The donut hole: a qualitative study of seniors who have fallen into the Medicare Part D coverage gap: a project based upon an independent investigation

Benjamin Todd Weiss

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Ben Weiss
The donut hole: A qualitative study of seniors who have fallen into the Medicare Part D coverage gap

ABSTRACT

When Medicare Part D was unveiled in 2006 one controversial feature was the inclusion of a coverage gap which potentially forced enrollees to pay thousands of dollars out-of-pocket. This thesis asked the question: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement? Two hypotheses were presented at the outset of this qualitative study. The first was that since seniors are a particularly active demographic they would respond to the donut hole experience with some kind of political action. The second supposed the opposite might be true: since the donut hole policy is potentially stigmatizing, seniors would react to it by experiencing themselves as powerless in the face of a large system. Initially the goal was to interview twelve seniors who had fallen into the donut hole, but because of recruitment difficulties only two seniors were interviewed. This researcher interviewed two health insurance experts to enhance the data. The major finding was that of the two hypotheses, the second comes much closer to describing the felt experience of seniors. Respondents described feeling powerless and resigned to their fate in the donut hole. Another major finding was that the role of social workers has proven important in helping seniors avoid the donut hole. A major implication of this finding is that social workers should closely monitor their older clients’ health insurance statuses as well as the ever-changing regulations governing insurance rules.
THE DONUT HOLE: A QUALITATIVE STUDY OF SENIORS WHO HAVE FALLEN INTO THE MEDICARE PART D COVERAGE GAP

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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CHAPTER I

INTRODUCTION

On January 1, 2006, Medicare Part D, the prescription drug coverage plan for Medicare beneficiaries, went into effect. There were close to 2,000 Part D plans, and the intention was to offer seniors access to a range of plans so that they could choose the drug plan that best fit their needs (Zhang, Donohue, Newhouse, & Lave, 2009). When the insurance program was unveiled, one controversial feature of the plan was a "donut hole" or "coverage gap". If a beneficiary spent over $2,250 on drugs in a given year, Part D stopped paying drug premiums until he or she had spent $5,100. This gap in coverage required some beneficiaries to pay thousands of dollars out-of-pocket. Almost immediately, the donut hole became emblematic of the confusing structure of Part D, and since 2006 many seniors have fallen into the coverage gap unaware of its existence (Pear, 2006).

As a review of the literature in chapter 2 will show, research has been done on the way seniors interface with Medicare Part D, but gaps remain. Some previous studies have looked at how insurance programs impact drug spending and other economic behaviors, while others have focused on how seniors integrate and understand insurance policy information. While these studies are important, they do not get at the felt experience of the many seniors who have fallen into the donut hole, nor do they seek to uncover the political response, if any, of donut hole victims. This thesis asks the following question: How has falling into the donut hole affected seniors’ views and
feelings of health insurance and government, and how has this experience informed their sense of civic engagement?

In addition to reviewing previous studies on seniors and health insurance, the literature review chapter will lay the theoretical foundation for the thesis project. The theory base for this project combines the concept of policy feedback – the idea that social welfare policies inherently create politics – and Schneider and Ingram’s (1993) notion of socially constructed target populations. These concepts, and their relationship to the Medicare Part D coverage gap, will be explained in full in Chapter II.

In Chapter III the methodology for this thesis project will be described. The choice to do qualitative study will be explained, as will the benefits and limitations of doing this kind of research. The eligibility criteria, screening process, and recruitment process will be discussed. The pace of recruitment and the subsequent use of expanded recruitment techniques will be laid out in detail. Lastly, the data collection process, including the qualitative interview guide, will be described in detail in this chapter.

The fourth chapter of this project will present the findings from the interviews. The sample will be described, and the responses of those interviewed will be presented in an organized fashion. In Chapter 5, these findings are subjected to thematic analysis, and the five most prominent themes culled from the interviews will be discussed. This chapter will conclude with a discussion of the barriers and challenges that made recruitment difficult, and scholarship around recruitment issues will be reviewed. Suggestions for future research will also be made.

The challenges to recruitment throughout this thesis project were very real. Initially, the researcher intended to get an $n$ of twelve participants. When only two
potential participants contacted this researcher, the recruitment goals were scaled back, but even then it was a challenge to find seniors who were willing to participate. In the early spring the decision was made to interview two health insurance experts, and in this way this researcher was able to collect an adequate amount of data.

While on the one hand the recruitment challenges were consequential, on the other there were a number of sharp themes which emerged from the interviews. The work done here was thus in a sense preliminary, but it was important. Understanding the ways in which social welfare policies affect peoples’ orientations towards structures of power is an understudied phenomenon, but this project shows the utility in doing this kind of qualitative research.
CHAPTER II

LITERATURE REVIEW

Introduction

This thesis asks the following question: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement? As its theory base this project will use the ideas of socially constructed target populations, policy feedback, and civic engagement. While research exists on these constructs, no studies have yet looked at the policy feedback effect of the Medicare Part D coverage gap on civic engagement, nor have any applied Schneider and Ingram’s (1993) notion of target populations to this particular policy. The following review of the literature will first survey recent studies on the impact of both the coverage gap in particular and Medicare Part D more generally. Then this chapter will build a conceptual basis for the thesis project by reviewing articles on the three theories mentioned above, as well as an interview with a social worker who specializes in Medicare issues.

The coverage gap and Medicare

Zhang, Donohue, Newhouse, & Lave (2009) noted that to date, there have been very few studies of what happens to seniors when they fall into the coverage gap. The authors looked at the effects of the coverage gap on drug spending in particular. They looked at two groups of Medicare beneficiaries in Pennsylvania: those who enrolled through their prior employer and those who purchased an individual Medicare
Prescription Drug plan. Importantly, those in the employer-based plan had coverage for brand-name drugs during the coverage-gap so the consequences of “falling in” were not as dire. This study assessed the beneficiaries’ responses to the donut hole by measuring the number of monthly prescriptions filled before and after a person reached it. They found that a full quarter of those enrolled in an individual drug plan with no donut hole coverage fell into the donut hole, and these beneficiaries reduced medication use by 14 percent once they fell in. Those with employer-based plans generally had coverage for only generic drugs once they reached the donut hole. These individuals did switch from brand-name drugs to generics once they fill in the gap, “and, as a result, reduced their overall use of medications to a much lesser extent than did those with no coverage” (2009, p. w315). A major limitation of this study was that the results are particular to a very specific group of Pennsylvania residents and not generalizable to the American seniors at large.

In a study that was completed just before the implementation of Part D, Stuart, Simoni-Wastila, & Chauncey (2005) conducted a simulated exercise estimating total and out-of-pocket drug spending in 2006 for an average Part D enrollee. The authors tracked a sample frame of 4,640 Medicare recipients for three years, from 1998-2000, and measured their drug spending. The authors made two key findings: that “Medicare beneficiaries react to interruptions in prescription coverage by reducing their drug spending and that the impact is magnified for beneficiaries with three common chronic diseases” (p. W5-175) – diabetes, chronic lung disease, and mental illness. In their paper, the authors urgently expressed the need for more research to be done into the coverage gap, reiterating that for consumers with diabetes, lung disease, or mental illness, the
ramifications may be severe. One weakness of this study, however, was that it relied upon simulations to predict the behavior of beneficiaries. It was necessarily speculative and should be viewed as no more than that.

Looking not at the coverage gap in particular but more broadly at Medicare Part D, Madden et al (2008) studied the impact of Part D on cost-related medication nonadherence (CRN) among seniors. Nonadherence is defined as skipping or reducing does and not obtaining prescriptions. The authors measured CRN in their sample in 2005 and then again after Part D was implemented in 2006. CRN levels were calculated using self-reported data from a survey called the Medicare Current Beneficiary Survey (MCBS). The MCBS is “the principal national survey for informing and evaluating health policies for Medicare beneficiaries” (p. 1923). This study found a small but significant overall decrease – 2.6 percentage points – in CRN following Part D implementation, however it found no change among the sickest beneficiaries. This study did not address the coverage gap and its effect on beneficiaries. However, the authors did offer a defense of Part D, writing that “only 10% of Medicare beneficiaries remain without prescription coverage after Medicare Part D implementation compared with rates of 25% to 38% in preceding years” (p. 1923). While it is important that this research proposal brings attention to the donut hole phenomenon, it is also necessary to appreciate that even if recipients are now at risk, they might be better off now than they were before they had Part D. It will be important not to lose sight of that fact through the course of this thesis project. Although the coverage gap might be a cause of hardships for some seniors, there may be many others who do not fall into the gap and are quite happy with their benefits but who will not be a part of this research. In fact, even donut hole victims
who participate in the study might appreciate the coverage they have received from Part D, and a limitation of this thesis project is that there will be no control group of seniors who have not fallen into the donut hole as a point of comparison.

In another study which touches upon similar themes to this thesis project, Hsu et al. (2008) looked at beneficiaries' knowledge of Part D programs and the ways in which seniors respond to drug costs. The authors conducted telephone interviews in a random sample of Medicare Advantage beneficiaries and asked about respondents’ knowledge of cost sharing. “To assess whether beneficiaries knew that their plan included a coverage gap, interviewers defined the meaning of a coverage gap and then asked respondents whether their drug plan included such a gap in 2006” (p. 1931). To assess responses to drug costs, the authors asked respondents whether they had engaged in cost-coping behaviors (receiving free drug samples, switching to a cheaper medication), decreased adherence (skipping pills without physicians’ consent, did not fill a prescription), and financial burden (borrowed money to pay for meds, skipped some other necessity). Importantly, the authors found that an estimated 40% of interviewed beneficiaries were aware that their drug plan included a coverage gap. 36% of respondents reported engaging in at least one of the three behavioral responses outlined above (Hsu et al., 2008). This study’s primary finding is striking: nearly 2/3 of respondents did not know that their Medicare Drug plan included a built-in coverage gap.

Issues of diversity must be attended to as well when looking at insurance issues. Gaskin, Briesacher, Limcangco, & Brigantti (2006) looked at racial demographics and prescription drug spending and Medicare use among seniors. Focusing on survey results from a nationally representative sample of black, white, and Hispanic Medicare
beneficiaries, the authors calculated total prescription drug spending, out-of-pocket spending, and number of prescriptions. By factoring in differences in population characteristics across racial and ethnic groups the authors were able to tease out the impact of race and ethnicity on spending and use. The results were striking: “Black and Hispanic had lower total spending and out-of-pocket spending than their white counterparts” (p. 105). The reasons for this phenomenon are not completely clear, and the authors hypothesized that patient skepticism about medicine and medical care, patient-physician communication, or over-use and spending by whites could all be explanatory factors. More research into this area is certainly needed.

*The theory base*

While many studies have looked at how seniors respond to the coverage gap, so far none have looked at the policy feedback of Medicare Part D. In particular, no researchers have yet studied the effects of the donut hole on civic engagement. The second half of this literature review will survey scholarship on a couple of key theoretical constructs in order to build a conceptual base for the thesis project.

Schneider and Ingram (1993) argued that the social construction of target populations is an overlooked and important political phenomenon. By defining through eligibility criteria which citizens are deserving of social welfare, the authors saw legislative policies as a force that created socially constructed demarcations within the population. These demarcations have consequences and can be positive or negative in flavor. The authors wrote:

Policies that have detrimental impacts on, or are ineffective in solving important problems for, certain types of target populations may not produce citizen participation directed towards policy change because the messages received by
these target populations encourage withdrawal or passivity” (Schneider & Ingram, 1993, p. 334).

The authors also argued that policies which subdivide target populations into different groups inherently impose judgments regarding who is deserving and who is not (1993). Importantly, Schneider and Ingram (1993) saw target groups as falling into four categories depending on their political and economic strength and their “value-based cultural image” (p. 335): advantaged (powerful/positively constructed), contenders (powerful, negatively constructed), dependents (weak, positively constructed), and deviants (weak, negatively constructed).

Seniors are generally viewed as good, intelligent people, deserving of public aid, and politically powerful, thus they fall into the advantaged group and receive particular messages and benefits from government as such. Not only will seniors respond favorably to public programs which meet their needs, but the rest of the electorate will approve of beneficial policies which are conferred on deserving people. In this sense the coverage gap runs counter to policies that powerful, advantaged target groups generally are used to. Schneider and Ingram might argue that seniors are used to hearing that their needs are important and deserving of government assistance. The coverage gap seems to send a much different message, one that will be explored in depth in this project. One hypothesis might be that because the coverage gap is a policy that treats beneficiaries like a dependent (weak/positively constructed) target population instead of advantaged as seniors are used to, elders will start to behave, think, and feel more like powerless, positively constructed target populations. Where beneficial policies produce mobilized, proud beneficiaries, punitive policies produce the opposite response. Powerful,
positively constructed populations understand that the game can be won within the rules, but that if policies are not meeting their needs they are likely to organize and work to create alternative solutions. Dependant groups, on the other hand, see politics as a “bureaucratic game where they wait in line and eventually get what others want them to have” (Schneider & Ingram, 1993, p. 342).

If the coverage gap policy treats seniors like dependants instead of like the advantaged, are victims more likely to see themselves that way? Will seniors respond to the policy like dependants, who generally participate less in fighting for change and instead see their relationship with government primarily as “applicants or claimants” (p. 342)?

Bearing in mind the idea that policies impose judgments on who is deserving of aid and who is not, it will be important in this thesis project to look at the particular subset of the senior population most affected by the coverage gap. Corinne Lofchie, an elder care advisor, noted in a recent interview that it is not usually the very poorest who fall in:

People with very low incomes usually qualify for programs that pay for their drugs while in the donut hole. It’s the bracket right above that, people who are over-income for the assistance programs but who still don’t have very much money, who falls in. And unlike the very poor elders who are usually used to receiving Medicaid and other kinds of assistance, generally these people who are falling in to the donut hole are people who have never gotten help before. I hear a lot of, ‘Well, I worked hard my whole life and now I don’t qualify for any help. If I hadn’t worked so hard I would be able to get all this help’. It’s the pitting of the lower-middle class versus the poor (personal communication, October 5, 2009).

This thesis will explore the experiences of donut hole victims, who in Ms. Lofchie’s formulations are usually people who are not used to receiving government
assistance. Have their subjective experiences of citizenship changed as a result of falling into the donut hole, and if so, how?

Pierson (1993) explicates a theory related to Schneider and Ingram’s target population construct called policy feedback. Policy feedback is the notion that on “a range of empirical issues, policies produce politics” (p. 595), and furthermore, that policies “influence the manner in which social actors make sense of their environment” (p. 611). Prominent examples include the creation of the American Association of Retired People (AARP), an organization borne out of frustration regarding the lack of adequate health care benefits for the elderly. AARP and other elderly lobbying groups developed because of certain political conditions rooted in policy – in this case the lack of a comprehensive federal health insurance policy for seniors prior to Medicare. Another example of feedback is the history of the Swedish labor movement. Pierson noted that when policies gave unions authority over unemployment funds, labor groups were able to develop powerful confederations. Because of this unemployment insurance structure, workers had a strong incentive to become members, and union membership rose more rapidly than in other countries (Pierson, 1993).

After citing a number of examples, Pierson then made a strong case for more research into the particulars of policy feedback. “While recent scholarship has emphasized that past policies themselves influence political struggles, moving from this general statement to more specific propositions about how policy structures matter has proven difficult” (p. 596). The author found that much of the research has focused on the effect of policies on policymakers and institutions, and he argues that future research should focus on the consequences policies have on individuals and the public at large,
findings that lend credence to this thesis proposal. Further, he urged future researchers to focus analysis on two dynamics: how the resources that policies provide shape behavior, and how policies convey meaning and information to citizens.

For this thesis project, it will be of central importance to look at the policy feedback of the coverage gap and in particular on those two areas recommended by Pierson. How is political and civic behavior shaped by the donut hole policy? What meaning is conveyed to seniors? If social actors do indeed make sense of their environment in response to welfare policies, how does the donut hole color one’s understanding of self in the world?

Picking up on the theme of policy feedback as it relates to seniors in particular, Campbell (2003) studied the reciprocal relationship between senior citizen participation and public policy. Focusing specifically on the correlation between elders and entitlement programs like Social Security and Medicare, Campbell found that seniors have a unique and active relationship with government compared to other social groups, in large part because of the history of entitlement programs in the United States in the last 80 years. For instance, with other groups income is oftentimes an indicator of civic participation – high income groups tend to have the power and resources to advocate for their needs, while poorer groups do not. With seniors, too, the affluent are active, but so are the less wealthy because they are the most dependent upon entitlement programs. “When interests are so large and tangible,” Campbell wrote, “they can shape behavior. And the keen interest in Social Security helps seniors – especially the less affluent – overcome the typical resource-based obstacles to participation” (p. 40).
Critically, seniors have historically responded quickly and en masse to perceived threats to their entitlement programs. Campbell traces the sharp responses by seniors when politicians have attempted to curtail or otherwise change Social Security and Medicare. In 1981 Ronald Reagan’s attempts to cut Social Security benefits were met with great resistance, and he was forced to drop his proposals. In 1989, when seniors realized that a Medicare expansion passed by Congress the previous year was funded by an increase in monthly Medicare premiums, they mobilized to protest and the bill was repealed. And in 1993 Bill Clinton tried to freeze an annual Social Security benefit increase, but he too had to immediately kill the proposal. More than other social groups, senior citizens “act when their programs are threatened” (p. 93), Campbell noted. The author also cautioned that “a threat can motivate action because it implies a change for the worse” (p. 100). For seniors, the costs of political activism are lower and the benefits are higher than for other groups. They are a “highly regarded segment of society” (p. 95) and thus are not perceived negatively when they advocate on their own behalves. Since the benefits these programs offer are so large, perceived threats are taken seriously since they could have severe consequences. Campbell found that during times when Social Security was perceived to be threatened, the rate at which seniors contacted their Congressmen spiked dramatically. Furthermore, the author found that both high income and low income seniors significantly increased their contacting of representatives during times of threat (p. 111).

The coverage gap could be viewed as a threat for seniors, not because it threatens the existence of Medicare drug coverage but because it was perceived publicly as threatening (Pear, 2006). Thus from Campbell’s work emerges another hypothesis for
this thesis that is quite opposed to the one offered above: because seniors are uniquely able and willing to protest changes to entitlement programs that they perceive and experience as threatening, those who fall into the donut hole may react by becoming more politically engaged and working to make political change. The fact that Campbell found low-income seniors to be more active than younger low-income groups would lend credence to this hypothesis, as according to Ms. Lofchie many of the donut hole victims are in the lower-middle income range.

Mettler (2002) extended Pierson’s policy feedback theory to “specify how policy affects civic engagement (p. 352). The author looked at the policy feedback effects of the G.I. bill for World War II veterans. Focusing in particular on the notion that public programs can promote or discourage civic engagement, Mettler studied veterans’ participation in civic organizations and political activities during the postwar period. To research this question the author collected original quantitative and qualitative data. For the quantitative portion of the project 1,000 veterans were surveyed by mail and 716 completed surveys were received back. For the qualitative piece Mettler conducted 28 semistructured, open-ended interviews with veterans and probed responses in greater depth. The most striking finding was that the “use of the G.I. Bill’s educational provisions was highly significant in determining the degree to which veterans joined civic organizations” (p. 357). The author also hypothesized that the G.I. bill fostered among beneficiaries a sense of obligation that led to higher levels of democratic participation, and found through qualitative analysis that this idea offered a partial explanation for why beneficiaries participate in civic life. There were two important shortcomings of this study. The first was that the data that was collected asked older respondents to recall
information about events that occurred several decades earlier. The second was that the
survey sample appeared to be composed of a particularly educated group of veterans –
among World War II veterans less than a third used G.I. bill benefits for higher
education, but nearly two-thirds of the respondents in this study used their benefits for
undergraduate or advanced degrees. Thus in an important way the sample seems not to
be representative of the study population. These drawbacks aside, the article’s discussion
of theory is useful for this thesis project.

Because this researcher will be attempting to qualitatively measure participants’
sense of civic engagement in this thesis project, Mettler’s formulation of that term will be
used as an operational definition. The author uses “resources (free time, money, and
civic skills) and psychological predisposition (attributes such as political efficacy, a sense
of civic duty, and a group consciousness of having one’s fate linked to others)” (p. 352)
as metrics to gauge individuals’ perceptions of themselves as citizens.

Soss (1999) sought to provide empirical evidence of Schneider and Ingram’s
target population theory. The author, who argued that policy “program designs structure
clients’ experiences in ways that shape their beliefs about the effectiveness of asserting
themselves,” (p. 364), looked specifically at how experience with welfare programs
affected recipients’ orientation towards government and political action. The author
conducted fifty in-depth interviews, half with citizens who participated in a public
assistance program (Aid to Families with Dependent Children) and the other half in a
social insurance program (Social Security Disability Insurance). From these interviews
Soss hypothesized that for structural reasons, receipt of AFDC benefits led individuals to
be less politically active, while recipients of SSDI participated civically at the same level
as the rest of the population. AFDC beneficiaries reported that they saw the welfare office as a persistently threatening place where they were frequently summoned with the threat of termination if they did not appear, long wait times when they did appear, and intrusive questioning. Many of the interviewees responded to this threatening agency with silence, and Soss found that feelings towards the AFDC office were extrapolated to government and power structures at large. Recipients of SSDI, on the other hand, reported that they felt more comfortable airing concerns when they arose, and generally felt they could actively contribute to agency decisions. These respondents too reported that because SSDI was the place where they interacted most closely with government, the feelings they held towards the SSDI office strongly influenced their feelings towards the government in general.

While Soss paints a convincing portrait of the contrasting effects of these two programs, one could criticize his study as being a bit too ideologically pure. His belief in certain theoretical principles provide a helpful scaffolding for his study, but do they make him less open to hearing opinions which do not conform to his hypothesis? In this thesis project it will be important to utilize the theories outlined in this literature review as a guide, but also to be open as each respondent tells of his or her experience.

Conclusion

In conclusion, a review of the literature has shown that the Medicare Part D coverage gap, or donut hole, impacts seniors in a number of ways, but as of yet there has not been an in-depth look at how this insurance feature affects seniors’ sense of civic engagement. This thesis intends to address this gap in the literature and undertake such a study. For its theory base this project draws upon Schneider and Ingram’s notion of
socially constructed target populations, Pierson’s theory of policy feedback, and Mettler’s conceptualization of civic engagement. The thesis question is: How has falling into the donut hole affected seniors’ sense of civic engagement?

In the above literature review, two very different hypotheses emerged as possible answers. The first comes from a close reading of Schneider and Ingram, who argued that certain types of policies send particular messages to citizens about their role in civil life. Policies that treat positively constructed social groups as dependent and needy tend to create a citizenry that is characterized by “disinterest and passivity” (p. 342), and the donut hole could be seen as such a policy. The second hypothesis comes from Campbell’s research on the way in which seniors respond to perceived threats to entitlement programs. The author argued that older citizens have a unique history of being politically active and fierce defenders of their government programs. Thus they could respond to falling into the coverage gap by mobilizing against a perceived threat. In the chapters that follow, this thesis project sets out to see if either of these hypotheses comes close to describing the felt experience of a group of twelve seniors who have fallen into the Medicare Part D coverage gap.
CHAPTER III

METHODOLOGY

This thesis is an exploratory qualitative study. The research question is: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement?

In choosing which research methods to use, the nature of the thesis question guided the decision. Because this project worked to uncover a felt sense of the experience of falling into the Medicare Part D coverage gap, qualitative research methods were deemed most appropriate. Rubin and Babbie (2007) noted that qualitative research methods “generate deeper understandings of the meanings of human experience” (p. 23), and the thesis question posed here strived to do that. Whereas a quantitative study might have been able to generate generalizable statistical findings, this researcher wanted to study in-depth the experiences of a smaller sample. Following the Smith School for Social Work’s thesis guidelines this researcher sought an $n$ of at least 12 research participants. By interviewing a small group of seniors who have all shared a similar experience, this researcher hoped to pull out key themes by comparing the data that emerged throughout the process.

In discussing sampling, a few definitions are helpful here. The population for this study is seniors in the United States. The study population is the seniors who have had the experience of falling into the donut hole. The sampling unit is seniors who respond when they hear about the study, and the sample is the seniors who participate.
The sample was selected through nonprobability sampling with some elements of snowball sampling. While the specific recruitment techniques will be described below, the basic manner in which this researcher conducted outreach was through health insurance counselors and social workers who aide seniors with insurance issues, as well as through flyering at senior centers. Thus seniors who gain access to insurance counselors or who visit senior centers had a much higher chance of being selected for this study, thus my sample was not representative of the population at large.

Statistics on all of the people who have fallen into the donut hole are hard to find and probability research, where each member of the senior community would have an equal chance of being selected for the study, was not feasible. There are risks to validity by using nonprobability sampling. There might be some respondents, for instance, who are so embarrassed by having fallen into the donut hole that they did not want to participate. Their experiences, which would have provided valuable information, were not uncovered in a study of this kind. Furthermore, because of time and cost restraints the participants came from the eastern part of the state of Massachusetts, a primarily urban area surrounding Boston. The results are thus particular to this area – seniors in rural western Massachusetts, or in any other state for that matter, may have much different experiences with the donut hole which this thesis will not explore. Furthermore, while the donut hole exists nationwide, different states have different programs that offer varying levels of assistance to seniors. This project attempted to tell the story of a small sample of Massachusetts seniors, and while that goal is an important one it meant that this project will hold little external validity.
Because of the challenge in obtaining the desired \( n \) (see below) it was difficult to accurately assess the reliability of the qualitative interview guide. As Rubin and Babbie wrote, qualitative researchers can show reliability by asking whether “different sources of data fit consistently with the researcher’s observations and interpretations” (p. 107). Although theme analysis in this case began to shape a narrative the sample was too small to argue that the interview guide and the interview techniques of the researcher were reliable.

_Recruitment_

To be eligible for this study the selection criteria was relatively simple. One must have been a senior, age 65 or older, covered by Medicare, who had fallen into the Medicare Part D coverage gap and who was not covered by Prescription Advantage. Prescription Advantage is the Massachusetts program that provides co-pay assistance to seniors who fall into the donut hole. This program has an income limit for eligibility, so coverage gap victims are either over the income limit or unaware of Prescription Advantage. Lastly, to be eligible for the study prospective participants must have read and understood the informed consent form and had the opportunity to discuss with this researcher any questions or concerns about participating in the study.

In the early stages of the thesis project this researcher conducted interviews with two key informants, both social workers who specialize in health insurance counseling -- Corinne Lofchie and Veronica Buckley. These counselors discussed at length their knowledge about and feelings towards the donut hole, and their expertise helped guide the literature review process as well as the construction of the interview guide. Ms. Lofchie is a Boston area SHINE (Serving Health Information Needs of Elders) counselor.
SHINE is a Massachusetts program, run through the state’s Executive Office of Elder Affairs, that provides counselors to educate seniors about their rights and benefits as health insurance recipients. Ms. Lofchie suggested a method for recruiting eligible participants: attend a monthly meeting of the Boston-area SHINE counselors, present the thesis project to them, disperse flyers at the meeting, and encourage the counselors to hand out the flyers to seniors who might be eligible and interested in the project. In early December this researcher met with the regional director of the SHINE program, Peg Kennedy, at her offices at Minuteman Senior Services in Burlington, MA. Ms. Kennedy, enthused about the project, invited this researcher to attend a monthly SHINE counselor meeting and present the project.

After receiving HSRC approval, this researcher attended a meeting of Boston-area SHINE counselors on March 2nd at Minuteman Senior Services. More than forty SHINE counselors were in attendance. The counselors, primarily volunteers and many themselves seniors, frequently encounter donut hole victims in the course of their work. SHINE counselors make it a point, when possible, to enroll eligible seniors onto Prescription Advantage. There are instances, however, when SHINE counselors encounter donut hole victims who are above the income limit for Prescription Advantage, and it was these seniors who the counselors were encouraged to refer for the research project. Seniors are referred to SHINE counselors through their local elder services agency or their local senior center.

This researcher had received approval for the presentation to the SHINE counselors, but when at the meeting a counselor asked whether or not he could post copies of the flyer at his senior center and in his community, this researcher responded
cautiously that it might be best for the counselors to give out the flyer to seniors but not to post it because this researcher had not received HSRC permission to post the flyer at random.

Three weeks went by in March and only one respondent had called. Concerned about the slow pace the study, this researcher asked for and received HSRC permission to expand recruitment techniques. Now flyers could be posted anywhere, and in working with his thesis advisor this researcher began to look for new recruitment avenues via email listservs that might reach seniors and professionals who work with seniors. Additionally the decision was made to return to the April SHINE counselor meeting to remind the counselors about the project and to encourage them to post the flyer at their local senior centers and other places they might find helpful. This researcher did so on April 6th. Additionally, the HSRC encouraged this researcher to contact the Smith College School for Social Work to ask whether or not the flyer could be dispersed to alumni. This was done, and the flyer was sent out to the entire alumni email listserv.

In the third week of March this researcher scheduled a meeting with Meckle Elston, Program Director of the Cambridge Health Alliance’s Geriatric Services, to discuss venues that might aid in recruiting participants. Ms. Elston, who has been working in the geriatric community in Boston for many years, suggested a number of promising methods of outreach which this researcher followed-up upon. An email along with the recruitment flyer was sent to Jim Callahan, a member of the Massachusetts Aging and Mental Health Coalition. Mr. Callahan forwarded the flyer, along with a description of the project, to the Coalition members. Another email was sent to the “SCIT” listserv, an email list of Somerville-area geriatric service providers. Elizabeth
Aguilo, Executive Director of an agency called Paine Senior Services, forwarded my flyer along with a description of the project to the SCIT list.

Separately, at the urging of Veronica Buckley, this researcher got in touch with Kathy Campbell, the outreach coordinator for the Prescription Advantage program. Ms. Campbell travels to senior centers around the state to discuss current Medicare issues and sign up eligible seniors for state assistance. Ms. Campbell agreed to disperse the flyer at her visits in March and April.

Lastly, Ms. Elston suggested this researcher contact the Executive Office of Elder Affairs and get in touch with the director of the statewide SHINE office. This researcher did so, and Cynthia Phillips, the Massachusetts state SHINE program director, responded enthusiastically in early April about the project. Ms. Phillips said that she liked the idea of dispersing the flyers to SHINE counselors statewide but needed to first consult with her department’s legal counsel, a process that could take a number of weeks and would not be feasible with the May deadline for project completion.

The sampling strategy used in this project was the non-probability technique called purposive sampling, as the SHINE counselors were encouraged to use their judgment and to hand out the flyers to donut hole victims who they thought might be representative of the larger senior population. This strategy was appropriate for a project of this size and scope. Snowball sampling techniques were also used, as the SHINE counselors were encouraged to spread the word about the project and tell their colleagues.

Data collection

As this project intended to use human research subjects, this researcher submitted an IRB application to the Smith College School for Social Work Human Subjects Review
Committee (HSRC). As is customary the committee asked for changes to be made to the application and final approval was granted on February 9th, 2010. As part of the HSRC application an Informed Consent form (see Appendix B) was included. The procedure for obtaining Informed Consent was as follows: when a potential participant was deemed eligible to take part in the project, the Informed Consent form was mailed to the participant. After completion of the interview a list of area resources was given to the participants.

The data collection instrument used for this study was an open-ended interview guide (please refer to Appendix C). The interview guide provided scaffolding for the interviews but allowed this researcher to explore in-depth unexpected responses and allowed the interviews to be conducted in a comfortable, conversational manner. The interview guide attempted to measure respondents’ level of civic engagement by listing a number of civic activities and asking respondents’ whether or not they had participated in these particular activities. For each “yes” answer, this researcher followed up by asking whether the experience of falling into the donut hole affected the likelihood that the respondent would participate in the activity in the future. Thus the intention was to explore any changed civic behavior due to the donut hole experience.

Separately, the interview guide asked respondents to describe their experience falling into the donut hole. Follow-up questions included asking participants whether or not they had changed their medication use because of the donut hole, and what their general reaction was when they found out they’d fallen in. This researcher also asked whether or not the experience had caused respondents to change their feelings towards their health insurer, towards the state government, and towards the federal government.
In April it was decided that to enhance the thesis project this researcher would interview two health insurance professionals. At this point the original interview guide was adapted and a new guide was created (also included in Appendix C). Many of the questions remained very similar but they were geared towards the perspective of a professional as opposed to a senior. As was the case with the interviews with the donut hole victims, informed consent was sent to the health insurance professionals and mailed back to this researcher.

Data analysis

The strategy used to analyze data in this project was theme analysis. Through theme analysis responses to these questions were coded and organized into key themes; attention was paid to both manifest and latent content.
CHAPTER IV
FINDINGS

The question asked by this thesis was: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement? This researcher suggested two opposing hypotheses. The first is that because the coverage gap is a policy that treats beneficiaries like a dependent target population instead of advantaged as seniors are used to, elders will start to behave, think, and feel more like powerless, positively constructed target populations. The second hypothesis is that because seniors are uniquely able and willing to protest changes to entitlement programs that they perceive and experience as threatening, those who fall into the donut hole may react by becoming more politically engaged and working to make political change.

This researcher interviewed both donut hole victims and health insurance experts who counsel seniors. From the analysis of the data generated by the interviews with the victims, one major finding was that the donut hole experience affected views and feelings towards insurance and government in a number of important ways, each of which will be spelled out in this chapter. Another major finding was that respondents reacted to the donut hole by feeling an increased sense of powerlessness, suggesting that of the two hypotheses the first is closer to describing the felt experience of donut hole victims. In terms of impact on civic engagement the findings were less clear. Perhaps because the research sample was small and the respondents were not very civically active to begin
with it was difficult to assess whether or not the donut hole experience had an impact on levels of civic engagement. That said, there did seem to be an almost paradoxical response: the seniors interviewed reported an increased desire to do something about their situation, and at the same time they reported feeling less able to affect change because of what had happened.

In many ways the results from the interviews with the health insurance counselors mirrored one another. The counselors both said that they found Medicare Part D to be a very confusing program. They reported that donut hole victims who they’ve worked with go through stages of emotions, from initial shock and confusion, to anger, to helplessness. They reported that seniors seem to aim their angry feelings towards both government and private insurers. Both counselors reported anecdotes of seniors reducing the use of important medications because they could not afford to pay for their prescriptions. And both also reported finding an increased sense of powerlessness on the part of the donut hole victims who they worked with. Looking at all of the data together, the theme of powerlessness emerges as one of the most important in this study.

Sample

Two seniors contacted this researcher expressing an interest in participating in the project. Both were deemed to be eligible, and interviews were conducted with these individuals in March.

The first interview was conducted by telephone per the respondent’s request – he was unable to meet in person due to health and travel issues. The respondent was an 87-year-old married Caucasian man. Informed consent was mailed to this gentlemen and he returned the form via mail.
The second respondent was a 70-year-old divorced Caucasian woman. This woman suffered from chronic anxiety and worked as a personal care attendant. After going over the informed consent form with this woman and mailing her a copy of the form, she agreed to sit for an in-person interview at her home.

When it became clear that this researcher would not be able to recruit the desired number of participants the decision was made to augment the research by interviewing two health insurance experts who counsel seniors.

Two counselors with a deep familiarity with Medicare Part D were interviewed for this project. Both were Caucasian women, social workers, and health insurance experts. One was an administrator for the SHINE program, a national network of volunteers who provide health insurance counseling services for Medicare eligible seniors. The second counselor was a resident services coordinator for a number of subsidized housing sites. She worked to connect her tenants – low-income seniors – with programs and services.

Before interviewing these professionals two copies of the Informed Consent were sent to each of them; they returned a signed copy of the form to this researcher.

Results from interviews with seniors

An analysis of the data showed that the respondents were generally happy with their health insurance before the donut hole experience. The seniors appreciated Medicare and their other previous health insurers, with one saying it had “covered most everything” and another calling her health insurance “perfect” before the donut hole. Respondents were seniors who were proud of having played by the rules and took pride in their long work histories. Both respondents were resourceful seniors who accessed
help when possible, be it through hospital social workers or SHINE health insurance counselors.

In terms of how they found out about the donut hole, one respondent reported finding out unexpectedly when the price of their medications suddenly increased, saying “I called in for a prescription and it was triple the price of what I had been paying, and I thought it was an error on the part of the pharmacist.” Respondents did not report reducing the use of their medications; one did say that although her doctors had suggested she get a second knee replacement, “the money’s not there” to do it. Respondents lamented the fact that deteriorating health had lead them to fall into the donut hole.

Respondents expressed emphatically that it was critical to take prescribed medication and so paying for meds was an unfortunate necessity. “I can’t afford it but I need it,” said one respondent. Both participants said that of the medications they took it was only a couple of very expensive medications that caused them to reach the donut hole. One respondent referred to these expensive medications, saying “Those big monsters, they put you in the hole quick.” Both respondents’ said that because of this, seeking out generic drugs was critically important. When one previously expensive brand-name drug began being offered in generic form, one participant said it made “a big difference cash-wise.”

When describing how the donut hole experience impacted their lives, one respondent said the result was “worry, worry, worry,” and the other said the experience had taken a “mental toll.” The first participant wondered how she would cope if another health issue came up. “How in the world am I gonna get through if something else happens to me?” The other respondent reported that since he and wife’s medical
expenditures were increasing every year as their health declined they were reaching the donut hole quicker and quicker. This knowledge that each year they’d be reaching the donut hole faster increased the respondents’ anxiety.

In terms of feelings towards health insurance since the donut hole experience, the female respondent directed harsh feelings towards her Part D insurer. She thought they should be clearer when dealing with customers. To help her understand her benefits, the company sent her “packages like this thick” and that the language was “not for a layman such as myself.” Further, she felt as though the company followed procedures that were intentionally confusing, and that she received large bills very suddenly; “they pop it on you, like,” she said. This respondent also suggested that her Part D insurer harbored animosity towards her as a consumer. When she called up initially to ask about the increased price of her meds “somebody giggled” at her.

The male respondent did not connect his feelings about the donut hole with Medicare, saying, “well, Medicare… has nothing to do with the donut hole. It’s with” his part D insurance company, “that’s the outfit that I end up in the donut hole with.” When asked about his feelings towards his part D insurer, he said he was “real disappointed. Surprised.” He went on to say that “they aren’t bashful,” noting that since Medicare was unveiled in 2006, the annual change in his monthly copay as well as in the amount of money spent in the donut hole “has increased a hell of a lot.”

When asked whether or not the donut hole experience had changed their feelings towards government, both respondents replied that it had. The male respondent said he was upset by the way Medicare Part D was enacted, saying that “the government gave an open checkbook to the pharmaceuticals so they could run their prices to whatever they
want.” He also said that he thinks the government doesn’t care about what average
citizens are paying for their drugs. The female respondent noted a similar feeling, saying
that she thinks the government “should be looking at the little fella’ instead of the Tiger
Woods of the world.”

In terms of civic engagement neither respondent reported a change in their level
of civic engagement since the donut hole experience. The male respondent, whose
history of civic engagement included serving on a committee of the Knights of
Columbus, said that he was no longer engaged civically but because of declining health
and time spent in Florida, not because of the donut hole. He said he would vote for a
politician who represented his views on health insurance issues if given the chance. His
main feeling about civic engagement since the donut hole was that he did not feel as
though there was much he could do to make his situation better. “You’d like to be more
active, and wish you could do something, but the problem is, what can you do?” he said.

The female respondent said that she used to be a very involved parent. She also
said that recently she joined a union for personal care workers in Massachusetts. In terms
of civic engagement and the donut hole, she reported that because of her declining health
and the health of her relative who she took care of, she was not likely to get involved
with any particular civic activity. Her main response to the donut hole experience has
been that she wants to maintain her health and “eat my Wheaties.”

Results from interviews with health insurance counselors

Both counselors learned about Medicare Part D and the coverage gap when Part D
was unveiled in 2006. Both reacted similarly as they began to familiarize themselves
with the policy: The first said she remembered thinking, “How absurd is this?” and she
now thinks about Part D as a “big black hole of misunderstanding. The second counselor thought the plan was “horribly confusing.”

In characterizing seniors’ reactions to the donut hole, the SHINE administrator said that people don’t understand it until they actually hit the donut hole. A primary reason for this is that the donut hole is calculated based on retail cost of medication and not on out-of-pocket spending. In the administrator’s view seniors only understand their out-of-pocket costs, so when they find out about the donut hole there is a sense of shock. The resident services coordinator offered the same assessment.

In terms of emotional reactions to the donut hole, the SHINE administrator saw seniors go through stages of emotion: confusion, shock, frustration, anger, then fear. The resident services coordinator noted something similar: initial shock and confusion, then anger, then a sense of resignation.

Both counselors said it is very difficult to explain the workings of Part D to seniors and that even after explaining it many seniors do not understand. The SHINE administrator said that “it doesn’t make sense why insurance would just shut off at one point in time, to pick up at a later point….regardless of how you explain it it’s very hard to understand.” To help clients understand, she likens the drug insurance to a faucet, and says that when the donut hole hits the “faucet shuts off.” The resident services coordinator said she explains the donut hole very succinctly but that even then seniors don’t seem to understand it until they’ve fallen in.

The resident services coordinator pointed out that whereas in 2006 there was an almost complete confusion around Part D, in the past few years counselors and social workers have gotten much better at doing outreach and making sure that eligible seniors
got enrolled onto Prescription Advantage. Also, whereas today health insurance counselors and computer savvy seniors can log onto www.myMedicare.gov, enter their prescriptions, and choose which plan suits them best, in 2006 this was much more difficult to do. So although confusion still exists, there are more resources, both human and technological, to assist seniors as they sort through their insurance options today.

That being said, the counselors reported that the information given out by the insurance companies to explain the workings of Part D were very hard to understand. “Most of the literature that seniors get is very unclear because of all the legalese that’s required,” reported the SHINE administrator. The service coordinator likened health insurance literature to a car insurance policy. “Do you read your car insurance policy?” she asked rhetorically. “I don’t. You just pay it. And I think that’s how the Plan D has evolved.”

Anecdotally both counselors described the way in which many donut hole victims discover that they have fallen into the gap. They go to the drug store to purchase a drug, the pharmacist tells them they must pay full price, which surprises them because they’ve been paying only a copay. The pharmacist often does not have the ability to tell whether or not the senior is in the donut hole, so the senior will leave the drug store, still confused, and often without their medications. They call the insurance company and struggle to get a customer service representative on the line. It is at this point, when the senior is still without their meds and getting quite angry, that they will hopefully reach someone with some knowledge of Medicare. “That’s typically when we get the phone calls,” reported the SHINE administrator, “that’s when SHINE hears from these folks the most.”
Both counselors said they had seen seniors change the use of their medications due to high costs. The SHINE administrator reported that although she counsels seniors not to reduce the amount of medications they’re taking, they do it anyways. She’d worked with one senior who cut their heart medication into half-dosages because they could not afford to pay for it. The resident services coordinator had a nearly identical story, saying she’d had a client start to take a heart medication every other day to get “two months out of a one month supply.” The counselors said that even seniors who do not reach the donut hole are taking less medication than prescribed because of the rising cost of drug co-pays.

In terms of where seniors direct their feelings about the donut hole, both counselors said they found that many directed anger towards both the government and towards the private insurer attached to their Part D plan.

When asked how they saw seniors responding to the donut hole in terms of civic engagement both counselors said it was rare to see an increase in engagement. In one instance reported by the SHINE counselor, a senior contacted their local state representative to let them know that they were not able to be helped by SHINE and had no one who could offer assistance. The representative then contacted the SHINE office asking if they could assist the senior. “The legislator just did not hear the message,” the SHINE administrator said.

Both interview respondents reported a sense of resignation among the seniors that they worked with. The SHINE administrator said that especially among older seniors she found many had given up on any form of activism. “A lot of them are just feeling like they just can’t fight City Hall on this,” she said at one point in the interview. Later she
said she saw seniors throw up their hands at the sheer confusion caused by their drug plans. “They just say, ‘I can’t beat the man,’” she reported. The resident services coordinator saw something quite similar, saying that health insurance issues seem “too big, too overwhelming….After the initial anger and shock there’s just a resignation, a ‘what can I do about it?’”

Another key issue that both counselors brought up is the issue of pride. They reported that many seniors they work with do not like asking for help, and thus they sometimes forego assistance out of a reluctance to ask. “Oftentimes they don’t ask so they’re not aware that help is available,” reported the SHINE administrator. The service coordinator said that when it comes to assistance programs, “it’s like they feel like they’re begging, they’re asking for a handout.”

The results of the interviews with the health insurance experts show multiple points of agreement, despite the fact that these professionals work in different areas of Massachusetts and with different senior populations. The important themes gleaned from these interviews as well as from the interviews with the seniors will be extrapolated and discussed in detail in the final chapter of this project.
CHAPTER V
DISCUSSION

Pierson (1993), who wrote that social welfare policies “must be seen as politically consequential structures,” (p. 624), sounded a call for action at the end of his article. He urged researchers to study in particular the way that policies affect “mass publics” (p. 605), his term for the general citizenry. Too often, the author noted, policy feedback scholars focus their attention on bureaucrats, politicians, and interest groups, while ignoring large swaths of the lay population.

This thesis project was an attempt to explore the relationship between a public policy and the mass public the policy purports to serve. When he signed the bill into law in 2003, President George W. Bush hailed Medicare Part D as a “victory for all of America’s seniors” and the “greatest advance in health care coverage for America's seniors since the founding of Medicare” (Rosenbaum, 2003, p. A22). Nearly seven years later it is important to look at how the law has interfaced with seniors on the ground level. Exploratory qualitative research is an ideal vehicle for answering the kinds of questions posed by this research project, as this kind of analysis attempts to get at the felt experience described by research participants.

Recruitment was a challenge throughout this thesis project, and attention will be paid to that fact throughout this discussion section. Although initially this researcher intended to recruit an n of twelve participants, in the end two seniors were interviewed as well as two health insurance experts who counsel seniors. Despite – or perhaps because
of – this small sample size, it was striking to sift through the data and find a number of intriguing similarities among the feelings expressed by the respondents. Although the sample was small, the themes which emerged are large, and it is this writer’s hope that future research continues the type of inquiry conducted here.

From an analysis of the data laid out in the findings chapter a number of key themes emerged. In this chapter five of these will be discussed. The themes discussed here are not always discrete areas of focus; elements of one may overlap with another.

*Powerlessness/ resignation*

This thesis project asked the following question: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement? Answers to both parts of the thesis question can be understood in terms of powerlessness and resignation.

In the literature review Schneider and Ingram (1993) wrote about the messages sent to target populations by social welfare policies. Historically seniors have been a positively constructed target population, meaning that they are often described as honest, hard-working, and worthy of welfare. The authors wrote that positively constructed target groups can be either weak (dependants) or strong (advantaged), and that social welfare policies send messages to these groups that create or reinforce an understanding of themselves as either dependant or advantaged. Schneider and Ingram argued that government policy treats dependants as needy and powerless, and that these groups oftentimes respond with disinterest and passivity. Further, these groups see their “primary form of interaction with the government… as applicants or claimants who are applying for services to a bureaucracy” (p. 342).
This researcher hypothesized that the coverage gap, with its confusing structure and costly financial burden, might be the kind of policy described by Schneider and Ingram that would send particular messages to seniors in line with messages normally received by positively constructed dependant groups. If this hypothesis were to be backed up by the data, respondents would report feeling helpless, confused or unimportant. Also, if this were the case, seniors would not respond with increased levels of civic engagement, and in fact they may report a reduced desire to engage. In a number of instances this hypothesis was borne out by the data.

The most prominent theme of the Findings chapter was the theme of powerlessness. One senior, when asked whether the donut hole experience had made him want to engage civically, asked rhetorically:

Well, yes, you’d like to be more active, and wish you could do something, but the problem is, what can you do? That’s the whole question, no matter who you talk to, they agree it’s a problem, people that I talk to, mostly seniors, but they say where do you go? Who do you approach? It’s all done for you. We have no say when they increase a price of a drug or if they change the limits on insurance. We have no say. Where can a person go to change that?

One of the counselors interviewed for the project noted something similar. “I think they pretty much give up,” she said, when asked about how seniors respond to the donut hole. She went on, “I’m not finding a lot of activism with the clients I deal with… A lot of them are just feeling like, “I can’t fight City Hall.”

The issues of powerlessness and resignation raise a number of important questions. As Campbell (2003) wrote, seniors have a unique history of political activism across class lines. What about the coverage gap seems to neutralize these activist instincts? Is it the fact that seniors seem to be up against both the government and the
private insurance companies? Is it that the financial wounds inflicted by the policy are such that a political response seems futile? What about the policy would have to be changed to bring about a different response?

In thinking about these questions, the work of Soss (1999) – outlined in the literature review – seems cogent. The author researched two groups of welfare recipients, half enrolled in a public assistance program (AFDC) and the other half in a social insurance program (SSDI), and found that AFDC recipients tended to be less politically active. He suggests that this is part due to the stigmatizing and stressful nature of program participation, something that comes to mind in listening to thesis respondents talk about their experiences with Part D. Soss wrote:

> Clients are given little opportunity to make consequential choices about their own life; they deal with the agency when they are summoned, and they must respond to the detailed questions and directives of their caseworker. What image of government does this convey to a group that already tends to be disadvantaged in political life (p. 376)?

Perhaps, then, the Part D program conveys an unflattering image of government and health insurers to the senior community. Although seniors have overwhelming choices in picking a Part D drug plan, they do not have a choice about the donut hole. Communication with insurance companies is seen as a frustrating and sometimes futile endeavor. In this light, a sense of powerlessness and resignation seems somehow understandable. “Prescription part D is this black hole of misunderstanding,” one of the insurance experts said. In thinking about whether to advocate for themselves, “they [seniors] just say, ‘I can’t beat the man.’”

*Feelings towards government and insurance companies*
While the theme of powerlessness speaks to a political response, how does the experience of falling into the donut hole affect the political views of seniors? Do donut hole victims report any changed views towards the government, towards Medicare, or towards their health insurance company?

All of the respondents reported having some kind of strong feelings regarding the donut hole, and the results presented in the Findings Chapter reveal multiple objects of those feelings.

Both seniors interviewed reported strong anger towards their Part D insurer. The female senior respondent expressed thinly veiled indignation towards her insurer. While she did express a feeling that government was unconcerned with the “little fella,” she saw her private insurance company as the primary cause of her donut hole experience, and her tone and speech when speaking about the company struck this researcher as anger-filled.

The other senior respondent blamed his Part D insurer as well, saying that Medicare “has nothing to do with the donut hole.” For him, too, the culprit was his Part D private insurer. He expressed dismay not only at the donut hole but also at what he saw as sharp monthly increases in his monthly insurance co-pays. In terms of feelings towards government, he said he thought the government:

> gave an open checkbook to the pharmaceuticals so they could run their prices to whatever they want… It makes me feel like apparently the government didn’t care too much about what the people are paying, what’s happening to their pocket books.

One health insurance counselor explained that since the donut hole was “designed by the insurance companies and signed off legislatively”, seniors “do get very angry at both the private insurance companies and Medicare in general.” But besides anger, the
health insurance counselors noted a range of other emotions that they detected among donut hole victims. Both counselors said that a deep sense of confusion was common among seniors they worked with, and both said that the insurance companies don’t issue clear guidelines for their consumers. One counselor said that the literature sent out by the health insurance companies is written in “legalese.”

One of the seniors interviewed took her anger in an interesting direction. She suggested that the health insurance companies themselves harbored animus towards consumers like her. Thus she said that a company representative “giggled” at her when she called to ask why she was suddenly paying full price for her medications. Later she said one of her insurers was a “shady company” and was “jerking” her around. Her sense that others were mocking her seemed to extend beyond just the insurance companies. When she fell into the donut hole she asked her pharmacist why her drugs were so expensive. “This is what your insurance is allowing,” she recalled him saying to her, “you have a problem with that?” At her most recent medical visit, her doctor, she said, had fed her a “ration of baloney.” Her experience with the donut hole had been so negative that it seemed she now saw most all health insurers or health care professionals as complicit in a villainous scheme.

Mental toll

Another theme which emerged in this project is that the experience of falling into the donut hole exacted a mental toll. One senior reported that “mentally, it’s costing you more and more.” When asked to elaborate, the respondent made it a point to say that “I don’t mean we got sick or anything like that.” He then described a recent interaction around trying to procure a medication:
We went to the drug store with the prescription, and they said, ‘the insurance company won’t cover this, you gotta get authorization from the doctors and somebody else.’ So I went back to my doctor, and he says I’ll give you a prescription for a substitute.’ So I went back to the drugstore with the new prescription and when I went there they said, ‘Hey, when you came here with the first prescription automatically we look for generics, and the price was $500, and that was the price, so you’ve got to get an authorization from the company, from the doctor, back to the insurance company, then from CVS.’ And I’m still waiting for that to come through, but when that comes through supposedly it’s a real expensive medicine, and I don’t know if the nurse, she called the doctor and the insurance company last week, and they claimed they’d do something. Now here it is Wednesday and I haven’t heard a word yet.

In reading through this respondent’s quote it is a bit difficult to try and piece together the chain of events he describes, and yet he thoroughly conveys his experience of trying to contend with an expensive and confusing system. This anecdote, about an elderly man and his wife, both battling health issues, ferrying back and forth between pharmacy, doctor, nurse and insurance company, illustrates the kind of experience that by its frustrating nature can exact a mental cost.

The other senior reported a similar feeling. “It’s worry, worry, worry,” she said, calling herself “panic-stricken” when she first fell into the donut hole. For her the mental toll was connected to a fear of unknown future costs, a concern that one more expensive medication or procedure could sink her. She worried that should “something else” happen to her, she could become homeless.

For both of these respondents the donut hole experience seemed to be connected to their emotional health. The first respondent sounded tired and exasperated when describing the story of trying to procure the medication, while the second reported having a diagnosed anxiety disorder that was exacerbated by financial concerns related to the donut hole.
Behavioral response

In the review of the literature a number of articles were discussed which pertained to Medicare and spending habits and medication adherence. Zhang, Donohue, Newhouse, & Lave (2009) looked at the effects of the donut hole on drug spending. The authors found that a quarter of those enrolled in an individual drug plan with no donut hole coverage fell into the donut hole and that these beneficiaries reduced medication use by 14 percent once they fell in. Stuart, Simoni-Wastila, & Chauncey (2005) conducted a simulated exercise estimating total and out-of-pocket drug spending in 2006 for an average Part D enrollee. These researchers found that donut hole victims reduced their drug spending and that the impact of the donut hole was magnified for beneficiaries with three common chronic diseases: diabetes, chronic lung disease, and mental illness. Madden et. al (2008) studied the impact of Part D on cost-related medication nonadherence among seniors and found a small but significant overall decrease – 2.6 percentage points – in nonadherence following Part D implementation.

Looked at together these studies strongly suggest that for certain seniors Part D does cause changed behaviors, oftentimes reduced drug spending. Both seniors interviewed for this thesis stated that they purchased all of the drugs prescribed to them, although they did look for generic substitutes whenever possible. One of the seniors did report that she was going to forego a suggested knee replacement operation because “the money’s not there.”

The health insurance counselors, however, said that in their work experience they had oftentimes come across seniors who reduced or stopped taking prescribed medications. Interestingly both counselors said that they’d worked with seniors who had
reduced the use of their heart medication – one counselor had a client who physically cut their pill in half, while the other had a client who reduced their use to every other day. In each case the client worked to get two months of medication out of one month’s supply.

While it is a reach to draw strong conclusions from the health insurance counselor’s anecdotal evidence, the similarities in their stories are important to note. The underlying implication, and the reason both health insurance counselors may have chosen heart medications as an example, is that donut hole drug costs are such that even vitally important medications are not always taken as prescribed.

Role of social work

One theme which emerged from the study was the important role that social workers have played in helping many seniors avoid the donut hole. Both counselors said that as opposed to in 2006, when many seniors tried to navigate Medicare Part D on their own, nowadays a large number of social workers and SHINE counselors fan out each year to help eligible seniors enroll in some form of insurance assistance. Assistance programs vary state-by-state – the Massachusetts drug assistance program is called Prescription Advantage – and some donut hole victims enter the gap when they could have received some kind of state aid.

One of the insurance counselors stated that in “the past few years we’ve done a big push to get people enrolled” at the elder services agency where she works. The other counselor said that there is a stark difference between the knowledge that exists about Medicare Part D now as opposed to when the policy was first enacted:

Back in 2006 the system was very vague and ambiguous and people didn’t know. They would pick, well, ‘I like Blue Cross Insurance, they have a good name, so I’m just gonna pick Blue Cross,’ because they couldn’t compare anything and
look at anything. But now I think that you can go to a CVS pharmacy or a Walgreen’s or go to an outreach person at a senior center.

The fact that more and more professionals are becoming familiar with the basics of Medicare Part D and the eligibility criteria for Prescription Advantage is important and laudable. For social workers, and in particular geriatric social workers, this knowledge should be even more widespread. Knowing when an older client might be eligible for an assistance program or when they may be in danger of falling into the donut hole should be a standard part of biopsychosocial assessment – the stakes are too high for it not to be.

**Recruitment challenges**

The original goal for this thesis project was to attain an _n_ of twelve participants. The initial recruitment tool was a presentation to a group of over forty SHINE counselors in the greater Boston area. When it became clear after a few weeks that recruitment was going slowly, additional tactics were employed. This researcher sent out the flyer to a number of area listservs and posted the flyer at local senior centers. Still the project fell far short of meeting the desired _n_.

As this writer would come to learn later, it is a common pitfall among researchers to “overestimate the pool of available patients who meet the inclusion criteria and would be willing to participate in research studies” (Gul & Ali, 2010, p. 228). In hindsight this researcher underestimated just how challenging recruitment can be, and a brief review of the literature on recruitment found that research on the geriatric population poses a particular set of challenges.

Ridda, MacIntyre, Lindley, and Tan (2010) lay out a series of barriers to recruiting older research participants. Most elderly people are more willing to consider
participation in studies when they see some tangible benefit to their well-being and reluctant to participate when they do not. Besides the opportunity to talk at length about their experience in the donut hole my study did not offer tangible benefit to the participant. The authors also note (and this fact was corroborated by the health insurance counselors interviewed for this study) that seniors are a particularly prideful group who tend to hold certain beliefs about “help-seeking behavior” (p. 903). The authors urge researchers to use personal recruitment strategies that employ direct contact with potential participants, family and community members, and health professionals. Also important among the senior population is the influence of gatekeepers – caregivers and family members of seniors. It is not uncommon, the authors write, for “family members and carers to be reluctant to allow participation” (p. 904) in research projects. The authors thus urged researchers to enlist the cooperation of gatekeepers in recruiting elder participants. While it is hard to know whether or not gatekeeper influence had any effect on recruitment in this thesis study, this researcher did not reach out to gatekeepers while recruiting for this study.

Boles, Getchell, Feldman, McBride, and Hart (2000) set out to conduct a study on seniors and aspirin use as part of a randomized clinical trial for Kaiser Permanente. When the researchers ran into recruitment difficulties they decided to conduct focus groups among “eligible refusers” (p. 283) – those who were eligible for the study but not interested in participating. Participants in the focus groups cited a number of reasons for not wanting to partake in the project, among them health concerns, confusion about the exact nature of participation, wanting to know whether there was any personal benefits to them, not wanting to be a guinea pig, and not wanting to upset the health balance of their
lives. Importantly, too, the authors found that many seniors did not express a belief that participation in the research project was altruistic. “Had our recruitment materials more strongly proclaimed the importance of our research,” the authors wrote, “we may have attained greater response” (p. 291).

In a review of the literature on research of older adults, Hawranik and Pangman (2002) delineated a number of factors which can affect recruitment. They note that physical factors like chronic illness and impaired sensory function can hinder ability to participate in research. They too cited the influence of gatekeepers, noting that “spouse and adult children of elderly individuals have been found to adopt a guarded attitude towards any procedure that involves their family member” (p. 172). They also found participation rates increase when seniors perceive a personal benefit for their participation. In terms of age, the authors found that non-participation in research “has been shown to have a linear relationship with age.” They noted that “those 75 and older… have the lowest response rate of all older adults” (p. 174).

Gul and Ali (2010) offered practical suggestions for researchers when it comes to recruitment. They urged researchers to make participation convenient for participants, to provide monetary compensation when possible, to make the research participant-centered by addressing participants’ needs and interests, and to tailor presentations about the rationale for the study depending on the cultural background of potential participants. On the whole, the authors’ contention that research should balance scientific rigor with the needs of potential participants seems important. In light of the recruitment problems in this thesis study it is important to ask: were the needs of participants sufficiently taken into account? Reflecting upon this question, perhaps more could have been done. Maybe
this researcher, by engaging seniors directly in community-based settings, could have explained the benefits of the project for participants and for seniors in general. Maybe transportation needs could have been addressed more directly, and perhaps reimbursement for travel could have been offered. It could have been helpful, at the outset, to have done informal interviews with a couple of key informant seniors. This researcher could have asked what scaffolding they would want in place in order to participate in this type of project. In this way, this researcher could have better understood and addressed the needs of potential participants.

Crosby, Salazar, DiClemente, and Lang (2009) offered a defense of sorts for researchers attempting to do work with hard-to-reach populations. The authors stressed that methodological rigor must be balanced by the “necessity of conducting studies in populations where inherent barriers exist relative to key issues such as recruitment” (p. 2). They asked whether there is a tendency to overvalue findings derived from large samples and undervalue those from small samples, a bias which could steer research away from studies involving hard-to-reach populations.

Through this brief literature review a number of important issues come to light and a number of questions are raised that have direct bearing on the recruitment challenges encountered by this researcher. In hindsight, should incentives have been offered to potential participants, and if so what kind? Should gatekeepers somehow have been enlisted where appropriate? Should this researcher have gone out directly into the senior community instead of trying to recruit first through the SHINE counselors? Should more time have been allotted to the recruitment phase of this research project?
And could the potential benefits of the project have been spelled out more clearly in the recruitment materials?

While it is impossible to know exactly what techniques would have yielded the desired number of participants, it is certain that if this researcher could do this project again he would have dedicated more time to recruitment and would have worked to engage seniors directly from the start in addition to speaking with the SHINE counselors. In future research endeavors this writer will bear in mind the recruitment challenges of this thesis and will plan accordingly.

Conclusion

Two points deserve reiteration here as this discussion section comes to an end. The first is that the barriers to recruitment outlined in this section and the subsequent small sample size force us to view the findings of this project with a skeptical eye. At the same time, the words of the seniors and the health insurance counselors interviewed for this project contain a number of common threads which are important and worthy of further study. Pierson (1993) wrote that the manner in which a public policy interfaces with constituents is an understudied locus of investigation. If any point emerges from this work, it is that seniors seem to have political responses to the donut hole which merit further scholarship.

This thesis project asked the question: How has falling into the donut hole affected seniors’ views and feelings of health insurance and government, and how has this experience informed their sense of civic engagement? Responses to the donut hole were found to fall into five key themes.
The most prominent finding was that seniors seem to respond to the donut hole experience with a profound feeling of powerlessness and an accompanying sense of resignation. The second important theme was that seniors do report changed feelings towards government and towards their health insurers. In particular donut hole victims report strong feelings of anger towards their Medicare Part D private insurer, despite the fact that the Medicare guidelines for the donut hole are consistent no matter who the insurer. The third theme was that donut hole victims report a mental toll; the mental health effects of falling into the donut hole would be a ripe subject for further investigation. Fourth, from interviews with the health insurance counselors it does appear that seniors do reduce the use of medications once they hit the donut hole. Finally, the health insurance experts reported that social workers have done a better job over the past couple of years in signing up seniors for assistance programs to get them insurance coverage for when they hit the gap. An important implication of this finding was that social workers must continue to monitor the health insurance statuses of their older clients and keep abreast of changing state and federal regulations.
References


February 9, 2010

Ben Weiss

Dear Ben,

You have done a fine job on your few revisions and we are happy to give final approval to this very interesting study. I would be interested to know how you got interested in this topic.

Please note the following requirements:

**Consent Forms**: All subjects should be given a copy of the consent form.

**Maintaining Data**: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

**Amendments**: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal**: You are required to apply for renewal of approval every year for as long as the study is active.

**Completion**: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your study. I would guess you will get recruits as this is something elders talk about a lot…the cost of health care! I’m sure there will be feeling about the original promise in health care reform to get rid of the donut hole and now the failure to get a health care bill passed.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Carla Naumburg, Research Advisor
APPENDIX B: INFORMED CONSENT FORMS

Informed Consent – For donut hole respondents

Dear potential participant,

My name is Ben Weiss, and I am a graduate student at the Smith College School for Social Work. For my master’s thesis I am conducting a study of seniors who have had the experience of falling into the Medicare Part D coverage gap, or donut hole. When Medicare Part D was unveiled on January 1, 2006, one controversial feature of the plan was a "donut hole" or "coverage gap". If a beneficiary spent over $2,250 on drugs in a given year, Part D stopped paying drug premiums until he or she had spent $5,100. This gap in coverage required some beneficiaries to pay thousands of dollars out-of-pocket. The purpose of the study is to bring attention to this important feature of Part D and to find out what this experience is like for seniors. The data collected in this study will be included in my thesis and will be shared at Smith College School for Social Work. All individual participant information will be kept confidential.

If you decide to participate in this study, you will be asked to sit for an in-person interview for about 60 minutes. In the interview you will be asked questions about your experience with Medicare Part D. All interviews will be conducted by me; I will tape record and transcribe them. To be eligible for this study you must be a senior citizen (65 years or older) and you must have fallen into the Medicare Part D coverage gap.

This study will ask questions about your experience falling into the donut hole, and about your feelings about government and citizenship. While these questions might cause some discomfort, the purpose of the study is to encourage participants to tell their stories. Because the results of this study will be shared with students it is my hope that the existence of the donut hole can become more widely known for both social workers and the seniors they work with. After participating in this study all participants will be given a list of referrals for local elder service providers. Compensation will not be provided for participation in this study. At the completion of this study I will make available a summary of the findings should you wish to see them.

Confidentiality will be maintained throughout the course of this study. While the data gathered by me will be seen by my thesis advisor and will eventually be presented to the Smith College School for Social Work community, all names corresponding to data will be removed so your name will not be attached to this project in any public form. When quotes or vignettes will be used they will be carefully disguised. All data will be kept in a secure location for a period of three years as required by federal research guidelines. Should I need the materials after three years I will continue to keep them in a secure location. As the researcher I alone will be conducting interviews and transcribing them.

Participation in this study is completely voluntary. You may withdraw from this study at any time before May 15th, 2010, and you may refuse to answer any question at any time. Should you withdraw all materials relating to you will be destroyed. Should
you wish to withdraw or if you have any concerns about your rights or about any aspect of the study, please call me at ________. You may also contact the Chair of the Human Subjects Review Committee at______.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Thank you for your participation in this study. Please keep a copy of this form for your records. Please sign below.

Participant signature_________________________ Date____________

Researcher signature__________________________Date____________
Informed Consent – For health insurance experts

Dear potential participant,

My name is Ben Weiss, and I am a graduate student at the Smith College School for Social Work. For my master’s thesis I am conducting a study of seniors who have had the experience of falling into the Medicare Part D coverage gap, or donut hole. When Medicare Part D was unveiled on January 1, 2006, one controversial feature of the plan was a "donut hole" or "coverage gap". If a beneficiary spent over $2,250 on drugs in a given year, Part D stopped paying drug premiums until he or she had spent $5,100. This gap in coverage required some beneficiaries to pay thousands of dollars out-of-pocket. The purpose of the study is to bring attention to this important feature of Part D and to find out what this experience is like for seniors. The data collected in this study will be included in my thesis and will be shared at Smith College School for Social Work. All individual participant information will be kept confidential.

If you decide to participate in this study, you will be asked to sit for an in-person interview for about 60 minutes. In the interview you will be asked questions about your experience counseling seniors about Medicare Part D. All interviews will be conducted by me; I will tape record and transcribe them.

Because the results of this study will be shared with students it is my hope that the existence of the donut hole can become more widely known for both social workers and the seniors they work with. Compensation will not be provided for participation in this study. At the completion of this study I will make available a summary of the findings should you wish to see them.

Confidentiality will be maintained throughout the course of this study. While the data gathered by me will be seen by my thesis advisor and will eventually be presented to the Smith College School for Social Work community, all names corresponding to data will be removed so your name will not be attached to this project in any public form. When quotes or vignettes will be used they will be carefully disguised. All data will be kept in a secure location for a period of three years as required by federal research guidelines. Should I need the materials after three years I will continue to keep them in a secure location. As the researcher I alone will be conducting interviews and transcribing them.

Participation in this study is completely voluntary. You may withdraw from this study at any time before May 15th, 2010, and you may refuse to answer any question at any time. Should you withdraw all materials relating to you will be destroyed. Should you wish to withdraw or if you have any concerns about your rights or about any aspect of the study, please call me at __________. You may also contact the Chair of the Human Subjects Review Committee at __________.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR
PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Thank you for your participation in this study. Please keep a copy of this form for your records. Please sign below.

Participant signature_________________________ Date____________

Researcher signature_________________________ Date____________
APPENDIX C: INTERVIEW GUIDES

Interview guide – For donut hole respondents

**Experience with health insurance prior to donut hole:**
1. How would you describe your overall experience with health insurance before you fell into the donut hole?
   Follow-up: What kind of insurance did you have before you enrolled in Medicare?
   Follow-up: How would you describe your experience with this insurance?
   Follow-up: What was your experience with Medicare like before falling into the donut hole?

**Experience with the donut hole:**
2. Can you please describe your experience of falling into the donut hole?
   Follow-up: How did you find out about the Part D donut hole?
   Follow-up: When did you find out about it?
   Follow-up: What was your reaction when you found out about it?
   Follow-up: How long were you in the donut hole for?
   Follow-up: Did your change your use of any medications after falling into the donut hole?
   Follow-up: How did your life change when you fell into the donut hole?

**Attitudes towards insurance and government:**
3. How have your feelings towards your health insurance changed since you fell into the donut hole?
4. Has falling into the donut hole affected your views of the state government?
   Follow up: If so, how?
5. Has falling into the donut hole affected your views of federal government?
   Follow up: If so, how?

**Civic engagement:**
6. Have you ever been involved in any of the following types of groups?
   · Fraternal groups (e.g. Lions Club, Rotary Club)?
   · Neighborhood or homeowners’ associations
PTA or school support groups
Any other civic/community organizations

For each “yes” answer to any of the above in question 6, explore with the three follow-up questions below. If answered “no” to all items in question 6, skip to question 7.

Follow up: When were you involved with this group?
Follow up: For how long were you involved with this group?
Follow up: Has falling into the donut hole affected the likelihood that you would be involved with this group again?

7. Have you ever participated in civic life in any of the following ways?
   · Membership in a political club or political party committee
   · Contacting a political official to communicate concerns about an issue
   · Working on a political campaign
   · Voting in an election
   · Serving on any kind of government board or council
   · Contacting a newspaper, radio, or TV talk show to express your opinion on an issue
   · Writing a letter to a local newspaper
   · Signing a petition
   · Contributing money to a candidate, party or political cause
   · Volunteering
   · Participating in a protest, march, or demonstration

For each “yes” answer to any of the items in question 7, explore with the three follow up questions below. If answered “no” to all items in question 7, skip to question 8.

Follow up: When did you participate in this activity?
Follow up: How often did you participate in this activity?
Follow up: Has falling into the donut hole affected the likelihood that you would participate in this activity again?

Demographics:
8. What is your date of birth?
9. What is your marital status?
10. What is the highest level of education you’ve completed?

11. Is your income (choose one):
   a. $12,000 or below  ($22,000 or below if a couple)
   b. 12,000-20,000    ($22,000-32,000 if a couple)
   c. 20,000-28,000    ($32,000-40,000 if a couple)
   d. 28,000-35,000    ($40,000-46,000 if a couple)
   e. 35,000 or above  ($46,000 or above if a couple)

12. Do you identify as (choose one): Black or African-American, American Indian and Alaska Native, Asian, Native Hawaiian and other Pacific Islanders, Some other race, Two or more races, Hispanic or Latino (of any race), White

13. Are you (choose one): Male, Female
Interview guide – For health insurance experts

1. In what capacity do you work with seniors?
2. How long have you been working with seniors on health insurance issues?
3. As a health insurance expert, when did you first find out about the Medicare Part D coverage gap or “donut hole”?
4. What was your reaction when you found out about it?
5. How would you generally characterize seniors’ reaction when they find out about the donut hole?
6. How do you explain the coverage gap to seniors?
7. Have you ever worked with a senior who has changed the use or the type of their medications because of falling into the donut hole?
8. Have you ever worked with a senior who has been impacted in any other way by the experience of falling into the donut hole (i.e. changed spending habits, emotional impact such as anxiety, etc.)
9. What do you find are the primary emotions seniors have towards the donut hole?
   Follow-up: Where do you find seniors direct these emotions? (For example, towards their part D insurer? Towards the Medicare program? Towards the state or federal government?)

10. The research question my thesis asked was whether or not the experience of falling into the donut hole affected seniors’ level of civic engagement. To get at the answer to this question, I listed a number of political activities (Membership in a political club or political party committee, contacting a political official to communicate concerns about an issue, working on a political campaign, voting in an election, serving on any kind of government board or council, contacting a newspaper, radio, or TV talk show to express your opinion on an issue, writing a letter to a local newspaper, signing a petition, contributing money to a candidate, party or political cause, volunteering, participating in a protest, march, or demonstration) and asked respondents whether or not they’d participated in any of these activities in the past. Then I asked whether or not the experience of falling into the donut hole had in any way affected the likelihood that the respondent would participate in this activity again. In your experience working with
seniors, do you think the experience of falling into the donut hole in any way affects the likelihood that seniors will engage civically? If so, how?
APPENDIX D: RECRUITMENT FLYER

Smith College Social Work Master’s Thesis

Have you fallen into the Medicare Part D Coverage Gap or Donut Hole?

Volunteers age 65 and over wanted for a research study

- Study looks at Medicare Part D “coverage gap” which forces some beneficiaries to pay thousands of dollars out-of-pocket
- Purpose of the study is to explore the experience of falling into the donut hole
- Eligible participants will sit for confidential, in-person interviews that will last about an hour in length