Then as now, his enthusiasm was infectious, he was a volcano of ideas, and his political and strategic savvy was extraordinary. I've been blessed to have Bob as a coach and thought partner me throughout my academic and personal journeys over the last decade. I couldn't ask for more from a committee chair, and I hope I will do him proud as I enter the career that he inspired.

Other members of Harvard's faculty have provided invaluable feedback on my work. I'd specifically like to thank Benjamin Sommers, who generously shared his dataset on state Medicaid policies as well as his profound expertise in issues relating to public program enrollment and retention. He read countless drafts, and responded to my data and coding questions with patience, speed, and thoroughness. Christopher Jencks, who served as a mentor during my time as a Malcolm Weiner Inequality and Social Policy Fellow, was also incredibly generous with his time and suggestions on the Medicaid paper.

In addition, I'd like to thank all faculty members and staff affiliated with the Health Policy PhD program, particularly Deborah Whitney, Ayres Heller, Kristin Collins, and Haiden Huskamp. Although she is no longer on staff, I would also like to thank Joan Curhan, who welcomed me into the undergraduate health policy program during college and encouraged me to apply for the PhD program. She helped me create a career path in a field that I loved, and I'm grateful to her for it.

Through my work on Alzheimer's disease, I had the privilege of working with members of the Harvard Opinion Research Program, including Gillian Steelfisher, John Benson, and Kathleen Weldon. I came to count on them not only for up-to-the-minute political news but also for technical and substantive help on any and all aspects of public opinion data and surveys.

I would also like to thank Simo Goshev, at the Institute for Quantitative and Social Sciences, for helping me troubleshoot modeling questions; David Molitor, who helped me develop the code for my first and second papers; and Jeoffrey Ysulan for his help in transcribing data for the third paper.

I have met some amazing people through this program, and would like to thank them for all the emotional and physical support they've provided over the years. I'd particularly like to thank Mike Botta and Ricky Gonzales, my partners in the political analysis track. Kirstin Scott and Alecia McGregor were also incredibly helpful in obtaining last-minute data for my third paper. Program alumnae, including Tara Oakman, Cara James, and Adam Block, have also offered useful career advice and have generously opened their networks to me. And everyone in the program, both in my cohort and in other years, has been there when it mattered.

The love and support of numerous friends and family members has made this dissertation possible. I'd like to thank Natalie Valpiani for her daily check-ins and inspirational notes; Jef Klazen, Ben Margetts, Bron York, and David Sievers for providing home offices away from home; Ella Hushagen and Dana Conroy for their loyal friendship; my high school girlfriends, who teach me how to combine motherhood with careers; my college roommates, who challenge me to think critically and celebrate joyously; Jesse Collins, for providing a sense of calm and grace in our home; and to our unofficial New York family, Eli Pariser, Gena Konstantinakos, Vivien Labaton, Nick Arons, Peter Koechley, Krista Williams, and Lachlan Koechley-Williams, who make our whole family so happy so often.

Most of all, I would like to thank my amazing official family. My husband's parents, Lynn McDonald, Michael Edwards, Sarah Marchand, and Daniel Wikler, have cheered me on at every milestone and helped me feel confident in my progress even when the mountain seemed insurmountable. I would especially like to thank Dan for his friendship and for bringing such happiness to our lives in Cambridge. I am grateful to my six siblings and their partners for all that they've done to help me tackle this dissertation, from buying me a lap desk to work on after Mac was born to convincing me that I don't have early onset Alzheimer's disease. Even if they're wrong, I'll never forget what they did for me.

I think I won the parent lottery. Richard and Suzanne McCarthy are awe-inspiring. Through their tireless efforts and overwhelming sacrifices, they made it possible for all seven of us to pursue our dreams. They challenged me to challenge myself, and kept me grounded in the tradition of the Mercy values. My parents helped give me the courage I needed to complete this journey, and have bestowed on me a legacy of service, faith, and tenacity that I hope to carry forward.

Lastly, I'd like to thank, Mac, my sweet baby boy, and my incredible husband, Ben Wikler. Mac, you've given me the greatest joy I've every known, and I hope that I can help create a more equitable and just world for you to experience. Ben, you've been my editor-in-chief, my cheerleader, my in-house expert, and my best friend. You've read countless drafts, you helped me format countless tables and spreadsheets, and you listened to the countless things said and unsaid. You never let me give up. From the bottom of my heart, thank you for believing in me.

For

My parents, Richard and Suzanne McCarthy

&

My husband, Benjamin Wikler

&

My son, Michael Wikler

Paper I: “Would You Want to Know?” An Analysis of International Public Opinion on Demand for Early Medical Testing for Alzheimer’s Disease

Introduction

In 2011, international experts revised the diagnostic criteria and guidelines used to identify Alzheimer's disease.[1–4] As part of this revision, the group proposed a research agenda focused on early detection of Alzheimer's disease (AD), particularly when the disease is in a preclinical stage: after key biological changes have started to occur, but before the onset of noticeable symptoms. Their hope was that identifying the disease in this preclinical state would facilitate the development of new treatments to slow or halt the progression of the disease.[5] Across the globe, early diagnostic and predictive tests using Alzheimer's disease biomarkers—early biological signals indicating the presence or absence of AD—are underway, and showing promising results. Although nascent, efforts to create an early medical test for Alzheimer's disease are gaining traction and may soon be available for broad populations of asymptomatic patients. While this may result in tremendous breakthroughs regarding treatment, it raises practical, ethical, and financial questions for individuals and communities across the globe. Most of all, people all over the world will face a decision: should they get tested? Would they want to know whether they will get this fatal, untreatable disease?

This paper draws on public opinion data from four Western European countries and the United States to assess potential demand for early diagnostic testing for Alzheimer's disease. While other public opinion surveys on Alzheimer's disease have focused on results from just one country, this survey offers a unique opportunity to examine beliefs across five countries to better assess how attitudes and beliefs vary across countries with different health systems, cultures, and experiences with Alzheimer's disease.[6] In an effort to delve further into some of challenges ahead, we explore some of the factors associated with high and low levels of interest in early medical testing for AD, employing constructs from the Health Belief Model, a commonly used theoretical model that predicts utilization of health services.[7] Our results suggest that demand for Alzheimer's testing among asymptomatic patients could be high across all five countries, particularly among those who perceive themselves to be at high risk for the disease.

Literature Review

Background on Alzheimer's disease

Alzheimer's disease is a terminal illness that slowly destroys brain cells, impairing a person's memory and ability to carry out activities of daily living. [8,9] Evidence suggests that a build-up of beta-amyloid plaques and neurofibrillary tangles precipitate the brain degeneration and memory loss associated with Alzheimer's disease.[10] This build-up can begin 20 to 30 years before the clinical onset of the disease, but historically, this change has been hard to detect using commonplace diagnostic protocols, which rely substantially on clinical observation of symptoms.[11,12]

There are two types of Alzheimer's disease: early-onset and late-onset. Early-onset Alzheimer's, which accounts for a small fraction of all Alzheimer's disease cases (about 5%), affects populations below the age of 65—typically individuals in their 30s, 40s, and 50s. Most of these cases are inherited—a form described as familial Alzheimer's disease—and linked to mutations in three genes: APP, PSEN 1, or PSEN 2. If a person has one of these mutations, she will definitely develop familial Alzheimer's disease, which has a more rapid clinical progression than late-onset AD. Late-onset Alzheimer's disease, which is more common in populations over age 65, accounts for about 95 percent of cases. The genetic risk profile for this form of the disease is less clear, leading experts to conclude that it is caused by a combination of genetic, environmental, and lifestyle factors.[13,14] Given its dominance, late-onset Alzheimer's disease is the focus of the remainder of this paper.

Medicine offers few tools to address Alzheimer's. Although some drugs have been developed to ameliorate mild-to-moderate symptoms of the disease, these drugs do not alter the underlying disease process, and results from clinical trials for other drug candidates have thus far not been promising.[15] Moreover, while several risk factors for the disease have been identified—such as cardiovascular health, low levels of education, smoking, and depression—only a few randomized control trials have evaluated potential interventions affecting these risk factors and the resulting impact on AD prevalence. Thus far, no intervention has gained wide acceptance as effective.[9,16] Overall, the average Alzheimer's patient lives about 8 years after symptoms appear, with survival ranging from 4 to 20 years.[17] In short, the disease is difficult to detect, cannot be prevented, is essentially untreatable, and fatal.

Worldwide, an estimated 33.9 million people are afflicted with Alzheimer's disease; due to demographic shifts, prevalence is expected to triple over the next 40 years.[16,18] Prevalence rates in Europe and the United States are some of the highest in the world, with an estimated 7 million and 5.4 million people, respectively, suffering from the disease. [19–21] The World Health Organization ranks AD and other dementias as the fourth leading cause of death among high-income countries, and the annual direct and indirect costs attributable to Alzheimer's and other dementias are estimated at roughly $234 billion in the European Union and $183 billion in the United States.[18,19,22]

Steps towards a test for Alzheimer's disease

Medical testing for Alzheimer's disease is not a new phenomenon. Genetic testing for Alzheimer's disease has been available since 1994, offering patients a probabilistic measure of their risk for the disease. Genetics play an important role in the development of Alzheimer's disease, particularly in the diagnosis of early-onset AD. Several potential risk genes have been identified for late-onset AD, with the apolipoprotein E (APOE) genotype accounting for most of the genetic risk in the development of the disease. Individuals with two *ApoE* ε4 alleles have more than seven times increased risk of developing AD than those with the *ApoE* ε3 allele.[8,17]

However, existing genetic tests analyzing apolipoprotein genotypes are inherently limited. The *ApoE* ε4 allele is neither a necessary nor sufficient predictor of the disease, meaning that people without this allele develop AD and not everyone with the allele does develop AD. [17] The association between *ApoE* ε4 allele and AD also varies by race and ethnicity.[23,24] For these reasons and others—including the test's low sensitivity and specificity, the difficulty of interpreting probabilistic results, and the lack of prevention options—experts have largely opposed widespread clinical adoption of these genetic tests.[25]

Efforts to develop additional medical tests for the early detection of AD continue. Work is underway to identify other susceptibility genes for AD, which could result in a more comprehensive set of predictive tests based on genetic makeup. Other initiatives have focused on emerging disease biomarkers— particularly those measuring changes in amyloid beta accumulation, synaptic and neuronal function, and brain structure—in hopes of developing tests that track pathophysiological changes related to the disease.[26–30] If these new tests prove successful, it's feasible that they could be incorporated into clinical practice and made broadly available. It is this possibility—that new genetic or biomarker tests could become available to the general public—that forms the basis for this paper.

Health Belief Model

The Health Belief Model (HBM) is a theoretical framework developed by the U.S. Public Health Service in the 1950s to help explain low participation rates in disease prevention and early detection programs.[7,31,32] The core premise of the model is that health behaviors are driven by personal beliefs about health conditions and the strategies available for their detection and treatment.[31] In the past half century, the HBM has been applied in a range of fields to help determine the factors that best predict participation in health services, especially in assessments of screening and testing programs for diseases such as Tay-Sachs, cancer, Huntington's disease, cystic fibrosis, and Alzheimer's disease. [33–37]

There are two primary components of the model: perceptions of the disease and perceptions of relevant health behaviors.[38,39] Perceptions of disease, also described as the "perceived threat," include beliefs about both the severity of the disease and the individual's susceptibility to the disease. Perceived threat captures the extent to which a person feels vulnerable to a particular health condition and thus is motivated to act on that feeling.[7] Perceptions of behavior include beliefs about the tangible and psychological costs of, or barriers to, an action, weighed against its potential benefits, including the ability of the action to reduce risk or the condition's impact on one's life.[40] A potential benefit of testing for a disease, for example, may be reduced uncertainty associated with being at-risk, whereas a potential cost may be discrimination.[25,41,42] The Health Belief Model operates in a sequential fashion: perceptions of threat provide the "energy or force to act" while perceptions of behavior—taking into account perceived benefits and costs—provide "a preferred path to action."[43,44]

It is worth noting that these perceptions are not always accurate, and may instead represent an over- or under-estimation of reality. While a person's family history with a disease may provide an objective perception of risk for the disease, difficult personal experiences, heightened media attention, or an incomplete understanding of the disease's trajectory could easily generate misperceptions regarding levels of risk regardless of actual genetic susceptibility. However, the literature demonstrates that it is the perception of risk—which reflects both accurate and inaccurate evaluations of risk—that shapes health behaviors, not the objective underlying risk.

The Health Belief Model accounts for two additional sets of variables that influence individuals' perceptions and, in turn, their health behaviors. The first set includes cues to action, which consist of people, places or events that spur a behavior change. These can be internal, such as the onset of a new symptom, or external, such as mass media campaigns, conversations, or physician reminders.[45] These variables tend to be the least well formulated in studies and, thus, relatively little is known about their role in health behavior. The second set includes diverse demographic, structural, and psychological variables that can inform individuals' views on their perceived threat and perceived costs and benefits of a particular action. These include age, race, education, knowledge of the disease, and other variables assessing coping styles and beliefs regarding self-efficacy (confidence in one's ability to take action).[40]

The present study draws on the Health Belief Model to inform our hypotheses about overall levels of interest in early medical testing for Alzheimer's and the factors motivating individual responses, both positively and negatively.

Hypotheses: Demand for Medical Care and Predictive Alzheimer's Testing

The Health Belief Model reflects a rational, cognitive view of decision-making, with the assumption being that if the person feels threatened by a disease and simultaneously feels that the benefits of taking action outweighs the costs, then she or he will take action. [7,40]

Perceived threat encompasses perceptions of both risk and severity. But with regards to interest in genetic testing, studies consistently find that these factors work in opposite directions: interest in genetic testing is associated with high levels of perceived risk, but with low levels of perceived severity.[32,33,37,46]

In a general population survey conducted in the United States, respondents with a family history of AD and respondents who had served as caregivers tended to show a strong inclination towards testing.[47] Moreover, a study of first-degree relatives of AD patients found that level of concern, when incorporated into a larger variable capturing multiple dimensions of perceived threat, was predictive of desire for an AD genetic test.[37]

While high perceived risk predicts higher interest in testing, perceived disease severity has the opposite effect. One of the seminal studies on the health belief model showed a curvilinear relationship between utilization of testing for Tay-Sachs disease and perceptions of that condition's severity, such that low perceptions of disease severity motivated participation whereas high perceptions of severity had an inhibiting effect.[32] This pattern has been confirmed in other studies evaluating utilization of genetic testing. Studies find that rates of testing are much lower for conditions in which there is perceived to be no cure, no treatment, and no method of prevention, while testing rates are higher for conditions in which people think something can be done.[41] For example, rates of genetic testing for hereditary forms of breast cancer, where a range of treatment options are available, are about 50% while rates of testing for incurable Huntington's disease are about 10%.[46,48]

In our study, we measure perceived threat using two categories of variables. The first characterizes a respondent's level of perceived risk. Our measures of perceived risk capture perceptions based on objective measures of risk—having a blood relative with AD—and subjective measures of risk borne from experience, such as whether the respondent served as a caregiver or decision-maker for person with AD, is "very" or "somewhat worried" about getting Alzheimer's disease, and is in fair or poor health. These objective and subjective measures interact; for example, if a respondent has a family member with AD, she may be more worried about the disease. In this paper, we group these reports of objective and subjective factors together, arguing that it is the overall perception of threat that matters rather than the underlying reality. The second category of perceived threat focuses on the perceived severity of Alzheimer's disease. For this, we ask respondents if they think Alzheimer's disease is fatal. Drawing on previous findings, we expect that our measures of perceived risk will predict higher rates of interest in testing, but expect that knowledge of the disease's fatality will predict lower rates of interest in testing. [34,36,47,49–52]

Perceptions of costs and benefits of testing are also shown to affect both rates of expressed interest in testing and actual utilization of available tests. In studies of genetic testing for Alzheimer's disease, cited benefits include having information available for purposes of future planning, such as signing advanced directives, resolving financial concerns, and purchasing long-term care insurance; being able to monitor developments in Alzheimer's disease and treatment; and reducing levels of anxiety associated with AD risk.[37,42,47,53,54] Perceived costs include potential social and economic discrimination; confidentiality; inability to cope with risk estimates; the financial cost of the test; and the lack of good treatment options.[41,47,55,56] In our analysis, we include measures capturing several of these costs and benefits.

In previous studies, individuals who underwent genetic testing for Alzheimer's disease cited the need to prepare their spouses and families for the possibility of AD; therefore, we expect that individuals who are married are more likely to pursue testing.[53,57] Similarly, since testing interest was positively associated with a desire to arrange future care options, we expect that individuals who anticipate relying on a hired caregiver in the case that they develop AD will be more likely to express interest in testing. Lastly, test utilization is associated with a desire for early access to treatment and prevention options; therefore, we anticipate that those who believe there is a treatment available now or that there will be one in the next five years—beliefs hereafter described as "treatment optimism"—will be more likely to express interest in testing.[37,42]

In our models, we control for demographic variables such as age, gender, education, and country of residence that could influence levels of perceived risk and perceptions of test costs and benefits. We also control for race in models evaluating rates of interest in the United States. (The US was the only country for which race data were collected). The evidence is mixed on the predictive power of demographic variables on demand for medical testing.[34,35,56] Across a range of conditions, including breast cancer, younger populations are generally more likely to express interest in and to actually undergo genetic testing, which could be due to the earlier age of onset for these conditions.[33,58] In studies on Alzheimer's disease, age either has had no effect on interest in testing or had a positive but statistically insignificant relationship.[37,47,49] However, in a trial for AD genetic testing, individuals who pursued testing were more likely to be aged 60 and younger.[52] We anticipate that interest in testing will be greatest for middle-aged to older populations, given that these groups are closer to the age of onset and, in our sample, are more likely to serve as caregivers for AD patients.

In terms of gender, studies of testing for other conditions find that women are more likely to undergo pre-symptomatic tests, carrier tests, and predisposition tests than men, which some suggest is due to differences in knowledge about health threats, differences in coping mechanisms, decisions related to childbearing, and a desire to pass information on to children.[46,59] However, in a study of interest in genetic testing for AD among first-degree relatives, men expressed greater interest than women, which may indicate a divide between those who express interest and those who follow through with testing.[37] Although the incidence of AD is similar across genders when accounting for age, women tend to live longer than men and are therefore more likely than men to develop Alzheimer's disease. Thus, we expect that women will be more likely to pursue early medical testing for AD.

The research on education is similarly variable. In surveys of interest in genetic testing for AD, respondents with the lowest education levels were more likely than their counterparts to report a willingness to undergo testing. [47,49] However, those with higher levels of education were generally more likely to pursue genetic testing for cystic fibrosis, Huntington's disease (HD), and breast cancer, and to indicate a desire for AD testing once it becomes available.[36,52,60–62] This dynamic is particularly troublesome since those with the lowest levels of education are actually at a higher risk of developing the disease.[63] Evidence suggests that this educational difference could interact with other socioeconomic conditions resulting in differences in knowledge about scientific advancements affecting the availability of early medical tests, access to testing technologies, and expectations about the test and its capabilities.[34,58,64]

We expect that country of residence will result in significant differences in levels of interest in testing. A whole host of factors have been shown to contribute to cross-country differences in utilization rates for genetic testing, ranging from clinical, individual, and family-level factors to nationwide cultural and health system-related factors.[65] We anticipate that cross-country differences in rates of interest for testing could reflect differences in understandings of health and this disease, clinical and social norms regarding an Alzheimer's disease diagnosis, cultural acceptance of testing, differences in incidence rates, family structure and communication patterns between family members, ideologies surrounding patient autonomy and physician paternalism, and concerns about insurance and long-term care provision.[46,59,63,66,67] While we control for some of these factors at an individual level, we expect that country of residence will simultaneously account for unspecified cultural and person-level differences as well as differences that are more concretely linked to political and economic factors.

Race may predict interest in early medical testing for AD. For example, a survey of professionals conducted in the Southeastern part of the United States found that, in comparison to white respondents, African-Americans showed less interest in genetic testing for AD and endorsed fewer reasons for seeking testing; nevertheless, they anticipated fewer negative consequences from a positive result.[68] Overall, these results are similar to those seen in testing for cystic fibrosis and hereditary breast and ovarian cancers, which found that whites were more likely to express interest in genetic testing, seek out genetic counseling, and undergo testing once available.[36,57,58,69,70] However, a national telephone survey conducted in 2000 found that African-Americans and Latinos, in comparison to whites, were more likely to express interest in adult genetic testing for untreatable conditions.[48] Given this conflicting evidence, we have no clear hypothesis for the role of race in predicting interest in testing.

Beyond demographic variables, we expect that other psychological factors, such as measures of self-efficacy and coping styles, will influence interest in early medical testing for AD. These measures account for some of the underlying emotional processing involved in decisions regarding health behaviors. In analyses of participants in HD genetic tests, researchers found that, compared to the general population, those who underwent testing were a self-selected group who believed that they were better equipped to handle bad news, had strong mental resources, and were less pessimistic about the impact of a test result.[61,71–73] Those who chose not to get tested scored higher on depressive and hopelessness scales, and/or viewed themselves as more psychologically vulnerable to potential consequences, such as fear, depression, and inability to cope with unfavorable results.[41,61,74]

People who underwent asymptomatic testing also had better coping strategies. According to one predominant theory, people typically fall into one of two camps: monitors and blunters.[75] Monitors include those seek out information when confronting a threatening situation, whereas blunters avoid it or distract themselves away from the stressor. Distraction enables at-risk persons to avoid confronting painful or anxiety-provoking feelings about a disease or his or her risk of contracting the disease.[72] Populations that sought out genetic testing for Huntington's showed more active problem solving, sought out social support, and consoled themselves with comforting and optimistic thoughts.[35] This "information-seeking style" is characteristic of monitors, and predicts useful coping abilities.

In our survey, we ask respondents whether they would visit a doctor if exhibiting confusion or memory loss, which are symptoms of Alzheimer's disease. We expect that those who demonstrate a more active information-gathering style, i.e. those who are willing to go to a doctor if showing symptoms, will seek out AD testing, whereas those who respond negatively, potentially showing signs of avoidance, will not express interest in AD testing.

Study Data and Analysis

Data Sources

The data for this paper come from an international telephone survey with a randomly-selected sample of 2,678 adult respondents age 18 and older, drawn from five countries: France, Germany, Poland, Spain, and the United States. The Harvard School of Public Health and Alzheimer Europe commissioned the survey to assess public understanding about Alzheimer's disease. The fieldwork was conducted from February 7 to 27, 2011 by TNS, which is an independent research company based in London with branches in each of the five countries surveyed. TNS is one of the largest survey research companies in the world, and conducts the Eurobarometer surveys of adults in the European Union for the European Commission. In each of the five countries, interviews were conducted both by landline telephone using random-digit dialing and by cell phone using numbers chosen randomly from a list of cell phone numbers across the country among adults age 18 and older. Interviews were conducted in the language of each country. In the United States, interviews were conducted in both English and Spanish. The average length of an interview was 12 minutes.

The survey, which has been described elsewhere, focused on eight broad topics, ranging from relative public concern about the disease to public beliefs about whether an effective treatment is available to slow the progression of the disease.[6] In this analysis, we focus on results related to interest in future early diagnostic testing for the disease, should such a test become available.

The following table (Table 1.1) shows interview dates, sample sizes, and margins of error at the 95% confidence interval for each country.

Table 1.1 Sample Sizes for Surveyed Countries

	Interview dates	Total interviews	Margin of error (percentage points)
France	February 7–14, 2011	529	+/-4.3
Germany	February 7–19, 2011	499	+/-4.4
Poland	February 7–10, 2011	509	+/-4.3
Spain	February 8–13, 2011	502	+/-4.4
U.S.	February 7–27, 2011	639	+/-3.9

Interest in Early Medical Testing

This analysis evaluates the likelihood that a respondent indicates that he or she will pursue early medical testing for Alzheimer's disease if it is available in the future. The relevant survey question begins with the statement, "[i]n the future, a medical test might become available that would tell people before they had symptoms whether they will get Alzheimer's disease in the future." The question then asks, "If such a test became available, how likely do you think it is that you would get the test—"very likely", "somewhat likely", "not too likely", or "not at all likely"?"

In overall assessments of potential interest, we include respondents who are either "very likely" or "somewhat likely" to seek testing. However, because literature suggests that take-up rates tend to be lower than rates of expressed interest once tests are actually available, our regression analysis pays particular attention to those who report being "very likely" to get the test, since these respondents are likely the group most motivated to obtain testing.[41] Similarly, we anticipate that those who report being "not at all likely" to obtain the test may reflect the views of people who would never seek out an AD test or accept it when offered. Therefore, we also use regression analysis to compare the characteristics of this "not at all likely" group to the rest of the sample. We created two dichotomous outcome variables, with the first coded as "very likely" = 1; "somewhat/not too/not at all likely" = 0 and the second coded as "not at all likely"=1; "not too/somewhat/"very likely""'=0. We dropped the "Don't know/Refused" respondents, of whom there were 53, from the analysis.

Independent Variables

The independent variables used in this analysis were drawn from the survey and include beliefs and attitudes about Alzheimer's disease, indicators of perceived costs and benefits, and other demographic and psychological factors that could affect views of the disease. We collected data on income and education, both of which serve as useful indicators of socioeconomic status; however, since the two are strongly correlated ($r= 0.394$, $p<0.05$), we only use education in our analysis. The coding and units for each of these variables is included in the Appendix. Race and ethnicity data was only collected for respondents in the United States, so models evaluating its impact are conducted for respondents living in that country only.

Analysis

To evaluate the hypotheses described above, we analyzed both the unadjusted and adjusted relationships between the outcome and independent variables included in these analyses. For the unadjusted bivariate relationships, we used chi-square tests to evaluate statistical significance, which we assessed at the conventional alpha level of $p<.05$. We then employed logistic regression models to estimate mean levels of interest in early medical testing for AD and the factors associated with high and low levels of interest. We estimated a series of models, beginning with variables measuring respondents' perceived threat and perceived costs and benefits. We then systematically added in additional control variables, assessing the models using differences in log-likelihood measures. Only the final models are shown in this analysis. As recommended in the literature, we did not aggregate items measuring the constructs of the health belief model, despite some measures being moderately interrelated, and instead evaluated the impact of each measure separately.[44] However, we did check for interactions between these variables to see if they enriched our understanding of the factors motivating interest in testing. As robustness checks, we ran country-specific regression models to check for between-country variation, and evaluated all models using probit regression.

Nonresponse in telephone surveys produces some known biases in survey-derived estimates because participation tends to vary for different population subgroups. To compensate for these known biases, the sample data are weighted to reflect the actual composition of the adult population in the surveyed countries, calculated on the basis of census data from each country, according to race/ethnicity (U.S. only), age, gender, and region. The sample data are also weighted by telephone status (landline, cell). Other techniques, such as systematic respondent selection within households and callbacks staggered over times of days and days of weeks, were used to help ensure that the sample in each country is representative. In our bivariate results, we present weighted percentages. After the weighting, the results for each country are generalizable to the adult population of that country.[6] All analyses were conducted using Stata 11 software.

Limitations

Imprecise wording in our survey may mean that we have overestimated underlying levels of interest in testing. As noted above, the survey asks:

> "[i]n the future, a medical test might become available that would tell people before they had symptoms whether they will get Alzheimer's disease in the future. If such a test became available, how likely do you think it is that you would get the test—"very likely", "somewhat likely", "not too likely", or "not at all likely"?"

This phrasing presents several problems. First, the phrase "in the future" is used twice: to describe both the potential existence of an early medical test for Alzheimer's, and to refer to the possibility that the respondent will get Alzheimer's disease later in life. Therefore, our results encapsulate respondents' beliefs about the timing and availability of such a test, their interest in the actual test, and their level of concern for events that may happen in the future. The use of the word "might" in the first part of the question ("a medical test might become available") compounds the possible variance based on respondents' beliefs about the likelihood of such a test coming becoming a reality. In our regression models, we attempt to focus in on interest in testing by controlling for treatment optimism, levels of concern about getting Alzheimer's disease, and age. Future research, however, could more effectively eliminate variance associated with respondents' views on scientific advancement by rewording the survey question, creating a hypothetical situation in which the test already exists.

Another potential issue with the question is that it implies that the test would be completely predictive and highly effective: the imagined test "would tell people before they had symptoms whether they will get Alzheimer's disease in the future." In reality, such a test might tell people that they were at greater than average risk to get AD, without predicting it with certainty. Interest in a probabilistic test might be lower than the interest expressed by our respondents.

Moreover, we do not include potentially relevant financial, social, and emotional variables, such as respondents' insurance status, willingness to pay for testing, concerns about test administration procedures, family size, country-level policies, AD media coverage, level of religiosity, history of depression, or fear of discrimination in the survey. Future research could delve more deeply into the roles that these variables play in predicting interest in testing. Future surveys could also benefit by including variables capturing the role of personal motivations and personality dispositions by using more refined measures of perceived costs and benefits, such as those used in earlier analyses of genetic testing for breast and ovarian cancer, and measures of psychological style, including the Miller Behavioral Style Scale.

One factor not directly included in the Health Belief Model is the role of fear in predicting interest and utilization of AD testing. However, previous work on mammography screening finds that levels of perceived risk help predict levels of fear.[40] Therefore, while we do not explicitly account for fear in the present analysis, we believe that our measures of perceived risk do control for some of the effects that fear might have in this study. Future analyses on early medical testing for AD could include more direct measures of fear as well as other emotional dimensions of health behavior.

Results

Descriptive Statistics

Table 1.2 displays levels of interest by our respondents in early medical testing for Alzheimer's disease, as well as weighted statistics on measures of perceived threat, costs and benefits of testing, demographics, and psychological status. In our survey, roughly a third of all survey respondents (30.0%) report that they would be "very likely" to get the test, whereas slightly more than a tenth (11.93%) reported being "not at all likely" to pursue testing. Our estimates for those who would be "very likely" to get an early medical test for AD fall roughly in line with results from a randomized clinical trial published in 2004, which found that the take-up rate for genetic testing for Alzheimer's disease was 24% among contacted participants.[52] If we combine respondents who are "very likely" and those who are "somewhat likely" to obtain the test (36.98% of respondents), about 67% of adults in our survey report that they would obtain an early medical test for Alzheimer's disease.

Table 1.2 Frequency (%) tables of support for early medical testing for Alzheimer's disease by response categories and social and demographic groups

	Entire Sample		Very likely to get early medical test for AD		Not at all likely to get early medical test for AD	
Entire sample			30.00%	[28.1-31.9]	11.93%	[6.4-21.1]
Have/had immediate blood relative with AD						
No	77.10%	[75.2-79.0]	27.8%***	[25.7-30.1]	12.30%	[6.5-22.2]
Yes	22.90%	[21.0-24.8]	35.30%	[31.2-39.7]	11.20%	[6.3-18.9]
Served as decision-maker or caretaker for AD patient						
No	83.00%	[81.4-84.7]	27.9%*	[25.8-30.0]	12.7%**	[7.1-21.8]
Yes	17.00%	[15.3-18.6]	40.40%	[35.6-45.5]	8.10%	[3.4-18.1]
Worried will get Alzheimer's disease						
Not too/not at all/don't know/refused	55.30%	[53.1-57.5]	23.5%**	[21.2-26.0]	15.5%*	[7.8-28.5]
Very/somewhat worried	44.70%	[42.5-46.9]	38.10%	[35.1-41.2]	7.40%	[4.7-11.7]
Health status						
Fair/poor	20.30%	[18.5-22.2]	34%*	[29.8-38.4]	12.10%	[6.4-21.4]
Excellent/very good/good	79.70%	[77.8-81.5]	28.90%	[26.8-31.1]	11.80%	[5.8-22.4]
Think AD is fatal						
No/Don't know/refused	55.50%	[53.3-57.7]	28.90%	[26.4-31.5]	12.00%	[5.9-22.8]
Yes	44.50%	[42.3-46.7]	31.40%	[28.6-34.4]	11.90%	[6.2-21.7]
Marital status						
No	46.30%	[44.1-48.6]	28.90%	[26.1-31.9]	12.20%	[6.6-21.3]
Yes	53.70%	[51.4-55.9]	30.90%	[28.4-33.6]	11.70%	[6.0-21.7]
Expect paid caregiver to be primary caretaker if develop AD						
No	70.80%	[68.7-72.8]	28.6%*	[26.3-30.9]	11.20%	[6.1-19.6]
Yes	29.20%	[27.2-31.3]	33.40%	[29.8-37.2]	13.20%	[6.6-24.5]
Believe an effective AD treatment is available now or will be in 5 years						
No/don't know/refused	32.10%	[30.0-34.2]	28.50%	[25.3-32.0]	14.3%*	[8.1-24.1]
Yes	67.90%	[65.8-70.0]	30.80%	[28.4-33.2]	10.60%	[5.4-19.9]
Age						
18-29	23.70%	[21.7-25.8]	25.3%**	[21.3-29.9]	10.50%	[6.0-17.6]
30-49	37.20%	[35.1-39.4]	25.10%	[22.2-28.2]	13.30%	[5.6-28.5]
50-64	21.60%	[19.9-23.3]	36.90%	[33.1-40.9]	11.50%	[5.8-21.4]
65-74	11.60%	[10.2-13.0]	38.90%	[33.2-45.0]	10.10%	[6.2-16.0]
75-85+	5.90%	[4.9-6.9]	34.30%	[27.0-42.3]	13.90%	[7.4-24.5]

Table 1.2 (Continued)

Gender						
Male	48.20%	[46.0-50.5]	27.7%*	[24.9-30.5]	12.30%	[6.7-21.4]
Female	51.80%	[49.5-54.0]	32.20%	[29.6-34.9]	11.60%	[6.0-21.2]
Educational attainment						
Low	32.50%	[30.4-34.6]	32.4%*	[29.0-35.9]	11.20%	[7.3-17.0]
Middle	30.20%	[28.1-32.3]	32.10%	[28.6-35.9]	11.30%	[5.7-20.9]
High	37.30%	[35.1-39.5]	25.90%	[23.0-29.0]	13.10%	[6.0-26.4]
Country						
France	20.80%	[19.0-22.6]	26.8%***	[22.9-31.2]	9.6%***	[7.0-12.2]
Germany	17.90%	[16.2-19.7]	23.60%	[19.7-28.0]	19.80%	[15.8-23.7]
Poland	17.80%	[16.1-19.5]	30.50%	[26.2-35.2]	5.20%	[3.2-7.1]
Spain	18.40%	[16.6-20.1]	39.60%	[34.9-44.4]	8.20%	[5.6-10.8]
United States	25.10%	[23.1-27.0]	29.70%	[26.0-33.7]	15.80%	[12.7-18.9]
Would see doctor if showing symptoms of AD						
No	9.20%	[7.8-10.5]	19%**	[13.3-26.6]	19.5%*	[11.1-32.1]
Yes	90.80%	[89.5-92.2]	31.40%	[29.4-33.5]	11.20%	[5.8-20.6]

Note: N=2,678; *p<.05; **p<.01; ***p<.001 using chi-square tests of differences between expected and observed distributions. Sample sizes vary across categories due to missing data. Confidence intervals in brackets.

Across all measures, we find broad support for our initial hypothesis that individuals who report high levels of perceived risk are more likely than those with low levels of risk to report that they are "very likely" to undergo testing. For example, we find that 35.3% of respondents who have had an immediate blood relative diagnosed with AD report that they "very likely" to get tested, as compared to 27.8% without a blood relative with AD. Similar patterns emerge for those who have served as a caretaker or decision-maker for person with AD (40.4% versus 27.9%) and for those who state that they are "very" or "somewhat" worried about getting AD (38.1% versus 23.5%). Those reporting "fair" or "poor" health status were also more likely than those with "excellent" to "good" health ratings to express interest in testing (34% versus 28.9%).

Unexpectedly, we find that our measure of perceived severity—knowing that AD is a fatal condition—had no statistically significant relationship to interest in testing.

Also, contrary to previous studies on rates of genetic testing for AD, we found only one statistically significant relationship between positive interest in early medical testing for AD and measures of perceived costs and benefits.[37] Those who expected to rely on a paid caregiver in the instance that they develop AD, as opposed to a spouse, child, friend or other, were more likely to be among those expressing strong interest in testing—a modest but significant difference (33.4% versus 28.6%). Other measures, such as marital status and treatment optimism, had no significant association with being "very likely" to get tested, although the direction of the association was as expected.

Older populations more often than younger populations report that they are "very likely" to get an early AD test (38.9% for 65-74 year olds versus 25.3% for 18-29 year olds); women are more interested than men (32.2% versus 27.7%); and those with the lowest levels of education are more interested than those with the highest (32.4% versus 25.9%). Across the five countries in our sample, Spain and Poland had the highest shares of respondents reporting that they are "very likely" to pursue testing (39.6% and 30.5%), and Germany the lowest (23.6%). Lastly, self-efficacy and coping styles affected rates of interest. Those with more active information-seeking styles were more likely to express interest in testing.

In the United States, whites were less likely than blacks and Hispanics to respond that they'd be "very likely" to get an early medical test for AD, and the differences were dramatic (25.3% compared to 45.1% and 34.6%, respectively). However, only the difference between whites and blacks was statistically significant in these bivariate analyses.

In our bivariate analyses of respondents who are "not at all likely" to get AD tests, our results (not shown) only vary slightly from what we would expect given the above results. Interestingly, we find that those who believed there currently was a treatment for AD or that one would become available in the next five years were less likely to respond that they were "not at all likely" to get tested (10.5% versus 14.10%). This suggests that while treatment optimism may not motivate people to express strong interest in testing, it does prevent people from ruling out testing all together.

Many of our measures of perceived threat are also significantly related to measures of perceived costs and benefits, as well as the other demographic and social characteristics included in our model. For example, women and caretakers are more likely to report being worried about getting AD, and having a close blood relative with AD is positively correlated with higher levels of treatment optimism. To disentangle the impact of our key independent variables on levels of interest in testing, we use multivariate logistic regression and check for potential interactions between these variables.

Regression Results

Logistic regression results confirm many of the findings in our descriptive analysis (Table 1.3). On average, after controlling for social and demographic factors, we find that 28.4% of survey respondents are "very likely" to get an early medical test for AD if and when it is available in the future.

Table 1.3 Logistic Regression Results Evaluating Variables Predictive of Being "Very Likely" to Get Early Medical Test for Alzheimer's Disease

Variables	Model 1	Model 2
Measures of Perceived Threat		
Respondent is or was decision-maker or caretaker for AD patient	1.306*	1.330*
Worried will get Alzheimer's	1.760***	1.22
"Excellent/Good/Very Good" Health Status	0.972	0.763
Worried*Excellent/Good/Very Good Health Status	—	1.610*
Have/had immediate blood relative with AD	1.312*	0.971
Think AD is fatal	1.112	0.96
Immediate blood relative*Think AD is fatal	—	1.783*
Measures of Perceived Costs and Benefits		
Marital status of respondent	0.963	0.977
Expect paid caregiver to be primary caretaker if develop AD	1.277*	1.291*
Believe an effective AD treatment is available now or will be in 5 years	1.064	1.051
Demographic Controls		
Age of Respondent		
30-49	1.019	1.019
50-64	1.573**	1.582**
65-74	1.702**	1.733**
75-85+	1.465	1.489+
Female	1.18	1.178
Educational Attainment		
Middle education	1.112	1.105
High education	0.846	0.844
Country of Residence		
Germany	0.838	0.841
Poland	1.568**	1.559*
Spain	1.463*	1.463*
United States	1.208	1.206
Measure of Psychological Status		
Would see doctor if showing symptoms of AD	1.44	1.416

Note: Table displays adjusted odds ratio; reference groups, in order of the categories displayed in the table are: Ages 18-29; Low Education; France; * $p<0.05$,** $p<0.01$, *** $p<0.001$.

In all of our models, measures of perceived risk are the strongest predictors of interest in testing. For example, in Model 1, holding all else constant, the odds of being "very likely" to pursue testing are 76% higher for those worried about developing AD than for those not worried. As in our bivariate analyses, knowing the disease is fatal had no statistically significant effect on interest in testing (OR=1.112, P>0.05). Expecting to rely on a paid caregiver as opposed to spouse, family member, or friend remained the only measure of perceived costs and benefits that was positively associated with testing (OR=1.277, p<0.05). Older age (aged 50 and above) and country of residence also remain positive, statistically significant predictors of being interested in early medical testing.

When we test for interactions between variables (Model 2), we find two interesting changes. First, knowledge of the disease's fatality does seem to matter for those at highest risk of the disease: among those who know the disease is fatal, the predicted probability of expressing interest in testing is far higher for those who have a blood relative with AD as opposed to those without (38.7% versus 26.8%).

Second, whereas poor health status is predictive of interest in testing in our bivariate analyses, it is the worried well who express higher levels of interest in our final model. Among those who are worried about AD, those in better health are more likely than those in worse health to desire testing (predicted probabilities of 36.3% versus 31.9%).

In Table 1.4, we evaluate country-level results and find largely similar patterns across measures of perceived threat and decision balance. For example, across all countries, respondents who were worried about getting AD were much more likely to express interest in testing, after accounting for other social and demographic variables. Similarly, caretakers, especially those in Poland, report higher interest in testing as opposed to those who have not served as a caretaker or decision-maker for an AD patient (OR=2.717, p<0.001). Single respondents in the United States were more likely than married respondents to report a desire for the test. In all other countries, marital status was not a significant predictor. However, since we did not include clinical or policy-level variables that are likely to affect country-level results, these models have limited explanatory value.

We also explore factors predicting being “not at all likely” to pursue early medical testing, and find one notable variation from the above results (analyses not shown). While having a positive information-seeking style—as measured by answering that they would visit a physician if exhibiting symptoms of Alzheimer’s—had no effect on positive interest in testing, it is inversely related to expressing no interest in testing (OR=0.534, $p<0.01$). Not surprisingly, this suggests that those who would avoid physician visits are also more likely to avoid early medical testing.

Table 1.4 Logistic Regression Results Evaluating Variables Predictive of Being "Very Likely" to Get Early Medical Test for AD

Variable	Entire Sample	France	Germany	Poland	Spain	United States
Measures of Perceived Threat						
Have/had immediate blood relative with AD	1.312*	1.194	1.042	1.739	1.386	1.411
	(0.165)	(0.336)	(0.340)	(0.624)	(0.389)	(0.325)
Respondent is or was decision-maker or caretaker for AD patient	1.306*	1.065	0.973	2.717**	1.170	1.066
	(0.175)	(0.362)	(0.363)	(0.977)	(0.307)	(0.288)
Worried will get Alzheimer's	1.760***	2.982***	1.647+	1.055	1.594	1.979**
	(0.203)	(0.755)	(0.469)	(0.320)	(0.476)	(0.432)
Think AD is fatal	1.112	1.332	1.271	0.758	1.329	0.907
	(0.117)	(0.302)	(0.346)	(0.204)	(0.316)	(0.196)
"Excellent/Good/Very Good" Health Status	0.972	0.814	0.969	1.028	1.016	0.923
	(0.125)	(0.261)	(0.352)	(0.308)	(0.306)	(0.231)
Measures of Perceived Costs and Benefits						
Marital status of respondent	0.963	1.445	1.383	0.601	1.393	0.641*
	(0.113)	(0.397)	(0.428)	(0.191)	(0.382)	(0.142)
Expect paid caregiver to be primary caretaker if develop AD	1.277*	0.936	1.991*	1.893+	1.359	1.001
	(0.146)	(0.228)	(0.561)	(0.650)	(0.327)	(0.224)
Believe an effective AD treatment is available now or will be in 5 years	1.064	1.090	0.920	1.196	1.057	1.173
	(0.118)	(0.276)	(0.251)	(0.339)	(0.242)	(0.277)
Age of Respondent						
30-49	1.019	1.558	2.491+	1.476	0.544+	0.677
	(0.165)	(0.578)	(1.370)	(0.595)	(0.189)	(0.221)
50-64	1.573**	1.291	3.494*	3.649**	0.827	1.291
	(0.270)	(0.563)	(2.077)	(1.529)	(0.329)	(0.417)
65-74	1.702**	2.670*	2.762	2.865*	0.966	1.322
	(0.345)	(1.241)	(1.887)	(1.411)	(0.443)	(0.510)
75-85+	1.465	3.191*	2.704	1.452	0.584	1.237
	(0.352)	(1.757)	(1.741)	(0.969)	(0.395)	(0.518)
Gender						
Female	1.180	1.035	0.944	1.342	1.090	1.247
	(0.123)	(0.241)	(0.261)	(0.358)	(0.245)	(0.268)
Educational Attainment						
Middle education	1.112	0.882	0.800	1.491	1.476	0.902
	(0.144)	(0.270)	(0.264)	(0.460)	(0.412)	(0.238)
High education	0.846	0.853	0.576+	0.813	0.976	0.943
	(0.109)	(0.261)	(0.182)	(0.267)	(0.279)	(0.236)

Table 1.4 (Continued)						
Country of Residence						
Germany	0.838					
	(0.147)					
Poland	1.568**					
	(0.271)					
Spain	1.463*					
	(0.235)					
United States	1.208					
	(0.192)					
Measure of Psychological Status						
Would see doctor if	1.440	0.903	1.055	1.695	3.711+	1.398
showing symptoms of AD	(0.341)	(0.407)	(0.569)	(0.844)	(2.857)	(0.631)
Observations	2357	494	423	419	436	585
Wald test	110.47	33.44	23.48	50.6	21.13	34.21
P-value	0	0.007	0.102	0	0.174	0.005

Notes: +p<0.10,* p<0.05,** p<0.01, *** p<0.001. Table displays adjusted odds ratios and standard errors in parentheses. Country-level sample sizes are reduced due to missing data. Reference groups, in order of the categories displayed in the table are: Ages 18-29; Low Education; France

The Impact of Race and Ethnicity in the United States

In the United States, we ran a separate analysis to consider the additional effects of race and ethnicity (Table 1.5). Blacks and Hispanics were more likely than whites to report an interest in testing, adjusting for levels of perceived threat, costs and benefits, and demographic differences. The predicted probability of pursuing an early medical test for AD for whites was 23.1%, but it was nearly double that for blacks (41.3%) and 35.3% for Hispanics. There were no significant differences between minority groups on rates of interest.

Table 1.5 Logistic Regression Results Evaluating Variables Predictive of Being "Very Likely" to Get in Early Medical Test for AD in the United States

Variable	US	Predicted Probability
Race		
White	1.000 (--)	23.1%
African American	2.391** (0.689)	41.8%
Hispanic	1.820* (0.499)	35.4%
Other (Asian, Native American, or Other)	2.259 (1.297)	40.5%
Observations	585	

Notes: +p<0.10,* p<0.05,** p<0.01, *** p<0.001. Table displays adjusted odds ratios and standard errors in parentheses. White is the reference category. Sample size is reduced due to missing data. Model controls for measures of perceived threat, perceived costs and benefits, demographic controls, and measure of psychological status.

Discussion

This is the first large, international, randomized survey of public interest in early medical testing for Alzheimer's disease. We find that, on average, after controlling for a number of social and demographic factors, three out of ten respondents would be "very likely" to get an early medical test for Alzheimer's disease if such a test were available in the future. Adding in respondents who are "somewhat likely," the figure rises to two out of three. These robust rates of interest complement Neumann et al.'s 2011 study on predictive testing in the United States, which also finds high levels of interest in and willingness to pay for Alzheimer's disease testing (between 70% and 74.8% of respondents reported that they would take an Alzheimer's disease).[76]

In line with earlier work, our results suggest that demand will be highest among those who perceive themselves to be at risk for the disease—including those with a family history of AD, those worried about getting the disease, and those who serve as caregivers or decision-makers for AD patients.[33,37,46,47] While our own study does not directly ask about motivation for test-taking, studies of other late-onset disorders find that those with high levels of perceived risk view testing as a way of coping with their worry, gaining control, and getting clarity about their future.[32,71]

We hypothesized that, per previous literature on the effect of perceived severity, knowledge that the AD is fatal would reduce interest in testing. In our study, however, such knowledge had no significant effect for respondents without a blood relative with Alzheimer's disease. Among respondents who did have such a blood relative, knowledge of the disease's fatality actually increased interest in testing. Moreover, in three of our countries (France, Poland, and Spain), having a family member with AD led to increased awareness of the disease's fatality.[6] As prevalance grows, experience of afflicted family members widens, and awareness of AD increases, we may see interest in testing rise correspondingly.

However, large numbers of respondents in our do not believe that Alzheimer's diease is fatal; but having a family member with AD increased this awareness in three of our five countries—France, Poland, and Spain. If educational campaigns improved levels of awareness in these countries, we may see even higher rates of interet in testing among family members of AD patients.

Only one of our measures of perceived costs and benefits affected rates of interest in testing—whether a respondent anticipated needing to rely on a paid caregiver. In our sample, these respondents were more likely to be female and single. These results highlight how aging needs and expectations can vary across gender and individual family circumstances. Although future work is needed in this area, these results affirm earlier work showing that people seek out testing in order to prepare for the future, especially since long-term care arrangements can be costly and logistically complicated to arrange.

Country-level variation was significant. Interest was highest in Poland, where support systems for AD patients are more fragmented and thus planning for care falls to individuals, and in Spain, where informal care giving is more common and AD-related media has been more prevalent.[77] For example, at the time of our survey, two popular films were released in Spain addressing Alzheimer's disease and its impact on caregivers.[i] It is unclear whether our results for Spain reflect this increase in attention or whether the popularity of the films reflects the same levels of concern we find in our survey. Compounding these factors, we expect interest and utilization of early medical testing for AD across countries to be affected by variations in clinical practice, care resources, cultural norms, disease epidemiology, levels of disease awareness, and public policy responses.[59,63]

Demographically, we find that, on average, middle- to older-age populations—who are both closer to the age of onset and more likely to serve as caretakers—are also more likely to express interest in testing.[52] Looking forward, as global populations age and as more people gain experience with the disease, demand for early medical AD testing could rise.

In the United States, race and ethnicity were strong predictors of interest in testing. Contrary to most of the literature on AD testing, we found that on average, blacks and Hispanics were more likely than whites to desire testing for AD, adjusting for differences in knowledge of disease, perceptions of risk, and other demographic differences. However, experience with other tests suggests that actual take-up may be lower among black and Hispanic populations than expressed interest would indicate. Looking ahead, if a test becomes available, clinicians, lawmakers, and advocates should pay close attention to the individual factors, such as perceptions about Alzheimer's disease, and structural issues that could depress rates of take-up for early medical testing in these communities.[78,79] Potential structural barriers include racial inequalities in rates of health insurance coverage, access to primary care, and preventive services; perceptions regarding historical patterns of

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[i] The two films were 'Bicicleta, cullera, poma', a 2010 film about a well-known Spanish politician suffering from Alzheimer's disease, and 'Cuidadores', los héroes anónimos', a 2011 film about caregivers for Alzheimer's patients.

mistreatment of minorities in medical research; and documented tendencies among physicians serving minority populations to less-frequently order or refer patients for genetic testing for conditions such as breast cancer, colorectal cancer, Huntington's disease, and others in comparison to those serving fewer minority patients.[48,80,81]

The same question applies more broadly: will levels of interest in testing, as expressed in our survey, match rates of take-up once and if a test becomes available? In earlier analyses of genetic testing, test uptake has been much lower than expressed interest, particularly for fatal conditions for which nothing can be done, such as Huntington's disease.[32,46] However, because AD is more prevalent than Huntington's disease, has a later age of onset, has greater advocacy support, and garners more media attention, we believe uptake for AD tests will be relatively high. In fact, rates of interest among survey respondents who are "very likely" to pursue testing in our survey are comparable to participation rates in a clinical trial of AD genetic testing in the United States.[52]

Transforming Medical, Political, and Legal Landscapes

If an early diagnostic test is indeed developed and our predictions are correct about demand, millions of people in each of the studied countries will become members of a new population group: asymptomatic adults living with a diagnosis of Alzheimer's disease. Consequently, policymakers and clinicians should expect significant changes in the utilization of medical and economic resources and address potential legal obstacles. In the medical realm, diagnosed but asymptomatic individuals are likely to press for follow-up testing, ongoing medical monitoring, and medical management of potential complications associated with Alzheimer's disease.[82] Given the uncertainty around the disease's pathogenesis and treatment mechanisms, the clinical value of such tests is unclear. Moreover, increased demand for early intervention and support services could strain already-overburdened health systems, making the tradeoffs involved in allocating medical resources even more difficult. These costs would be in addition to the already daunting estimates projected for long-term care needs over the next forty years.[19,77]

However, Neumann et al. found that even in circumstances where no treatment is available, respondents valued testing because of it's ability to provide useful information regarding disease status or predisposition, either in the form of reassurance to those who are negative or certainty for those who are positive. Moreover, respondents reported that test results could inform health and non-health behavior changes, such as seeking out second opinions, signing advanced directives, and spending more time with family and friends.[76] Policymakers should consider the non-clinical value of these tests in their assessments of coverage in the years ahead.

In the legal realm, early medical testing raises challenging questions related to testing protocols, disclosure practices, confidentiality protections, discrimination, and the availability of follow-up care.[83] For example, policymakers will have to gauge the financial and psychological costs of early diagnosis against the research benefits of endorsing a broad-based screening program for an incurable, fatal condition such as AD. While such an effort could advance research towards a cure, it could endanger those who might be psychologically vulnerable to test results.

If a test is developed, fear of employment and insurance discrimination could remain a barrier to participation. For instance, when hiring, employers may want to discriminate against diagnosed but asymptomatic individuals for fear that over time they would more frequently be absent from work, less productive on the job, and require more extensive health services.[84] This may be less of an issue since the age of onset is typically after age 65 for most AD patients, but it remains an issue for those with early onset AD, which can affect people in their 30s, 40s, and 50s.

Similarly, insurers—including health, life, disability, or long-term care insurers—may want access to private health information to protect against adverse selection. These desires are not unreasonable. In the United States, one study found that individuals who underwent genetic testing for Alzheimer's disease were five times more likely than those who were untested to change their long-term care insurance coverage in the year following testing.[54] However, if undergoing a test for Alzheimer's could endanger one's ability to buy insurance, such privacy issues may depress testing rates.

The US and Europe have enacted a range of laws and treaties with measures protecting individuals against employment and insurance discrimination on the basis of genetic information and protecting private medical information, such as the Health Insurance Portability and Accountability in the US and the 1999 Oviedo Convention of Human Rights and Biomedicine in Europe. However, research suggests that the laws protecting against genetic discrimination in Europe have had mixed results and have not always kept pace with scientific advancements.[85] Furthermore, if an early medical test were developed for Alzheimer's disease that did not involve genetic information, such as blood tests evaluating protein levels, it is unclear to what extent these anti-discrimination protections would apply to diagnosed individuals. Before introducing early medical testing for AD into clinical practice, government leaders will need to examine whether existing protections are sufficient for diagnosed individuals and how these protections affect the viability of voluntary private insurance markets.

Conclusion

In summary, our survey indicates that across four European countries and the United States, interest in early medical testing for Alzheimer's disease is high. We expect those with high levels of perceived risk—those who are worried about getting AD as well as those with more experience with the disease, including caregivers and blood relatives of AD patients—will be among those most likely to pursue testing once it becomes available. While early detection could hasten the development of treatment protocols, high demand for testing and the creation of a large group of asymptomatic adults with an Alzheimer’s diagnosis could have significant political, economic, and legal implications, and could transform the way AD is addressed by countries in the future.

Paper II: Race, Ethnicity, and Geography Matter: Disparities in Medicaid Enrollment Among Low-Income Parents

Introduction

The Supreme Court's ruling on the Patient Protection and Affordable Care Act created an option for states to forego the law's intended expansion of Medicaid eligibility to adults under 133% of poverty ($30,657 for a family of 4). Prior to this ruling, many experts praised the expansion because of its anticipated effects on reducing racial and ethnic disparities in access to health insurance coverage.[86] To date, more than a dozen states have indicated they might not undertake the Medicaid expansion.[87,88] Although uneven adoption of the expansion would stymie efforts to reduce disparities in coverage, other provisions in the law—including those that standardize Medicaid enrollment procedures—could still significantly improve access to care among minority populations.[89]

Medicaid enrollment, at the national level, varies significantly across different racial and ethnic groups.[90,91] Prior research also shows that Medicaid enrollment varies across states—take-up is highest in liberal states, where Medicaid benefits are most generous, and lowest in conservative states, where benefits are less generous.[90] What has not previously been studied is whether racial and ethnic disparities in Medicaid enrollment vary across states along ideological lines, and how state Medicaid policies mediate these enrollment patterns.

This paper examines the interacting effects of ideology, Medicaid policy, and race/ethnicity on take-up rates at the state level. Overall, we find that between 2003 and 2010, minorities in conservative states, particularly Hispanics, were significantly less likely than all other groups to enroll in Medicaid when eligible. However, adjusting for differences in state Medicaid policies significantly reduced these disparities in take-up across states.

Understanding the dynamics of these racial and ethnic disparities and how they vary at the state level could inform policymakers—even those in states that oppose the Medicaid expansion—seeking to reduce racial and ethnic disparities in access to health insurance coverage. [92,93]

Literature Review

State-level determinants of Medicaid enrollment: the role of state ideology

Building on research on individual-level determinants of program take-up, Sommers and colleagues found that where someone lived was among the strongest predictors of Medicaid participation—second only to category of eligibility.[90,94,95] Adjusting for individual demographics, take-up rates among all eligible adults ranged from 43% in Arkansas to 82.8 percent in Massachusetts. Moreover, these state-level differences correlated strongly with state ideology scores: adjusted take-up rates were 69.1% in liberal states, 61.1% in moderate states, and 54.0% in conservative states ($p<0.001$).[90] The authors argued that differences in state Medicaid policies explain most of this state-level variation. For example, controlling for individual demographics, liberal states were more likely than conservative states to have generous Medicaid benefit packages—offering more services and requiring lower levels of cost-sharing—which, in turn, were associated with higher rates of take-up among eligible adults. [90]

Extensive research has established the correlation between state ideology scores and the left-right distribution of state policies: Even controlling for state wealth, urbanism, and education, ideologically liberal states (as measured by public opinion polls) enacted laws that were, on average, far more liberal than policies in conservative states. [96,97] In a separate analysis, we found similar results for the Medicaid policies used in this study (see Appendix).

Medicaid Enrollment and Race/Ethnicity at the National Level

Although overall rates of insurance coverage have been consistently lower for minority populations, Medicaid enrollment historically has been high among eligible African Americans, and lower among whites, Hispanics, and individuals of other racial and ethnic backgrounds.[86,98] Between 2005 and 2010, among adults, 66.4% of eligible blacks enrolled for Medicaid coverage compared to just 60.8% of eligible whites.[90] Moreover, a study of Medicaid expansions between the years of 1996 and 2001 found that eligible black mothers were more likely than whites or Hispanics to gain coverage.[95] However, no previous studies have examined racial and ethnic inequalities in Medicaid take-up at the state level.

Study Data and Analysis

Data

Demographic and health insurance eligibility data for years 2003 to 2010 came from the Annual Social and Economic (ASEC) supplement of the Census Bureau's Current Population Survey (CPS), which was downloaded from the Integrated Public Use Microdata Series (IPUMS-CPS).[99]

We estimated Medicaid eligibility using self-reported family income data from the survey matched against income eligibility thresholds published by the Kaiser Family Foundation.[100–106] Eligibility thresholds also varied with state ideology, ranging from 17% of the federal poverty level in Arkansas to 207% in the District of Columbia in 2010.

Our sample of 24,230 adults included U.S. citizens, aged 19-64, who had at least one child under age 19 living in their home. We excluded parents who reported having private health insurance or Medicare coverage. We focus on parents because they are the largest group of low-income adults currently eligible for Medicaid coverage.

Our models' primary outcome was take-up: whether a given respondent who was eligible for Medicaid in the prior year reported having Medicaid coverage. The key predictor variables were race/ethnicity and state ideology. Respondents were divided into four racial/ethnic categories: white non-Hispanic, black non-Hispanic, Hispanic, and other racial groups (including Asian and Pacific Islanders and other non-Hispanic mixed-race individuals). Drawing on methods introduced by Erikson, Wright, and McIver, we generated state ideology scores using public opinion data from the Gallup Daily Tracking poll from 2008 through 2010.[96] For each year, we subtracted the percent of a state's population that identified as liberal from the percent that identified as conservative.[107] We then ranked states (50 states plus the District of Columbia), and divided them into three categories of equal size—conservative, moderate, and liberal. For a full listing of states in each category, see Table 2.1.

Table 2.1. Ideology Scores for US States

Conservative	Moderate	Liberal
Alabama	Alaska	California
Arkansas	Arizona	Colorado
Georgia	Delaware	Connecticut
Idaho	Florida	D.C.
Kentucky	Indiana	Hawaii
Louisiana	Iowa	Illinois
Mississippi	Kansas	Maine
Nebraska	Michigan	Maryland
North Dakota	Missouri	Massachusetts
Oklahoma	Montana	Minnesota
South Carolina	Nevada	New Hampshire
South Dakota	New Mexico	New Jersey
Tennessee	North Carolina	New York
Texas	Ohio	Oregon
Utah	Pennsylvania	Rhode Island
West Virginia	Virginia	Vermont
Wyoming	Wisconsin	Washington

Note: Ideology scores are based off three-year averages of Gallup polling data available from 2008-2010.

We adjusted for additional demographic and state-level variables that may affect Medicaid enrollment, including disability status, age, gender, employment status, educational status, family income, self-reported health, marital status, metropolitan status, family size, and having a noncitizen household member. [90,94,95,108] We also included measures of state economic well being, such as state unemployment rates, median household income, and annual Federal Medical Assistance Percentages (FMAP), which represent cost of enrolling an additional person in the state Medicaid program and is tied to the state poverty rate. To account for other time-varying measures, such as the effects of the economic recession beginning in 2008, we included year fixed effects.

We also included both individual and composite measures of state Medicaid policies that have been described elsewhere.[90] These policy measures capture both levels of administrative hassle—including the availability of combined family applications, face-to-face interview requirements, and the length and reading level of applications—and policies related to the generosity of benefit packages—such as cost-sharing requirements, scope of covered services, and provider reimbursement rates.

Analysis

We first calculated survey-weighted means for rates of take-up at the national level, and then ran logistic regression models to evaluate the interaction of race/ethnicity and state ideology in predicting disparities in rates of Medicaid take-up. We ran additional analyses to evaluate the amount of variation in take-up explained by state Medicaid policies, and tested whether the composition of the Hispanic population influenced disparities in take-up. For this analysis, we looked specifically at differences between Hispanics of Mexican descent and all other non-Mexican Hispanics. For all of our models, we also generated predicted probabilities of take-up across racial/ethnic groups in conservative, moderate, and liberal states, holding all other variables in the model at their observed values. We clustered the standard errors at the state-level, and include person-level weights. We used Stata 11 to account for complex survey design.

Limitations

Our study has several limitations. First, our methods of estimating eligibility relied on total family income figures provided by the Current Population Survey, but state Medicaid agencies use monthly income data to determine eligibility, which may bias our sample. Also, the Kaiser Family Foundation data on eligibility thresholds may not include some income disregards implemented by particular states. Given that the Census survey does not collect data on assets, we were unable to adjust directly for these asset limits. Our analysis also excluded parents enrolled under Section 1115 waivers that offered fewer benefits than traditional Medicaid.

Another limitation is that the Current Population Survey does not include information on immigration status, meaning that we are unable to identify legal permanent residents who are potentially eligible for coverage; instead, we limited our analysis to U.S. citizens. This is particularly relevant for estimates of participation among Hispanics, since this ethnic group is likely to have a higher number of legal permanent residents than other racial/ethnic groups. If anything, we suspect that excluding these legal residents may cause our study to underestimate disparities in take-up based on ethnicity.

A related concern is that our analysis relies on self-reported citizenship status, raising the possibility that some immigrant CPS respondents may misstate their status and thus bias our results. However, analyses comparing the CPS and the 2000 Census find no evidence of this type of misrepresentation, concluding that the citizenship measure in the CPS is accurate and reliable.[109]

Prior research has documented that the CPS underestimates Medicaid enrollment due to enrollee confusion about enrollment status and program stigma, although recent studies have suggested that the scope of such misreporting is limited.[110,111] This underreporting may lead us to underestimate overall take-up rates, though to our knowledge, no studies exist exploring whether underreporting varies by race/ethnicity.

Lastly, we recognize that family incomes among the poor and near-poor tend to fluctuate over time, such that families "churn" on and off the Medicaid program, often within a single year.[112] If income volatility varies by race/ethnicity, then the administrative hassle of enrolling and re-enrolling could lead to higher disparities than documented here since our study examines only year-by-year enrollment.

Results

The unadjusted average Medicaid take-up rate for all eligible parents between the years 2003 and 2010 was 54%, similar to estimates in previous studies.[90] We also found that take-up varied dramatically by state and correlated significantly with state ideology, with take-up rates around 20%

for eligible parents in conservative states, such as Arkansas, Louisiana, and Texas, and around 75% in liberal states such as Maine and Massachusetts. Nationally, eligible African American respondents had the highest levels of take-up of any racial group (57%)(Table 2. 2). Descriptive statistics for the entire sample can be found in the Appendix.

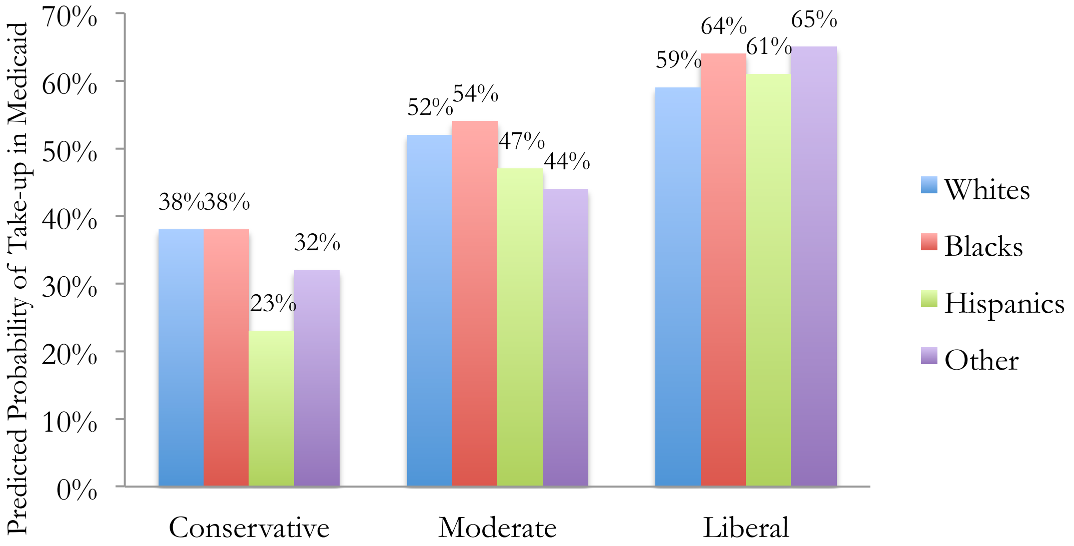
Table 2.2. Mean Take-up Rates for Parents Eligible for Medicaid Coverage By Race/Ethnic Group, 2003-2010

Race/Ethnicity	Mean Take-up Rate	Standard Error
All groups	0.54	0.02
Whites	0.54	0.02
Blacks	0.57	0.03
Hispanics	0.51	0.05
Other	0.51	0.03

Note: Data weighted using person-level weights provided by IPUMS CPS. N=24,230

However, these racial differences were not consistent across all states. Interacting race/ethnicity with state ideology, we found that in conservative and moderate states, Hispanics were less likely than whites or blacks to enroll when eligible (Figure 2.1). For example, in conservative states, 23% of eligible Hispanics enrolled in Medicaid compared to 38% of both whites and blacks, adjusting for individual and state characteristics ($p<0.01$). In moderate states, we found similar differences between whites and blacks versus Hispanics ($p<0.05$). Parents of other racial backgrounds were also significantly less likely than whites or blacks to enroll in Medicaid when eligible ($p<0.001$). However, in liberal states, these trends reverse— eligible whites were less likely than blacks and parents of other backgrounds to enroll for coverage (59% versus 64% and 65%, respectively; p<0.01). Differences in take-up between whites and Hispanics in Liberal states were not statistically significant.

Figure 2.1 Interaction of Medicaid Take-Up and State Ideology by Racial Group, Controlling for Individual- and State-Level Factors; National Sample of Parents Eligible for Coverage, 2003-2010, n=24,230.



Looking across the ideological spectrum, the differences were even more dramatic. Hispanics living in liberal states were two and a half times more likely than Hispanics in conservative states to enroll in Medicaid when eligible (61% versus 23%, $p < 0.001$). These racial and ethnic differences persisted over the entire study period.

The Role of State Policies

The design and implementation of state Medicaid policies affected racial and ethnic disparities in enrollment (Table 2.3). Controlling for differences in state Medicaid policies increased the predicted probability of take-up by 13 percentage points for blacks and 17 percentage points for

Hispanics who lived in conservative states (see graph in the Appendix). In fact, when we evaluated the total magnitude of the ideology effect on Hispanics (by comparing Hispanics and whites in conservative states), we found that roughly 46% of the disparity in participation can be explained by state policies, particularly policies relating to the generosity of Medicaid benefits, while the other 54% appears to be a 'direct' effect of ideology, persisting after adjustment for state policies.

Yet, even after adjusting for demographic and policy differences, predicted rates of Medicaid enrollment for Hispanics in conservative states (40%) remained significantly lower than for whites (49%) and blacks (52%) in those same states ($p<0.01$).

Table 2.3 Logistic Regression Models Evaluating Whether the Interaction Between Race and State Ideology Affects Medicaid Enrollment

Variable	Interaction Model	Model with Interaction and State Medicaid Policies
Race, Ethnicity, Ideology, & Interactions		
White	--	--
Black	1.010 (0.145)	1.138 (0.207)
Hispanic	0.464** (0.119)	0.681** (0.088)
Other	0.754 (0.191)	0.816 (0.130)
Conservative	1 (.)	1 (.)
Moderate	1.853* (0.500)	1.532* (0.284)
Liberal	2.492** (0.753)	1.086 (0.292)
Whites in Conservative states	--	--
Whites in Moderate States	--	--
Whites in Liberal States	--	--
Blacks in Conservative States	--	--
Blacks in Moderate States	1.052 (0.167)	1.007 (0.188)
Blacks in Liberal States	1.245 (0.197)	1.097 (0.205)
Hispanics in Conservative States	--	--
Hispanics in Moderate States	1.696+ (0.469)	1.226 (0.206)
Hispanics in Liberal States	2.332** (0.729)	1.494* (0.299)
Other Racial Groups in Conservative States	--	--
Other Racial Groups in Moderate States	0.947 (0.255)	0.794 (0.150)
Other Racial Groups in Liberal States	1.747* (0.484)	1.538* (0.299)
Factors Related to Benefit of Coverage		
Scope of covered Medicaid Services		1.013*** (0.003)
Dental Coverage		1.431*** (0.154)
Percentage of state enrollees in managed care		1.000 (0.000)
Annual Cost Sharing		1.001 (0.001)
Provider Reimbursement (percent of national mean)		1.273 (0.349)
Factors Related to Hassle of Enrollment		
Face-to-face interview when applying		0.955 (0.147)
Face-to-face interview when renewing		0.870 (0.122)
Shared application for family members		1.068 (0.101)
Frequency of eligibility renewal (months)		1.019 (0.016)
Self-declaration of residency		0.998 (0.152)
Application length (pages)		1.004 (0.004)
Application literacy level		1.004 (0.054)
Application available in Spanish		0.559** (0.108)
Application available in other languages		0.979 (0.127)
Application can be submitted by telephone		1.094 (0.192)
Application can be submitted online (by consumer)		0.659** (0.091)
Application can be submitted online (by provider)		1.058 (0.135)

Table 2.3 (Continued)	
Separate application for disabled adults	0.935 (0.103)
Application combined with other programs	0.869 (0.107)
Asset test used for eligibility determination	0.741* (0.103)

Notes: Authors' calculations of Current Population Survey Data from 2003-2010. Sample of 24,320 United States citizens with no alternative form of coverage. Estimates are odds ratios; Standard errors clustered at state level and located in parentheses; + $p<0.10$, * $p<0.05$, ** $p<0.01$,*** $p<0.001$. All models control for education, employment, family income, health status, age, gender, urban status, marital status, family size, noncitizen household member, annual state unemployment rates, FMAP rates, median household income, and year.

Compositional Effects

Subsequent analyses showed that the composition of Hispanic populations across liberal, moderate, and conservative states contributed to disparities in rates of take-up. Previous research has found that insurance rates vary across Hispanic subgroups, with adults of Mexican descent consistently reporting the lowest rates of insurance coverage of any kind.[113] Consistent with this research, we found that, on average, Mexican citizens eligible for Medicaid had consistently lower take-up rates than non-Mexican Hispanics across conservative, moderate, and liberal states, adjusted for demographics and state policies (see graph in the Appendix). The differences were starkest in conservative states, where Mexicans made up more than 80% of the eligible Hispanic population. Controlling for differences in state policies, take-up among eligible Mexicans was 38% whereas take-up among non-Mexican Hispanics was 50%, similar to rates for whites and blacks ($p<0.001$).

Discussion

Our results indicate that national analyses of Medicaid enrollment miss important state-level variation in rates of take-up across racial and ethnic subgroups. Exploring the interacting effects of state ideology and race/ethnicity among U.S. citizens, we found that Medicaid enrollment varied across racial and ethnic subgroups in liberal, moderate, and conservative states. These disparities were most dramatic in conservative states: take-up rates for Hispanics were 23%, whereas take-up was 38% for both whites and blacks in those same states, controlling for state and individual demographics.

Moreover, within racial/ethnic groups, enrollment varied across liberal, moderate, and conservative states. While whites were significantly less likely to enroll in Medicaid in conservative states than in liberal states (38% versus 59% take-up), the differences were much larger for blacks (38% versus 64%). Enrollment disparities were again starkest among Hispanic populations: a Hispanic parent in a liberal state was fully two and a half times as likely to be enrolled in Medicaid than a Hispanic in a conservative state, even after controlling for demographic and socioeconomic variables (23% versus 61%).

We estimated that about half of the effect of ideology on racial/ethnic disparities in Medicaid enrollment was explained by differences in state Medicaid policies, particularly those related to the generosity of Medicaid benefits.

Among Hispanics, part of the observed disparity appeared to be due to compositional effects. Across all states, Mexican Americans were less likely than whites, blacks, and non-Mexican Hispanics to enroll for Medicaid when eligible. While Mexicans represented a higher proportion of the Hispanic population in conservative states than in other states, this concentration only explained a part of the Hispanic under-enrollment in those states. Mexican parents in liberal states enrolled at much higher rates than in conservative states, even controlling for policies—in line with other ethnic and racial groups. Additional research is needed to better understand why Mexican-Americans who are U.S. citizens enroll in Medicaid at lower rates than other racial and ethnic groups.

After controlling for state policies and compositional effects, state ideology continued to exert a significant effect on racial/ethnic disparities in Medicaid enrollment. This could be due to any of several hard-to-quantify factors: states' methods of program outreach, office culture, real or perceived racial/ethnic bias, or dynamics in the broader policy environment. Recent state-level analyses demonstrate that these factors can powerfully influence—both positively and negatively—rates of take-up, especially among minority groups. In California, for example, proximity to bilingual application assistance increased monthly Medicaid enrollment by seven to nine percent among Hispanics and by about 30% among Asian children, and efforts to revamp eligibility determinations in Louisiana and South Carolina using data from other public programs increased rates of enrollment and redetermination among eligible children.[114–116] Meanwhile, another study found that heightened Federal immigration enforcement, measured by the number of deportations between the years 1992 and 2003, reduced Medicaid participation among eligible children of non-citizens.

Further research on the experiences of eligible families who do not enroll in Medicaid may be helpful in elucidating the mechanisms for these ongoing disparities.

Policy Implications: Implementation of the Affordable Care Act

The Affordable Care Act streamlines Medicaid enrollment and moves state Medicaid programs towards a more uniform package of benefits, even for states that do not participate in the eligibility expansion. This analysis suggests that such changes, by reducing variation in state policies, could ameliorate racial/ethnic disparities in Medicaid enrollment.

However, our results also suggest that policy changes alone will not eliminate disparities in rates of enrollment. Even if states have identical Medicaid policies, our research suggests racial and ethnic inequalities may persist in politically conservative states. Some states may implement the new laws only to the letter, while others could go beyond pro forma compliance and, as a group of Medicaid directors suggested in a recent report about Obamacare implementation, embrace a broader culture shift among Medicaid administrators away from welfare-style "gatekeeping" and towards inclusivity.[117] Significant federal oversight may be necessary to encourage such a shift in states that are ideologically resistant to robust implementation. And even with such oversight, still stronger reforms, such as automatic enrollment of eligible adults and aggressive, culturally-specific outreach, may be necessary to sharply reduce disparities in Medicaid take-up among racial and ethnic minorities.[11]

Paper III: Does Market Concentration Affect Administrative Costs?

Introduction

Over the past two decades, the markets for health insurance and hospitals have become increasingly consolidated. Empirical research indicates that this consolidation has resulted in higher health care costs, particularly higher insurance premiums and hospital prices, and, in some cases, lower quality of care.[119,120] Less research has been done, however, on whether increased consolidation has brought about greater levels of efficiency through improved economies of scale, less duplication of services, and increased investment in quality and efficiency.[121] If economies of scale exist, we would expect to see some reduction in administrative costs across the health care system as consolidation rises. In 2009, health administrative expenses were estimated to be about $361 billion, or 14 percent of total health care expenditures.[122] Recent work suggests that about half of these billing and insurance-related expenses are excessive.

In this analysis, we evaluate how levels of administrative staff and related labor costs in health insurance companies and provider organizations vary across states with different levels of insurance market and hospital concentration between the years 2007 and 2010. Understanding the role of market consolidation as either a driver of, or a partial solution to, high administrative costs could help inform efforts to reduce unnecessary administrative expenses.

Literature Review

Insurance Market Competition

Over the past thirty years, there have been hundreds of mergers in the U.S. health insurance market, catalyzing research on both the beneficial and detrimental effects of increased health insurance consolidation.[119,123,124] Dafny, Duggan, and Ramanarayan showed that health insurance market concentration increased in the large-group market between 1998 and 2006.[119] The American Medical Association, which publishes annual reports on insurance market competition, has found similar levels of concentration across states, although they found a slight decrease in market concentration in recent years. [125]

In theory, market consolidation could generate value by reducing management inefficiencies and increasing economies of scale. In the health insurance market, these gains could come from consolidation of administrative services, firm locations, provider networks, and technological processing, and so forth. [126] For example, the National Health Lawyers Association reported that the merger between Aetna and U.S. Health Care in 1996 resulted in the closure of half of their claim processing centers and a reduction of 4,000 jobs in their health divisions, producing some cost savings. [127]

Nevertheless, studies on the aggregate effects of these mergers on efficiency have not shown promising findings. Engberg and others evaluated HMO mergers between 1985 and 1997 and found no relationship between increased consolidation and gains in production efficiency.[126] Similarly, Weech-Maldonado assessed the effect of HMO mergers between 1988 and 1994 on both insurance companies' administrative expense ratios and medical loss ratios and found no evidence of improved financial performance on either measure.[128] While a study on the California HMO market between 1986 and 1992 did find evidence of increased efficiency, this only applied to mergers between HMOs with less than 115,000 enrollees. As with other studies, these returns disappeared for mergers among larger firms.[129] Another study pegged the enrollee threshold even lower, at 50,000. [130]

At least two mechanisms may be driving the association between insurance market competition and administrative costs in the health care system. First, as insurance market concentration increases, insurance companies could use their increased market power to impose cost reductions on others, by, for example, negotiating lower payments to hospital or provider organizations.[131,132] This could, in turn, pressure providers to reduce internal costs through increased efficiency.[131,133] Dafny, Duggan, and Ramanarayan argue that this has indeed occurred. Their research indicates that the increase in market concentration associated with the Aetna-Prudential merger of 1999 resulted in significant declines in health-care-related employment and reductions in wage growth. Moreover, nurses, compared to other health professionals such as physicians, experienced smaller employment decreases and even slight wage increases after the merger—suggesting a substitution of nurses for physicians.[119] Other work has shown that increases in insurance market concentration are also associated with decreases in hospital prices.[134] For example, a descriptive analysis of U.S. hospital markets found that hospital prices in the most concentrated health plan markets were 12 percent lower than at hospitals in more competitive health plan markets.[135]

A second possibility is that consolidation reduces the number of insurance companies with which providers must interact, thus lowering their costs. Casalino et al. conducted a national survey of provider offices in 2006 and found that physicians spent an average of 43 minutes per day interacting with health plans, while nurses spent 3.8 hours per day per physician and clerical staff spent 7.2 hours per day per physician conducting such administrative transactions. The authors estimate that these interactions cost between $23 and $31 billion at the national level.[136] Other observational studies have yielded similar cost estimates.[137] One might expect that administrative costs would decrease as the number of insurance companies in a given market decreased—if, in fact, the consolidated entities streamlined their internal processes post-merger.

Hospital Market Consolidation

Hospital consolidation began in the late 1990s, tapered off in the early 2000s, and recently picked back up, in part due to policies passed under the Affordable Care Act.[138] The number of hospitals that are part of a health care system increased from 2,542 in 2000 to 3,007 in 2011, an 18 percent increase.[139] Moreover, the percent of primary care and specialist physicians employed by hospitals rose from about 18 percent and 6 percent, respectively, to over 30 percent and 15 percent in 2008.[140]

As in the case of insurance market consolidation, hospital consolidation could have positive effects for consumers: it could reduce costs by enhancing economies of scale, boosting purchasing power, consolidating services, and transferring managerial techniques and skills across organizations.[121] Evidence, however, shows mixed results. Dranove and Lindrooth examine hospital mergers between previously independent entities and found cost savings only in those hospitals that achieved meaningful integration through combined clinical and economic operations.[138,141,142] In other hospitals, however, such integration did not occur, and consolidation just created bigger and less efficient bureaucracies.[121] Thus, hospital market consolidation could result in increased administrative efficiency if it precipitated financial and clinical integration across hospital departments.

Study Data and Analysis

Table 3.1 summarizes our data sources and variables.

Table 3.1. Data Sources and Variables

Data Source and Type	Variables
Clerical Data and Demographic Data	
IPUMS-CPS	Number of clerical workers by Industry and Occupation (only health care providers), wages
Statistics of U.S. Businesses	Number of health insurance firms, employees, and payroll at state and metro area
Market Concentration Data	
American Medical Association Competition in Healthcare Reports, Interstudy	HMO/PPO market share, top two insurance carriers, HHI by state
American Hospital Association Annual Statistics	Hospital admissions, location, beds
Physician Distribution and Location Data	
American Medical Association Physician Characteristics Reports	Distribution and location of Physicians Across States
Demographic Data	
U.S. Census Bureau	Population, Percent Urban
Bureau of Labor Statistics	Median Household Income, Unemployment Rate
Centers for Disease Control	Death Rate (per 100,000)
Market Characteristics	
Kaiser Family Foundation, Interstudy	HMO Penetration Rates

Administrative Staffing Levels and Cost Data

To analyze changes in administrative staff between 2007 and 2010, we drew data from two sources. For insurance companies, we used the US Census Bureau's "Statistics of U.S. Businesses" to look at the number of firms, employees, and payroll for health and medical insurance carriers, coded under the 2007 North American Industry Classification System (NAICS) as 524114. These data were not broken down by occupation groups within firms, but did provide overall staffing levels for health insurers by state. We include the total number of employees within health insurance carriers in our administrative staffing calculations since none of these staff serve in a clinical capacity.[2]

Information on clerical staff for provider organizations came from the Integrated Public-Use Microdata Series-Current Population Survey (IPUMS-CPS) database.[99] We focused our analysis on respondents who worked in office and administrative support occupations (Standard Occupational Classification codes 5000 through 5930) within the in "Health Care and Social Assistance" industries (NAICS Sector 62). The survey also includes pre-tax wage and salary income data, which we used to generate administrative cost data. We weighted this data using person-level weights supplied by the Census Bureau, and then summed these totals at the state level to create a state-year panel dataset.[3] We adjusted income data to 2010 dollars, and we increased it to include the value of employee benefits, which accounted for 30 percent of total compensation packages in 2010.[143]

We analyzed the number of administrative staff across different health care industries, benchmarking these estimates by numbers of physicians to ease interpretation. We scaled the number of administrative staff in health insurance companies and hospitals by the total number of physicians involved in patient care in the state for each year, as reported by the American Medical Association, and similarly, scaled administrative staff in providers' offices by the number of office-based physicians in each state and year.[144–147]

Health Plan and Hospital Concentration Data

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[2] For states where employment numbers were suppressed for confidentiality or quality reasons, we relied on employment ranges provided by the Census bureau, using the lower of the two estimates. A significant number of states do not report payroll data for health insurers for confidentiality reasons, so we do not conduct cost estimates for health insurance companies.

[3] For the purposes of this analysis, we include Washington, D.C. as a state.

Our insurance market concentration data came from the American Medical Association's annual "Competition in health insurance" reports, which were generated by Interstudy, a health care data company.[125,148–150][4] Hospital data came from American Hospital Association Annual Surveys.

To measure concentration across health plans and hospitals, we employ a standard concentration index variable—the Herfindahl-Hirschman Index (HHI), which is the sum of squared market shares for all firms in a given market. Scores range from zero (many competitors) to 10,000 (one facility with 100% market share). The Federal Trade Commission and the Department of Justice use this index as a diagnostic tool to assess how proposed mergers and acquisitions will affect market competition. In 2010, the Department of Justice and the Federal Trade Commission revised its horizontal merger guidelines, increasing the threshold for highly concentrated markets from 1,800 to 2,500.[151]

In calculating our insurance market concentration scores, we used state-level concentration scores for the combined health maintenance organization and preferred provider organization market. Although some argue that these products should be considered separately because of differences in costs and benefit design, lines between these products are becoming more blurred for consumers, and empirical work suggests that the correlations between measures of concentration that consider these products separately and combined are very high.[132,135,152] We analyze insurance market concentration as both a continuous variable and as a categorical variable, with thresholds based on previous research and the recently revised Department of Justice Guidelines: less than 1500, 1500-2500, 2500-3200, 3200 and above.[135]

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[4] The reports included data on the market share of health insurers by enrollment as well as state-level scores of market concentration for the combined HMO/PPO market. Interstudy did not report results for some states each year, largely because some states did not meet their 30 percent threshold for the ratio of total enrollments reported by all health insurance plans to the population eligible to be covered in that area. In 2010, reported state-level data captured about 70 percent of the eligible insured population.

We used hospital admission data in the metropolitan statistical areas to calculate hospital concentration scores. We then used metropolitan statistical area population data to weight these scores and aggregate them at the state level. We measure hospital concentration as both a continuous measure and as a categorical variable: less than 1500, 1500-2500, 2500-3200, 3200 and above.

In recent years, hospitals have also increased their market power by employing larger numbers of physicians.[153] To account for changing these changing physician arrangements, we include a ratio of the number of hospital-based physicians (including residents, fellows, and hospital staff) to the number of physicians who are office-based in each state and year, using American Medical Association data.[144–147] These data are self-reported, so although hospital-based generally refers to physicians who work in hospitals, the term may also include some physicians who work in practices owned by hospitals.

Data on Control Variables

We include controls for other aspects of health insurance markets that might influence administrative staffing levels or demand for health care services, which drives up the number of administrative transactions conducted. Using Census data, we include demographic factors such as the percent of people living in urban areas as reported in 2000, the percent of the population over 65, and median household income. We also control for health care quality, incorporating crude mortality rates (e.g. the number of deaths per 10,000 people in state).[154] Studies of managed care in the late 1990s showed that the rise of HMOs was largely responsible for reducing health care cost growth mainly by negotiating better rates with provider organizations.[155] Although the effect of HMO penetration has waned since 2000, Shen et al. show that it remains an important driver of hospital operating costs.[156] To account for the impact that managed care could have on administrative costs, particularly for providers, we include a state-level measure of HMO penetration from 2010.[157] During this time period, some states either enacted or continued implementing state-level reforms to simplify administrative costs, most notably Minnesota, Washington, Colorado, and Utah; we include a dichotomous variable to account for states with such reforms and the years they were enacted.[158] Finally, we include year fixed effects measures to account for changes in administrative staff over time. The final sample included 175 state-year observations.

Analysis Plan

We ran descriptive statistics on administrative staffing levels and costs across states with different levels of market concentration in both health plans and hospitals. We then used regression analysis to explore the association between administrative staffing levels and insurance market and hospital concentration scores, adjusting for related factors. We tested for potential interactions between provider market and insurance market concentration scores. For each outcome predictor, we include only those control variables that are significantly correlated with our outcome variables and improve the performance of the overall model. Standard errors were robust and clustered at the state-level.

Using results from our pooled regression model, we also ran a series of simulations to test how changes in market concentration would affect administrative staffing levels across payers and providers. We consider the effects of an increase in 1000 points in market concentration; the effects of all states becoming as concentrated as the most concentrated state in our sample; and the effects of all states becoming as concentrated as the least concentrated state in our sample. We estimate similar changes in the ratio of hospital-based to office-based providers: the effects of changing the ratio in all states to mirror the state with the highest hospital-based office-based physician ratio, and the effects of changing all states to mirror the state with the lowest ratio. We conducted our analysis using Stata MP software.

Limitations

Recent work has argued that the year-to-year volatility observed in the insurance market concentration data released by the American Medical Association is more likely due to measurement error than a true changes in market conditions.[159] To account for this volatility, we use pooled regression models that control for year fixed effects and cluster the standard errors at the state level rather than using random-effects models (see table in the Appendix).

We also focus on state-level measures of market concentration and administrative costs, which may mask important variation across geographic markets within states. Prior work on the effects of market concentration has defined geographic markets in numerous ways, using state boundaries, metropolitan statistical areas, and zip codes.[151,152,160,161] Although more local data is ideal, both the volatility in our insurance market concentration data and small sample sizes for administrative staff limit our ability to analyze trends within states. Nevertheless, we believe that this analysis provides an important first look at the relationship between market concentration and administrative expenses.

Because our measure of administrative costs does not capture all the expenses that have traditionally been attributed to administrative spending, such as clinician time spent negotiating with insurance companies or capital expenditures, our results may underestimate the impact of market concentration on absolute levels of administrative burden.[136,137,162–164] Nevertheless, given that administrative jobs and office functions are the ones most likely to be consolidated after a merger, we believe that this measure, as opposed to medical loss ratios used in earlier studies, may be a more sensitive measure and thus more informative on the effects of consolidation.[128,165]

Lastly, the nature of our data and analysis constrains our ability to make causal claims about levels of market concentration and administrative staffing and costs.

Results

Table 3.2 displays descriptive statistics for our sample broken down by levels of insurance market and hospital concentration. For every physician providing patient care in a state, 1.27 administrators are employed by hospitals and 0.56 are employed by health insurance companies. For each office-based (as opposed to hospital-based) physician, provider offices employ an average of 0.89 administrators. Our administrative staff ratio in provider offices is similar to estimates published by Casalino et al. who found that clerical staff spent an estimated 35.9 hours per physician per week interacting with health plans, which is equivalent to 0.89 staff per physician assuming a 40-hour work week.[136] The costs associated with these administrative staff are roughly equal to average annual incomes for these positions, suggesting that changes in staffing coincide with similar changes in cost levels (see Appendix for regression results). The mean ratio of hospital-based to office-based physicians is about 0.32.

Table 3.2. Concentration of health plans and Hospitals by State, 2007-2010

	Number of State-Years	Mean Admin Staff in Provider Offices/MD	Mean Provider Office Admin Costs /MD	Mean Hospital Admin Staff /MD	Mean Hospital Admin Costs /MD	Mean Health Insurance Staff /MD	Mean Health Insurance Concentration	Mean Hospital Concentration	Mean Hosp/Office-based MD Ratio
Overall Mean	175	0.89	$37,663.99	1.27	$39,508.40	0.56	3477	2502	0.32
Health Plan Concentration Index									
Less than1500	2	1.09	$39,973.61	1.48	$40,206.60	0.53	1401	1438	0.38
1,500-2,500	44	0.99	$39,628.99	1.12	$36,378.71	0.55	2073	2112	0.29
2,500-3,200	48	0.87	$38,553.84	1.24	$38,630.82	0.59	2849	2367	0.32
3,200	81	0.85	$36,012.23	1.36	$41,711.28	0.55	4663	2819 (a,+)	0.32
Hospital Concentration Index									
Less than1500	34	0.88	$36,009.41	1.04	$33,872.69	0.48	2756	1018	0.37
1,500-2,500	76	0.96	$43,351.35	1.22	$37,892.83	0.57	3383	1992	0.31
2,500-3,200	25	0.84	$29,672.90	1.44	$45,384.34	0.61	4079	2900	0.29
3,200	40	0.81	$33,258.82	1.45	$43,695.86	0.57	3891.75 (a,+)	4482	0.29

Notes: Statistically significant differences noted in parentheses, + = $p<0.10$. Differences in mean insurance concentration scores were statistically significant across all levels of the health plan concentration index, as were mean hospital concentration scores across all levels of the hospital concentration index. Numbers of administrative staff in hospitals and health insurance companies were scaled by the total number of physicians involved in patient care as reported by the American Medical Association. Numbers of administrative staff in provider offices were scaled by the number of physicians in provider offices. Cost estimates derived from reported income/wage data from Current Population Survey adjusted to include value of benefits.

Overall, levels of administrative staff per physician vary little across categories of insurance market and hospital concentration. Yet, there is a slight decrease in administrative staff at provider offices in states with higher levels of insurance market concentration, but a slight increase in administrative staff at hospitals in states with higher levels of hospital concentration. These differences are not statistically significant. Hospital concentration is significantly, inversely correlated with insurance market concentration.

Table 3.3 displays our data broken down by year. Because shifts over time are more likely due to statistical noise than to any underlying shift, these figures should not be interpreted as reflecting temporal trends.[121,159]

Table 3.3. Mean Values of Key Predictor Variables Over Time

	Health Plan Concentration		Hospital Concentration		Hospital/Office-based Physicians	
	Mean	*SE*	Mean	*SE*	Mean	*SE*
2007	3622	225	2594	233	0.28	0.01
2008	3192	220	2531	229	0.31	0.01
2009	3538	207	2416	185	0.33	0.02
2010	3542	214	2467	186	0.34	0.02

Table 3.4 displays results from pooled linear regression models estimating the relationship between administrative staffing levels per physician and market concentration scores. Most notably, we find that, on average, levels of insurance market and hospital concentration appear to have little to no relationship with administrative staffing levels across payer and provider settings, with provider offices being the one exception. For every thousand-point increase in insurance market concentration, the number of administrative staff per physician in provider offices goes down by 0.04, a small but significant change ($p<0.05$) (Tables 3.4). Potential interactions between insurer and provider concentration are not statistically significant.

Table 3.4. Results from Linear Regression Models Predicting Relationship Between Administrative Staffing Levels and Market Concentration

	Health Insurers		Provider Offices		Hospitals	
Variable	Coefficient	*P-Value*	Coefficient	*P-Value*	Coefficient	*P-Value*
Health Insurance Concentration (HHI)	-0.000019	0.199	-0.000035*	0.047	0.000040	0.13
Hospital Concentration (HHI)	-0.000014	0.634	0.000001	0.975	-0.000021	0.531
Ratio of Hospital-based Physicians to Office-Based Physicians	-0.501664+	0.056	-0.886270**	0.008	-0.567442	0.155
Percent of Population in Urban Areas			0.010513*	0.021		
Death Rate (per 100,000)			0.001049*	0.011		
HMO Penetration	0.099983	0.736	-0.793911*	0.013	-1.41662***	0
Median Household Income					-0.000013*	0.013
Percent of Population Over 65	0.040899+	0.065			0.08468***	0
Unemployment Rate			0.036971	0.121		
2007	---	---	---	---	---	---
2008	0.049554	0.121	-0.116227	0.27	0.140562	0.155
2009	0.077219*	0.013	-0.25878+	0.097	0.004422	0.968
2010	0.068085+	0.063	-0.323972*	0.028	-0.055920	0.61
Constant	0.222709	0.346	-0.277635	0.633	1.129171**	0.009
Observations	175		175		175	
R-squared	0.126		0.185		0.289	
F	1.981670		6.168729		8.799905	

Note: Standard errors were clustered at the state level. + $p<0.10$, * $p<0.05$, ** $p<0.01$, *** $p<0.001$

Using results from these pooled regression models, we simulate the effects of changes in insurance market competition and in the ratio of hospital-based to office-based physicians (Table 3.5). We estimate that if all health insurance markets became as concentrated as the most concentrated state, Alabama, the number of administrative staff per physician in provider offices would decrease by 0.15 each year, or about 17 percent. (In 2010, Blue Cross Blue Shield of Alabama held 93 percent of the market, and the overall concentration index for the state was 8,627, out of a maximum score of 10,000. The state very nearly had a single-payer system, albeit a private one.) If we multiply this change by average salary levels for administrative staff in provider offices ($40,833.90), then this increase in market concentration would be associated with a decrease in administrative staffing costs of about $6,315.86 per physician. Multiplying these savings by the total number of office-based physicians in 2010 (565,024 physicians), we estimate national level savings to be about $3.6 billion for provider offices alone if all states had high rates of insurance market concentration.

Table 3.5. Simulated Changes in Administrative Staff Per Physician in Provider Offices

Variable	Change in Admin Staff/MD	Percent change	Dollar Change
Health Insurance Market Concentration (1000 point increase)	-0.04	-4%	-$1,429.16
Health Insurance Market Concentration (all states become as concentrated as MOST concentrated health insurance market: Alabama)	-0.15	-17%	-$6,315.89
Health Insurance Market Concentration (all states become as concentrated as LEAST concentrated health insurance market: Florida).	0.05	6%	$2,156.88
Ratio of Hospital-Based Physicians to Office-Based Physicians (All states have same ratio as state with highest ratio of hospital-based to office-based physicians: District of Columbia)	-0.45	-50%	-$18,175.01
Ratio of Hospital-Based Physicians to Office-Based Physicians (All states have same ratio as state with lowest ratio of hospital-based to office-based physicians: Nevada).	0.14	16%	$5,872.49

Note: Author's calculations based on pooled regression model results presented in Table 3.4. Simulations of high and low market concentration values report average decreases or increases in administrative staff in provider offices across all states and years.

We also find that increasing the ratio of hospital-based to office-based physicians is associated with decreases in administrative staffing levels across payers and providers, controlling for insurance market and hospital concentration. For example, when we increase the ratio of hospital-to office-based physicians in all states to match the state with the highest ratio, the District of Columbia, this change is associated with an average decrease in administrative staff provider offices of -0.45, a decrease of 50 percent, equal to $18,175 per physician or $10.3 billion nationally.

Discussion

Overall, we do not find a statistically significant relationship between insurance market or hospital market concentration scores and administrative staffing levels across payers or hospitals. Health insurers and hospitals in more consolidated markets do not enjoy lower administrative costs themselves, and neither do the payers and providers that have to interact with them.

Provider offices are an exception to this. We find a small but statistically significant relationship between insurance market consolidation and reduced administrative staffing levels per physician in provider offices. Physicians and other provider organizations currently pay more than $214 billion each year on administrative expenses, more than 60 percent of total administrative costs and double the amount borne by health insurance companies.[122] According to our results, nationwide Alabama-level health insurance concentration would be associated with provider-office administrative savings of $3.6 billion, or 1.7 percent of provider administrative costs.

We also found large reductions in provider office administrative expenses associated with an increase in the ratio of hospital-based to office-based physicians. This suggests that, as physicians move into hospital settings—or hospitals buy physicians' practices and consolidate financial administration—the administrative costs per physician go down.

Although our results cannot provide conclusive answers on the mechanisms underlying our association between insurance market concentration and administrative staff in provider offices, they do provide some useful insight on why administrative costs might be lower in concentrated insurance markets. As mentioned, consolidation may lower the cost to providers of dealing with multiple health plans. However, for this to be true, it would require that consolidated health insurance companies invest in revamping the processes that drive up provider administrative costs.[122] We found no significant relationship between employment levels of administrative staff in health insurance companies and levels of insurance market concentration, which we would have expected if these companies were in fact making their internal administrative systems more efficient.

The other possible explanation is that, in highly concentrated insurance markets, health insurers simply offer lower payments to physician organizations, spurring providers to reduce spending on administration.[119] Assuming that both provider offices and hospitals will spend resources to process claims as long as the financial return on these claims exceeds the staffing costs required to process them, reduced payments per claim from insurers could push more claims below the threshold at which they are worth processing. If, due to volume, the marginal cost of submitting a claim is higher for provider offices than for hospitals, then lower payments will trigger reductions in administrative spending by provider offices before they would do so in hospitals. This description matches our findings: greater insurance industry concentration is significantly associated with lower administrative staff among provider offices but not among hospitals. Future research is needed to clarify whether these or other mechanisms are responsible.

The Impact of Health Reform

Looking ahead, a suite of policy changes associated with the Affordable Care Act could affect levels of insurance market concentration, provider market concentration, and administrative costs.

The introduction of the individual mandate, state-based health insurance exchanges, and state Medicaid expansions will substantially increase the number of people purchasing private health insurance coverage. This could lead to a rise in insurance market competition as more plans compete for shares of expanded state markets. Our results suggest that this could be associated with a reduction in provider office efficiency as the market power of insurers falls.

Payment reforms introduced under the Affordable Care Act have already spurred increased consolidation across providers.[166] Our results find no relationship between administrative staffing levels and provider market concentration, suggesting that prior to 2010, hospital mergers and acquisitions were most likely focused on increases in market power rather than on producing integrated, streamlined care systems. It is possible that health reforms could succeed in encouraging providers to integrate clinical and financial systems more comprehensively, which could bring down administrative complexity and costs. Future research is needed to test this hypothesis.

Lastly, the administrative simplification reforms included in the Affordable Care Act are designed to increase electronic transmission of administrative data. If the new rules reduce unnecessary variation in data requirements across health plans and reduce staff time spent on administrative transactions via automation, we could see reductions in administrative staffing levels across all insurance markets, regardless of concentration levels. However, given that the law stopped short of requiring all stakeholders to adopt electronic transactions and failed to make all transactions uniform, there will still be some variation across health plans in how they conduct administrative transactions. Therefore, in markets with fewer health plans (e.g. more concentrated markets), we expect to see these costs go down more rapidly—particularly, given our results, for provider offices

Appendix

Appendix 1A. Item wording and coding for Independent Variables

Variable	Survey Question	Coding
Measures of Perceived Threat		
Have or had an Immediate blood relative with AD	"Do you believe that any of your grandparents, parents, or siblings has or had Alzheimer's disease?"	Yes, No
Respondent is or was decision-maker or caretaker for AD patient Combination of two questions	"Are you or were you one of the people most involved in decision-making about or financial support of the care for any of the people you have known with Alzheimer's disease?" and "Are you or were you one of the people most involved in the day-to-day care for any of the people you have known with Alzheimer's disease?"	Yes, No
Worried will get Alzheimer's Disease	"How worried are you that you will get Alzheimer's disease? Are you very worried, somewhat worried, not too worried, or not worried at all?"	Yes, No
"Excellent/Good/Very Good" Health Status	"In general, would you say your health is excellent, very good, good, fair, or poor	Excellent, very good, good=1; fair, poor=0
Think AD is fatal	"Do you think that Alzheimer's disease is a fatal disease or not?"	Yes, No
Measures of Perceived Costs and Benefits		
Marital status of respondent	"Which of the following best describes you? Are you: Married, Living with partner but not married, Separated, Divorced, Widowed, Have never been married?"	Married=1, Not Married=0
Expect paid caregiver to be primary caretaker if develop AD	"If you had Alzheimer's disease and required significant day-to-day care, who would you expect to be the primary person to provide it – your spouse, your child, another relative, a friend, a caregiver you hire, or a caregiver provided by a government agency or charitable organization? (Allow only one answer)"	"Caregiver you hire" or "caregiver provided by a government or charitable organization"=1, Else=0
Believe an effective AD treatment is available now or will be in 5 years. Combination of two questions.	"To the best of your knowledge, is there an effective medical or pharmaceutical treatment to slow the progression of Alzheimer's" disease and make the symptoms less severe, or not?" Of those who responded no, respondents then asked "Do you think there will be an effective medical or pharmaceutical treatment for Alzheimer's disease in the next five years, or not?"	Yes, No

Appendix 1A (Continued)		
<u>Demographic Controls</u>		
Age of Respondent	"Can you please tell me your age?"	18-29, 30-49, 50-64, 65-74, 75-85+
Gender	Coded from Sample	Female=1, Male=0
Educational Attainment	"Which is the highest level of school completed?"	Low, Middle, High
Country of Residence	Coded from Sample	France, Germany, Poland, Spain, United States
Race	"Which of the following best describes your race: White or Caucasian, Black or African American, Asian or Pacific Islander, Native American or American Indian, or Other?" and "Are you, yourself of Hispanic or Latino origin or descent such as Mexican?"	White, Black, Hispanic, Other
<u>Measures of Psychological Status</u>		
Would see doctor if showing symptoms of AD	"If you were exhibiting confusion and memory loss, would you go to a doctor to determine if the cause of the symptoms was Alzheimer's disease or not?"	Yes, No

Appendix 2A. Linear Regression Models Testing the Relationship Between State Ideology and State Medicaid Policies

	Admin Hassle with SES		Admin Hassle with SES & Ideology		Benefit Generosity with SES		Benefit Generosity with SES & Ideology	
	Coefficient	S.E.	Coefficient	S.E.	Coefficient	S.E.	Coefficient	S.E.
Median Household Income	-0.00342*	(0.001)	-0.0169***	(0.002)	0.0207***	(0.001)	0.0154***	(0.001)
Percent of High School Graduates	-0.00429*	(0.002)	0.0270***	(0.002)	0.0246***	(0.002)	0.0193***	(0.002)
Percent Living in Urban Areas	-0.00485***	(0.001)	0.00365***	(0.001)	0.0256***	(0.001)	0.0229***	(0.001)
Percent Non-white	0.0171***	(0.001)	0.0134***	(0.001)	-0.0201***	(0.001)	-0.0187***	(0.001)
Conservative			0	(.)			0	(.)
Moderate			-0.830***	(0.021)			0.315***	(0.020)
Liberal			-0.380***	(0.021)			0.369***	(0.020)
Constant	0.589***	(0.164)	-1.529***	(0.167)	-4.701***	(0.153)	-4.112***	(0.158)
Observations	24230		24230		23718		23718	
R-squared	0.040		0.104		0.204		0.216	
F	254.1		469.4		1523.5		1091.5	

Note: Data Primarily from Census Bureau and from Annual Social and Economic Supplement to the Census Bureau Current Population Survey. Number of observations drops in models predicting benefit generosity due to missing physician reimbursement data, which is a component of the benefit generosity index, for Tennessee. + p<0.10, * p<0.05, ** p<0.01,*** p<0.001

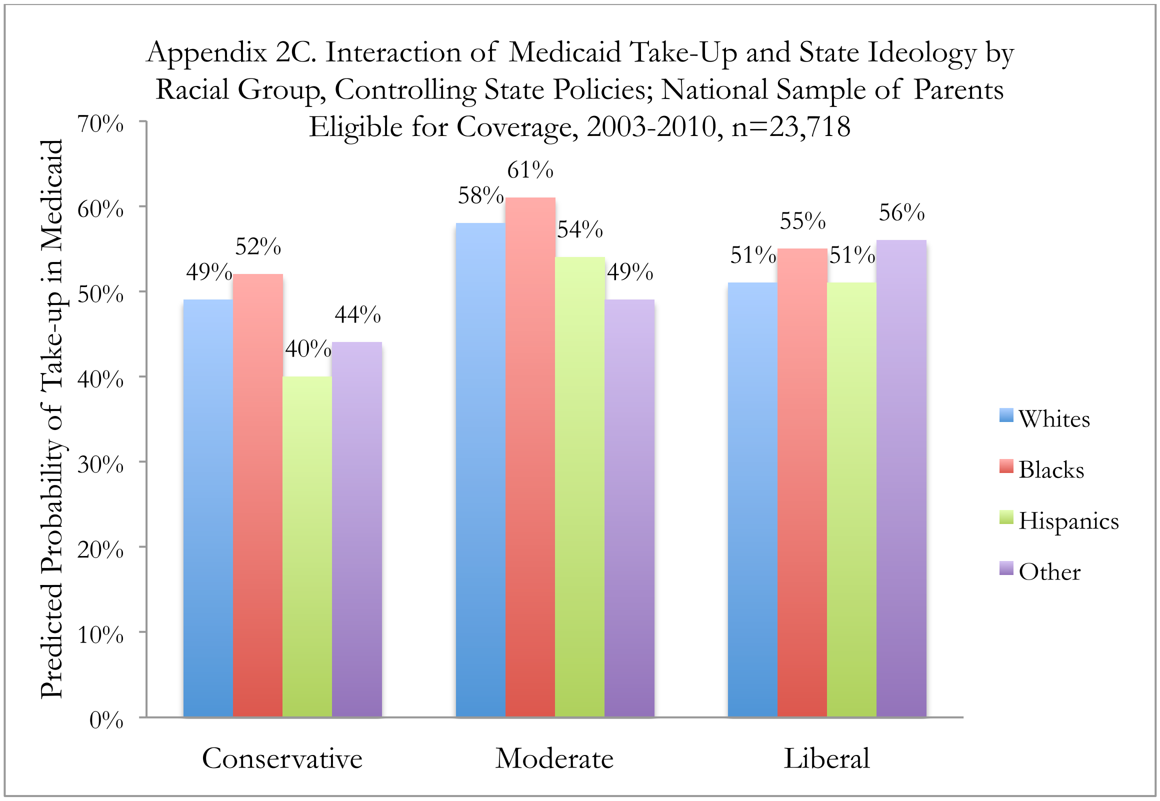
Appendix 2B. Descriptive Statistics for Sample of Parents and Eligible for Medicaid Coverage, 2003-2010

Variable	Mean	Standard Error	Variable	Mean	Standard Error
Medicaid Take-up	0.54	0.02	Metropolitan Status		
Race			Urban	0.79	0.03
White	0.48	0.04	Noncitizen Family Member	0.07	0.02
Black	0.25	0.03	Family Size	4.1	0.07
Hispanic	0.20	0.04	Annual Unemployment Rate	0.06	0.19
Other	0.07	0.01	Federal Matching Rate	0.57	0.02
Gender			State Median Household Income	$48,682.00	$1,063.00
Female	0.75	0.01	Factors Related to Benefit of Coverage		
Male	0.25	0.01	Scope of covered Medicaid Services (z-score)	0.08	0.24
Marital Status			Dental Coverage	0.66	0.09
Married	0.35	0.02	Percentage of state enrollees in managed care	65.65	4.44
Age			Annual Cost Sharing	25.87	5.46
19-24	0.20	0.01	Provider Reimbursement (percent of national mean)	0.99	0.06
25-30	0.24	0.01	Factors Related to Hassle of Enrollment		
31-40	0.32	0.01	Face-to-face interview when applying	0.22	0.10
41-50	0.18	0.01	Face-to-face interview when renewing	0.12	0.05
51-64	0.06	0.01	Shared application for family members	0.63	0.11
Working Parent	0.45	0.01	Frequency of eligibility renewal (months)	10.28	0.57
Education			Self-declaration of residency	0.24	0.04
Did not complete high school	0.28	0.01	Application length (pages)	13.33	1.45
High School Graduate	0.67	0.01	Application literacy level	9.37	0.44
College Graduate	0.05	0.00	Application available in Spanish	0.95	0.02

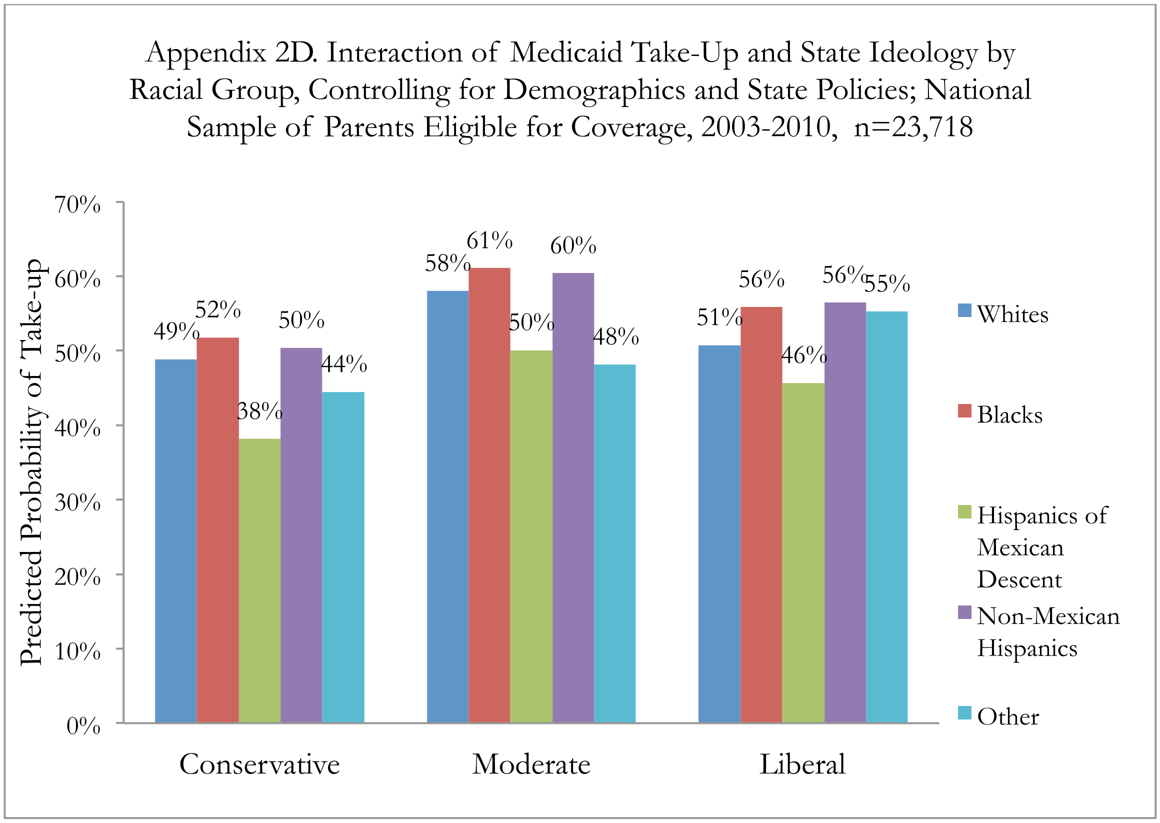
Appendix 2B (Continued)

Disability Status			Application can be submitted in other languages	0.26	0.12
Disabled	0.14	0.01	Application can be submitted by telephone	0.23	0.11
Health Status			Application can be submitted online (by consumer)	0.42	0.11
Excellent	0.21	0.01	Application can be submitted online (by provider)	0.27	0.08
Very Good	0.29	0.01	Separate application for disabled adults	0.38	0.11
Good	0.31	0.01	Application combined with other programs	0.49	0.12
Fair	0.14	0.00	State Ideology		
Poor	0.06	0.00	Conservative	0.18	0.07
Family Income	$10,362.00	$1,036	Moderate	0.30	0.10
			Liberal	0.52	0.12

Note: Sample limited to adult U.S. citizens, aged 19-64, eligible for Medicaid coverage and having no alternative form of health insurance. n=24,230



Appendix 2C. Interaction of Medicaid Take-Up and State Ideology by Racial Group, Controlling State Policies; National Sample of Parents Eligible for Coverage, 2003-2010, n=23,718



Appendix 2D. Interaction of Medicaid Take-Up and State Ideology by Racial Group, Controlling for Demographics and State Policies; National Sample of Parents Eligible for Coverage, 2003-2010, n=23,718

Appendix 3A. Results from Linear Regression Models with State Fixed Effects Predicting Relationship Administrative Staffing Levels and Market Concentration

	Health Insurers		Provider Offices		Hospitals	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Health Insurance Concentration (HHI)	0.000022+	0.081	0.000013	0.81	-0.000085	0.179
Hospital Concentration (HHI)	0.000021	0.707	0.000362	0.146	0.000473+	0.095
Ratio of Hospital-based Physicians to Office-Based Physicians	-1.192575+	0.075	-1.833419	0.528	2.41456	0.465
Constant	0.408059	0.15	0.212611	0.863	0.830068	0.554
R-squared	0.910		0.481		0.575	
F	21.872295		2.001632		2.930946	

Note: Models included year and state fixed effects; n=175; + p<0.10,* p<0.05, ** p<0.01, *** p<0.001

Appendix 3B. Results from Linear Regression Models Predicting Relationship Between Aggregate Administrative Staffing Costs and Market Concentration

	Provider Offices		Hospitals	
	Coefficient	P-Value	Coefficient	P-Value
Health Insurance Concentration (HHI)	-1.507033	0.163	1.446172	0.151
Hospital Concentration (HHI)	-1.985203	0.396	-0.546790	0.659
Ratio of Hospital-based Physicians to Office-Based Physicians	-39258.23*	0.033	-22113.67	0.135
Percent of Population in Urban Areas	468.41*	0.012		
Death Rate (per 100,000)	56.55*	0.027		
HMO Penetration	-49159.99*	0.024	-21076.15	0.127
Median Household Income			-0.175716	0.381
Unemployment Rate	-457.89	0.829		
Percent of Population Over 65			1756.35*	0.033
Constant	-7099.95	0.741	30205.90*	0.042
R-squared	0.114		0.113	
F	4.733495		3.620839	
Year Fixed Effects	Yes		Yes	

Note: Standard error were clustered at the state level; n=175; + p<0.10,* p<0.05, ** p<0.01 *** p<0.001

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