

Education and Care Center and Crown Point Health Suites who picked up the slack on my behalf whenever I needed days off or time off to attend to my studies.

Dr. Jason Wasserman who put life into my work by introducing me to Bourdieu's and Foucault's work, and in doing so enriched my view of the world. It is this world view that has helped me develop my skills as a social scientist, to understand agency in context, and use research to expose the symbolic violence to which people are subjected .

My parents who gave me the liberty to grow into the person I am, and who stood by the sidelines and provided me with the care, compassion and love I needed for this journey. The patience with which they have waited for me to finish my studies is finally here.

My husband, who like my parents has let me find my niche in life, and has supported me through the thick and thin of my academic and professional life.

Finally, my children Dhyan and Priyanka, who also patiently supported me and helped me by not demanding too much of my time during the course of my studies.

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ABSTRACT

The purpose of this study was to explore the experiences and perceptions of elderly beneficiaries who have been denied health services by Medicare. With the adoption of devolution and a consumer driven health care system following the Medicare Modernization Act of 2003, informed consumers are essential to ensure equitable access to health care. Examining Medicare consumers' access to care and the challenges they face is important, not only for Medicare recipients but because Medicare's rules and payment approaches for health services are often adopted by private insurers.

Bourdieu's theory of practice and symbolic violence provided the theoretical framework for conceptualizing the structure-agency dialectic of Medicare-beneficiary transactions. The method of this study, including sampling, interview, and analysis procedures, was guided by Interpretive Phenomenology. Semi-structured interviews were conducted with twelve individuals who had experienced denial of Medicare services (four beneficiaries, 65 years and older, and eight proxy navigators who had acted on behalf of elderly beneficiaries).

Of the five main topics and associated themes identified in the analysis, there was strong consensus among respondents in four areas. These were the perception of Medicare at the time of enrollment, the use of Medicare resources, the consequences of denial of Medicare services, and participants' perceptions of Medicare following denial of services. Denial of services was seen by the respondents as having a major physical, psychological, and financial impact. The resulting perception of Medicare was as a cumbersome, difficult to negotiate system where the beneficiary was often the ultimate loser. Variation among participants occurred in the fifth topic area—actions taken in

response to denial of services. Seven respondents told an essentially passive narrative in response to this denial, but five others took a more active, agentic stance, engaging in various ways with the medical system in an attempt to have their needs met.

Exploring lived experiences of beneficiaries and their families when beneficiaries face the challenge of not qualifying for needed medical coverage sheds light on the nature of interactions that take place between Medicare and the respective beneficiaries and their families, and the impact of such experiences. There is a need to expose pitfalls beneficiaries are likely to experience in this climate of cost containment and rationing of health care. Findings of this study and others like it can increase the awareness of beneficiaries and policy makers of the current state of equity of access to health care.

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CHAPTER 1

INTRODUCTION

Statement of the problem

Little is known about the issues and challenges that Medicare beneficiaries face when they experience gaps in the delivery of health care due to denial/termination of services (Antos, 2008; DeJong, 2005; Estes & Linkin, 1997; Krause, 2006). The Institute of Medicines Committee on Quality Healthcare in 2001 adopted “patient centeredness” as one of its six aims for this century (Guterman, Nelson, Rollow & Roman, 2005; Krause, 2006). Its intentions were to focus on “patient’s experiences of illness and health care and on the systems that work or fail to work to meet individual patient’s needs (p.579).” However, with cost containment of Medicare taking center stage in the Medicare debate for reform, issues of patient centeredness and patient’s experiences in health care have been overshadowed and neglected (Oberlander, 2003; Krause, 2006; Oliver & Lee, 2009).

Medicare has the responsibility for overseeing health care benefits for the fastest growing segment of the population, and it also is dealing with the changing dynamics of this population due to the epidemiological transition of longevity and an increased risk of chronic disease and disability (Cockerham, 2007; Kahn & Juster, 2002). Medicare has been lauded as being even more successful than private insurers in containing costs. Its success in establishing equitable access to health care is important as it is a trend setter for private insurers who adopt its rules and payment approaches for health services (Antos, 2008, Svihula, 2008). Although the Medicare program is highly popular with beneficiaries because of the security it affords them, its complex mode of delivery of

services and the varying practice patterns of Medicare providers has created an environment of passive consumerism (Adkins & Corus, 2009; Antos, 2008; DeJong, 2005; Estes & Linkin, 1997).

Access to adequate health care is central for overall health (Aday, Begley, Lairson & Balkrishnan, 2004; Beckingham & Watt, 1995), and low health literacy is frequently cited as a reason for inadequate health care (Aday, Begley, Lairson & Slater., 1993, Fiucane et al., 2002; Hibbard, Jewett, Engelmann, & Tusler, 1998; Williams et al., 1997). Yet denial of services to beneficiaries, increasingly a byproduct of cost containment, occurs irrespective of social categories and cognitive abilities of beneficiaries (Estes & Linkin, 1997). Although numerous litigations regarding Medicare denials of services are being contested in the U.S. courts, and several positional papers have referred to this topic, there is little research relevant to this issue. Studies of the challenges beneficiaries face when navigating Medicare have the potential to address the problems associated with consumers interacting with an hierarchical medical system that strives for equity of access to care, but may fail to deliver. Therefore, the goal of this study is to highlight the interaction of beneficiaries with Medicare with a focus on the consequences of denial of the services that beneficiaries perceive as necessary to maintain or regain their quality of life.

Use of narratives is rare in the Medicare literature. According to Biggs (2001), narrative serves a vital function in opening up the space between description and intention and allows room for exploration of human experiences. By using this approach to give voice to the struggles and experiences beneficiaries encounter while navigating

Medicare, this inquiry has the potential to influence a renewed focus on patient centeredness and the social issues that are grounded in beneficiaries experiences.

Issues Impacting the Delivery of Health Care for Older Adults

Ideology and Medicare reform. Medicare, at its inception in 1965 as part of the civil rights movement and the Great Society program, was designed to alleviate the ravages of illness and poverty for older adults and consequentially their families (Oliver & Lee, 2009; Preston, Chua & Neu, 1997). This government undertaking was intended to protect citizens by spreading the risk across its population, limiting financial risk to individuals (Aday et al., 1993; Svihula, 2008). However, over the past 45 years there has been a general turning away from traditional safety net roles played by the federal government, a decline in legitimating social support for programs for older people, and a deepening concern over the growth and cost of entitlements for senior citizens (Brown, 1999). Consequentially, with the passage of the Medicare Modernization Act of 2003 (MMA '03), values such as competition, individual choice and control, personal responsibility and incentives for private plans, created a shift towards market rationalism and privatization, eroding the social insurance structure that had formed the basis of Medicare (Svihula, 2008). Although the guiding principles of the Medicare Quality Improvement Program (HCQIP) continue to promote equity in access to care and patient centeredness with a vision of “the right care for every person every time” (p. 201), the impact of the restructuring of Medicare is not clear (Guterman et al., 2005; Krause, 2006).

Medicare restructuring to deliver health goods. The major issue policy makers have been debating, according to Preston et al. (1997), is, “How and through what

mechanisms is the cost of health care to the elderly to be contained in such a way that access to and the quality of health care for the elderly would not appear to be limited or compromised?" (p. 152). The restructuring in part has resulted in indirect government control from a distance, allowing the Medicare mechanism to operate by linking together multiple intermediaries consisting of "individuals or groups equipped with particular kind of expertise, but might also be technologies and bodies of knowledge such as accounting, statistics, medicine, operations research, etc." (Preston et al., 1997, p.148). With the passage of the MMA'03, numerous provisions were introduced to address the role of providers, health plans, durable equipment vendors, the consumers and others (DeJong, 2005).

Additionally, the complexity of Medicare increased with the introduction of plan options for its consumers (DeJong, 2005; Oliver & Lee, 2009). The mode of access has changed from equally providing health care to all beneficiaries based on their need to a system of "devolution" (DeJong, 2005, p.9), giving the prerogative to the beneficiary to make informed choices about their coverage (Harris-Kojetin et al., 2007). The passage of MMA'03 has been ultimately responsible for switching from government-sponsored health care for all to one which depends on access based on an individual's choices (Svihula, 2008).

Scholars and advocacy groups question the feasibility and the usability of such a complex delivery of health care by even the best educated (DeJong, 2005; Allsup, 2009 <http://www.disabled-world.com/medical/healthcare/us-medicare/medicare-plans.php>). The restructuring of Medicare has increased the number of older adults considered to be low in health literacy, defined as a lack of understanding of one's health care coverage

(Adkins & Corus, 2009; Hibbard et al., 1998). Low health literacy creates an environment of increased dependency on health care providers (Adkins & Corus, 2009; Béhague, Kanhonou, Filippi, Lègonou, & Ronsmans, 2008; DeJong, 2005). DeJong (2005) and Svihula (2008) consider this restructuring as a ploy to conceal the strategy of rationing and limiting access to care at beneficiaries' expense. However, policymakers and advocates of cost containment refer to this system as promoting efficient high quality care (Basanta, 2007; Guterman et al., 2005).

Medicare health insurance programs offered to the beneficiaries. While Medicare provides health insurance for those 65 and older, a few select categories of people such as people under 65 with certain disabilities and people of any age with End Stage Renal Disease are also included in its scope of care. There are different plans and different combinations of plans that beneficiaries can opt for depending on their needs and status. The different plans are as follows: (a) Medicare Part A covers inpatient care in hospitals and helps cover skilled nursing facility (SNF) care, hospice, and home health care; (b) Medicare part B covers doctors services, hospital outpatient care and health care, and helps cover some preventative services; (c) Medicare part C referred to as Medicare advantage plan, which combines part A, B and usually part D services; and (d) Medicare part D is a drug option that is run by Medicare-approved private insurance companies. This helps cover the cost of prescription drugs. There is an eligibility criterion for the various plans; while some people automatically qualify for premium part A (free), part B and part D services; others are required to purchase their coverage. Also, those 65 and older who are not working and have paid the Medicare taxes when not employed qualify for free Part A services. For those that continue to work past 65 years

of age, Medicare offers these services for a fee. Potential Medicare beneficiaries are required to contact Social Security three months before they turn 65 years of age, and their coverage starts from the first day of the month they turn 65.

There are two main ways Medicare dispenses its health care coverage: original Medicare (traditional plan) or Medicare advantage plan. The original Medicare plan consists of part A and part B plans. The Medicare advantage plans introduced by MMA'03 consists of private insurance companies such as health maintenance organization (HMO) and preferred provider organizations (PPO) that are run by Medicare- approved private insurance companies. They are also called Part C, and include Part A, Part B and usually the Medicare prescription drug coverage (Part D). Those enrolling in either the original Medicare or the Medicare advantage plan have to determine if they need drug coverage and procure it for an extra cost as the plan stipulates. In making a choice between traditional Medicare and Medicare Advantage Plans, beneficiaries are required to compare the services covered, the premiums, deductibles and other out of pocket expenses, the choice of hospitals and doctors the plan offers, the type of prescription drug coverage one needs, the quality of care one desires, and the locations covered by the plan (other states or outside the US) (Medicare & You, 2011). As Medicare part A and part B follow a set criteria for types of specific coverage and do not always cover a 100% of the actual costs, those opting for the original Medicare policy may need to enroll for supplemental insurance (Medigap), a Medicare supplemental insurance policy from a private Medicare approved company. The costs vary by policy and company. Those 65 and over who are Medicaid recipients are eligible

for all Medicare services, and their Medicaid coverage is their supplemental insurance. Those enrolling for Medicare advantage plan cannot be sold a Medigap policy.

Medicare urges beneficiaries to reconsider their finances and their health each year, and accordingly select a plan that suits and meets their needs. Each year during the enrollment period, beneficiaries have the opportunity to change their Medicare health or prescription drug plan based on the cost of the plan as well as what they cover each year. Medicare recommends that its beneficiaries keep abreast of changes with the various policies Medicare provides, as the changes could affect their coverage. As well, this would allow them to take advantage of new coverage options (Bann, Bayen, McCormack & Uhrig, 2006; Medicare & You, 2011).

The reasonable and necessary test to receive Medicare services. While Medicare attempts to provide health care for a population with widely varying demographics, the American Enterprise for Public Policy research has cited Medicare for inconsistent standards of care due to widely varying access and practice patterns of Medicare providers across the country (Antos, 2008; Guterman et al., 2005). Although this is a complex topic and reasons for this inconsistency are multiple, one factor that is pertinent to this research and may be responsible in part for this inconsistency is Title XVIII of the Social Security Act of 1965. This clause stipulates that Medicare will provide benefits covering health care that is “reasonable and necessary for the diagnosis or treatment of an illness or injury to improve the function of a malformed body member” (SSA 1862 (a) (1)).

The two general stipulations that guide the determination of services are: (a) A beneficiaries’ unique condition and specific needs should determine the intervention,

with disregard of the nature of the illness/injury in terms of being acute, chronic, terminal or the possible length of the illness. (AOTA, 2011 <http://www.aota.org/DocumentVault/Surveys/LCD-Outpatient.aspx>); and (b) with services recommended the probability of improvement of the beneficiary's condition should be reasonable and generally in a predictable period of time, based on the health care providers assessment of the restoration potential and the patient's unique medical condition, or the services are necessary to establish a safe and effective maintenance program specific to the disease of the beneficiary (AOTA, 2011 <http://www.aota.org/DocumentVault/Surveys/LCD-Outpatient.aspx>). The gatekeepers that make the determination of services being reasonable and necessary are health care providers (Aday et al., 1993; Karlin & Humphreys, 2007). Although beneficiaries have the right to contest the denial of services and are encouraged to do so, the process is difficult in that (a) it requires familiarity with technology that Medicare uses such as their automated hot line service or website to report complaints; (b) assistance from a Medicare contact person/office who is not always readily available, and (c) the limited time given to beneficiaries to act after receiving notification of discharge from health care facilities (Medicare & You, 2011). Further, studies indicate that beneficiaries are not fully aware of their rights nor of the one-on-one counseling program Medicare has established to help beneficiaries use Medicare (Bann, Berkmen, Kuo, 2004; Olson, Grossman, Fu, Sabogai, 2010)

Medicare has provided a broad overall definition of reasonable and necessary but has not provided specific criteria (Foote, 2002; Karlin & Humphreys, 2007). While various Medicare carriers (contracting private insurers) and fiscal intermediaries of

Medicare are delegated with the responsibility to define and determine reasonable and necessary as they see fit, they further outsource this responsibility to street level health care providers such as doctors, rehabilitation specialists, and other auxiliary health care providers who address this issue on a case-by-case basis. (Aday et al., 2004; Karlin & Humphreys, 2007). In a market economy, a consequence of such an arrangement is that the distinction between being a caring professional and managing their own as well as their organizations' fiscal interests can get increasingly blurred (Aday et al., 1993; Davitt & Choi, 2008; DeJong, 2005). Estes and Linkin (1997) predicted that with privatization and devolution, Medicare providers would resort to strategies to prevent denial of payment from Medicare and maintain their profit margins, ignoring the needs of the beneficiary and transferring the burden of caring to families and the community.

Reasons for denial of services include failure to meet the improvement standard, too sick to engage in Medicare requirements to qualify for a SNF admission (gaming), termination of services secondary to condition not requiring skilled intervention (dumping), and early discharges from hospitals and skilled nursing facilities secondary to lack of a skillable (billable) diagnosis (dumping) (Davitt & Choi, 2008; Estes & Linkin, 1999; APTA, 2011 <http://www.apta.org>). No matter whether the driving force is to terminate or deny services, health care providers attempt to interpret their decisions based on Medicare guidelines and policies (Davitt & Choi, 2008; Krause, 2006). A lack of complete knowledge of the bases for denial of coverage or termination of services by a health care provider, and a lack of knowledge of their right to receive all reasonable and necessary care to enhance their welfare, puts beneficiaries at a disadvantage in contesting the denial of services.

Summary. Medicare is charged with the responsibility of providing effective, efficient and equitable access to care to a highly variable and expanding population. The role of the Medicare bureaucracy has shifted from a social insurance structure that provided health care for all over 65 who qualify for Medicare services, to that of a consumer driven system based on market rationalism. This shift in strategy has transformed Medicare into a complex hierarchical system with a mode of delivery that is reported to be hard to understand by even the best educated. While health care providers are authorized with gate keeping of health care goods based on a Medicare mandate of cost containment and a competitive cost effective practice mandate, these practices are in direct conflict with its principles of equitable access to care and patient centeredness.

Bourdieu's Theory of Practice and Symbolic Violence

The theoretical framework of Bourdieu's theory of practice and symbolic violence is applicable to studying transactions between beneficiaries and the health care system. Although few studies in illness and health care have utilized Bourdieu's theory of practice, this theory is useful as a guide to studying beneficiaries who navigate within a complex hierarchical system such as Medicare. The philosophical underpinning of this theoretical framework is that hierarchical systems are impregnated with unequal symbolic powers (Bourdieu, 1977). Social domination is taken for granted to be natural and is therefore incorporated not just by individuals but also by institutional, social and collective rules of society (Araújo, Montagner, daSilva, Lopez, & de Freitas, 2008; Swartz, 1997). This theory speaks to the unconscious acceptance of domination but also to the potential for resistance and transformational changes (Béhague et al., 2008; Swartz, 1997).

Structure –agency dialectic. In Bourdieu’s theory of practice, the conduct and representations of individuals are viewed as byproducts of the interaction between social structures embedded in our systems and mental schemas based on past and current experiences and objectives of individuals (Bourdieu, 1977; Swartz, 1997, Wacquant, 1992). While social structures mold agentic behavior by constraining and prescribing possible paths, individuals “mental schemas” (mental structures a product of one’s life experiences including the current) guide the individual and collective practices and struggles that seek to conserve or transform these very social structures that impact behavior (Wacquant, 1992). It is this interaction that is the focus of this study and is viewed as a struggle for beneficiaries and their families who endeavor to maintain their quality of life when the odds are against them in a hierarchical bureaucratic health care system.

Fields. To understand the structure–agency dialectic, Bourdieu introduced concepts such as field, habitus and capital (Swartz, 1997). Field in this theoretical framework represents distinct sites consisting of arenas of struggle in social life (Adkins & Corus, 2009; Swartz, 1997). A field is recognized as a system of social positions structured in a hierarchical power relationship in which specific norms, rules, values, and forms of authority apply, where individuals are in constant negotiation striving for desirable resources (Adkins & Corus, 2009; Béhague et al., 2008; Swartz, 1997). The complex health field with Medicare at its epicenter is such a field with rules set by those authorized to regulate the provision of health care. Fields are viewed as being relatively autonomous because although resources and rewards are context specific, they can be transferred across fields to influence the powers of negotiation and the overall agency of

the individuals for rewards in other fields (Béhague et al., 2008; Bourdieu, 1993; Swartz, 1997). This concept of relative autonomy of fields guides research to examine a wide range of factors that may influence behavior rather than limiting investigation to a specific area of activity (Bourdieu, 1993; Swartz, 1997).

Habitus. Bourdieu's theory of practices views social practices as structured by habitus and the interplay between the agent's habitus and their interaction with diverse fields (Swartz, 1997). Habitus is conceptualized as a combination of dispositions and schemas (cultural and symbolic) which predispose actors to a logic of practice within a field. Dispositions stem from the socialization experience where actors internalize social structures and develop a sense of boundaries and parameters for their action within the stratification of a system (field) (Ming-cheng & Stacey, 2008; Swartz, 1997). The internalized cultural and symbolic schemas of habitus, in accordance with the structural limitations of dispositions, generate perceptions, aspirations and practices in social life (Ming-cheng & Stacey, 2008). These schemas correspond to past socializing experiences and work to maximize material or symbolic profit for the individual (Swartz, 1997). Ming-cheng and Stacey (2008) summarized habitus as described by Bourdieu as: "A type of cultural mechanism embodied in social agents, functioning below consciousness, structured yet improvisatory, generative but context-bound" (p.745).

Capital. According to Bourdieu (1977), what empowers actors to be agentic is the possession of resources that he refers to as capital. Capital includes not just material resources but also an accumulation of cultural, social and symbolic resources as necessary to enhance ones position and negotiating powers in a social order (Swartz, 1997). Adkins and Corus, (2009) define the various capitals one can possess as follows:

(a) economic capital is money or goods directly convertible into money; (b) social capital is the actual and potential resources possessed through social relationships; (c) cultural capital includes objectified cultural capital such as material goods (books paintings, heirlooms etc.), institutional capital such as credentials granted by authorized institutions, and embodied cultural capital which involve skills and etiquette acquired through the socialization process. The unequal access and distribution of these resources or capital give rise to power relations, and become the object of struggle within a field (Bourdieu & Wacquant, 1992). In the Medicare health field, power relations stem from the undue advantage providers have in terms of knowledge from their education, the institutional capital they possess, and the access they have to the rules of the game as distributors of health care goods. Although Medicare has created provisions that are supposed to give beneficiaries access to resources to navigate Medicare, the question of the effectiveness of these resources has not been adequately addressed.

Symbolic violence and symbolic power. The character of hierarchy and domination within a system or a field are internalized as natural positions and are considered to be part of the natural order within a society (Araújo, et al., 2008; Bourdieu, 1993, 1977). Although Bourdieu views these social constructions as arbitrary, the consequences of such interactions in a system he believes are far from arbitrary (Swartz, 1997). He refers to the consequences of symbolic power within the hierarchy which exerts obedience and submission from the dominated as symbolic violence. According to Araújo et al., (2008), Bourdieu defines symbolic violence as “violence that extorts submission, which is not perceived as such, based on collective expectation and is instilled in social beliefs” (p.664).

Symbolic power has the potential to translate into symbolic capital and creates an ability of the dominant group to find actors who submit to this socially established domination in an unreflective way, subjecting themselves to symbolic violence (Araújo et al., 2008). Bourdieu refers to the concept of hidden structures that are within institutions and cause people to create a constant source of violence as misrecognition (Swartz, 1997). The power differential that exists between Medicare providers and beneficiaries creates an environment for symbolic violence and the wielding of symbolic capital to be naturalized within this field (Swartz, 1997).

Transformative agency. Even though hierarchical systems reinforce the power structures within a field, research indicates that the influence of capital from other fields such as education and employment can modify and transform the health system habitus (Adkins & Corus, 2009; Béhague et al., 2008). Transformations are not solely the function of transfer of capital from one field to the other but require individuals to actively transform capital to be of value in new alternate social fields (Béhague et al., 2008; Swartz, 1997). Tensions in such systems are directed by individuals' capital and objectives and have the potential to break from the status quo and engage in transformative agency (Adkins & Corus, 2009; Béhague et al., 2008). A study by Béhague et al. (2008) explored the habitus of obstetric patients (N=74) within a hierarchical health care system in Benin using patient-centered in-depth interviews to assess Quality of Care (QoC) in five hospitals. They found a minority of patients (n=10) to have engaged in transformative agency. Good social support systems (social capital) and capital gained due to employment in hospital systems were found to empower these individuals to engage in improvised habitus to seek appropriate care. In the hospital QoC

review there emerged the development of a new social pattern of habitus based on the social conflicts and injustices these participants' addressed during the interview process. Research using this theoretical frame work gives credence to the transformative agency in both habitus and field that can be stimulated by crises encountered with illness when exposed to symbolic violence (Béhague et al., 2008).

Summary. Bourdieu's theory provides a framework for interpreting the structure-agency dialectic that determines the habitus of Medicare beneficiaries as they use their capital to vie for health care goods in this technologically advanced hierarchical system. Although explicit and implicit assumptions and rules of the culture and the system are arbitrary, they have real consequences that impose a symbolic violence on beneficiaries in this health field that go unnoticed. Although hierarchical systems promote conformity, individual habitus emerging from the tension between the system and individual's objectives may result in transformational agency.

Related Research

Medicare studies to date have focused on unearthing factors that limit navigational skills of older adults such as low health literacy with regards to race, gender and SES; and preferences in decision making of older adults (Fiucane et al., 2002; Harris-Kojetin et al., 2007; Hibbard et al., 1998). Both these lines of research have contributed to an understanding of older adults' capital and possible implications for their habitus as they navigate in a hierarchical technologically advanced health care system. In the following section, this research will be reviewed to as background for understanding the challenges of navigating Medicare and why beneficiaries may be denied coverage despite having insurance.

Passive consumerism. Adkins and Corus (2009) using an interpretive methodology found that consumers (n=23) with low health literacy levels in hierarchical health care systems tended to adopt passive strategies to minimize their social exposure and shortcomings to maintain their self esteem. However, consumerism was contingent on the types of interaction that existed between patient and providers. Their definition of health literacy was defined as “the ability to derive meaning from different forms of communication by using a variety of skills to accomplish health-related objectives” (p. 202). Providers that recognized patients’ capital served to legitimize a higher status for the patient and power for independent decision making. Williams et al. (1995), in examining functional health literacy in older adults (N=2695) in two urban hospitals, reported low health literacy levels of 81.3% for English speaking patients and 82.65 % for Spanish speaking patients. Although race and gender were not examined, these participants came from a predominantly lower SES and were primarily Black and Latino. Hibbard et al. (1998) employed a national sample (N=1673) to examine beneficiaries’ abilities to make informed choices. They reported that only 11 % of the sample had adequate knowledge about plans Medicare offers, 59% had inadequate knowledge, and 35 % were equal to or worse than guessing. Although each of these studies used different methods, populations from different geographic areas, and different instruments to understand health literacy and navigational skills of older adults/consumers, they suggest that Medicare consumers’ health literacy is generally fairly low.

A problem posed by low health literacy is the likelihood of dominant groups with greater sources of capital (social, cultural and institutional capital) legitimizing their authority by imposing their values and standard rules of conduct on consumers (Adkins

& Corus, 2009; Béhague et al., 2008; Ming-cheng & Stacey, 2008; Monaghan, 2008; Swartz, 1997). Passivity and marginalization is reported to be a residual effect of such interactions with hierarchical systems and systems that consist of power relations of social domination (Adkins & Corus, 2009; Araújo et al., 2008; Monaghan, 2008). Alternatively, studies have also reported that individual agency is not entirely shaped by social structures but is a result of the inherent tension between the actions directed between the broader social structures and the action directed by individual objectives, causing some to engage in modifying their values and practices in creative ways (Adkins & Corus, 2009; Béhague et al., 2008; Swartz, 1997). Variations in resources and multiple intersecting fields are responsible for this variation seen in patient provider interactions within systems of domination (Adkins & Corus, 2009; Béhague et al., 2008). While health literacy is considered a vital resource that beneficiaries need to get their health care needs met, the types of interaction consumers have with medical staff are also contingent on the social, the economic, and the cultural capital of beneficiaries engaging in passive consumerism versus active consumerism that takes place in health systems.

Beneficiaries' capital (resources). The variability that exists among adults, who are 65 and older, is a combination of resources and health (Hooyman & Kiyak, 2008). Social capital of older adults which includes both instrumental (material) and expressive resources is linked to better health (Moren-cross & Lin, 2006). Although social network sizes of older adults tend to remain the same over time, the number of close relatives in the network reportedly increases and the number of friends declines (van Tilburg, 1998). In general, even mentally capable older adults are reported to depend on families to make health care decisions (Kapp, 1991). Dependence on family to make health care decisions

increases the likelihood of a dyadic interaction of a health provider--family, with the older adult being left out of the loop (Haug & Ory, 1987). Bann, et al. (2004) reported that a consequence of beneficiaries depending on help to make health insurance decisions may result in a lack of knowledge of insurance and options, and a failure to use the Medicare sources of information.

The economic status of older adults is subject to events such as retirement, death of a spouse and the onset of chronic diseases and disabilities (Hardy, 2006). The trends in the increasing inequality in economic capital and the health disparities of older adults are linked to the structural shifts in the economy and the structural changes of entitlement programs that have taken place over time (O’Rand, 2006). With the restructuring of Medicare, older adults are now faced with increasing out of pocket expenses and limited access to specialists in rural areas, and health care providers denying medical coverage (Aday et al., 1993; Antos, 2009; Goss, Alecxih, Gibson, Corea, Caplan, & Brangan, 1999; Neuman, & Cubanski, 2009). Poor choices in Medicare plan selection have resulted in beneficiaries finding themselves in a coverage gap with regard to prescription drug coverage (Dallek, Biles & Nicholas, 2003 as cited in Schlosberg, 2004). Poor selection of managed care plans increases the likelihood of denial of coverage and out of pocket expenses (Centers for Medicare Advocacy, Inc., 2011; Jasso-Aguilar, Waitzkin, & Landwehr, 2008; Johnson, 2006; Neuman, & Cubanski, 2009). Although comparisons indicate that older adults fare better than those 18 and younger, the increasing out-of-pocket expenses for health care, increasing incidence of health issues, and limited income creates a burden on older adults who are attempting to maintain their health, independence and quality of life (Ferraro, 2006; Goss, et al., 1999).

The cultural capital of beneficiaries has been affected by what Schillings and Mellor (2007) refer to as a technological life which includes use of everyday technologies (the internet, hot lines with automated messages), increasing use of biomedical interventions, and instrumental rationality. Familiarity with technology is becoming a requirement for people to pursue, maintain and negotiate life (Kelly & Loe, 2010; Schilling & Mellor, 2007). Medicare has utilized this technology in an attempt to be patient-oriented and to be an efficient and a prudent purchaser of health care for its beneficiaries (Guterman et al., 2005; Sparrow, 2008). Quantitative studies that have examined the utilization of technological resources that Medicare makes available report that these services have only served to isolate beneficiaries and limit their interaction with Medicare (Harris-Kojetin, 2007; Hibbard et al., 1998). Bann et al. (2004), in examining insurance knowledge and decision making practices of beneficiaries and care givers, report that out of their sample who made their own decisions, 39.3 % (n=8805) had not heard of the Medicare toll free telephone and 71.8 % had never used it. Of the sample of beneficiaries that made their decisions with help (n=3173), 48.8 % had never heard of the Medicare phone line and 69.6 % had never used it. Finally, out of the proxies (n=1401) that helped severely disadvantaged beneficiaries make decisions, 45.6 % had never heard of it and 65.6% had never used it. Among these three groups, lack of access to internet service ranged from 64.7 -76.1%. Although experience and intuitive judgment work to the advantage of older adults, issues associated with increasing age such as slower processing, decreased fluid intelligence, visual and hearing impediments, and disabilities associated with chronic diseases make compensating for the lack of

familiarity with technologies of modernization difficult (Hooyman & Kiyak, 2008; Kane, 2005).

Cognitive compatibility. Hibbard et al. (1998) reported that only 16 % of beneficiaries in their sample (n=1,171 who passed the screening test of minimal knowledge of Medicare) were able to use the comparative information of plans that Medicare provides. Uhrig and Bann (2006) reported that of their national sample (N=16,000), beneficiaries using traditional Medicare are reported to be better informed about their coverage than are those enrolled in managed care plans. Factors that they associated with low knowledge about Medicare and its plans included older age, lower education, lower income, non white, and those with Medicaid or other public insurance. Reading habits and meta memory are also reported to be significant predictors of Medicare knowledge, in particular knowledge about Medicare Managed Care (Bann et al., 2006; Hibbard et al., 1998). Fiucane et al., (2002) reported that older adults rely more on experiential/ oral information processing than analytical information processing, and Short et al., (2002) found that beneficiaries show a limited interest in using comparative information. In contrast to these findings, Medicare's assumption is that beneficiaries have the skill to navigate Medicare independently (DeJong, 2005; Bann et al., 2004).

Denial of coverage. Although beneficiaries have the right to appeal, research indicates that they have a limited understanding of their rights, and as a result, complaint and appeal rates are low (Olson et al., 2010; Schlosberg, 2004). Medicare's auditing systems and outreach programs keep track of providers' performances but lack an adequate system to monitor the gate keeping practices and the intentions of providers and beneficiaries' experiences (Guterman et al., 2005; Olson et al., 2010; Sparrow, 2008).

Sparrow (2008) refers to denial of services by managed care companies and organizations that deny services to maintain their profit margins as one of the invisible problems that Medicare faces. These pass undetected or largely unreported. An internet search of databases for literature on denial of services yielded literature on denial of payments to providers rather than denial of services to beneficiaries. Specific strategies used by providers to limit services when payments from Medicare are questionable, such as gaming and dumping, have been studied with populations without insurance policies. With Medicare, however, this topic has been limited to scholarly discussions and opinions based on audits of services rendered following the enactment of various laws (Davitt & Choi, 2008; Mayes & Berenson, 2006; Rice, Jones & Rouge, 1991). Some coverage denials have been and are being contested in the courts, but there is a lack of research examining this issue (Centers for Medicare Advocacy, Inc., 2011 <http://www.medicareadvocacy.org/hidden/highlight-improvement-standard/>).

Summary. Research conducted by various disciplines exploring the resources/capital of older adults as they seek to maintain their health and well being imply a disconnect between beneficiaries' needs and Medicare's affordances to the beneficiary, which as a rule have served to isolate rather than empower beneficiaries. Quantitative research has identified categories of people based on age, gender, race, and SES that have difficulty navigating Medicare and has also linked the incompatibility between the use of Medicare and beneficiaries, to the cognitive skills and preferences of beneficiaries in such a technologically advanced system. In terms of equity in access to care, the role of providers in determining what makes particular health care goods "reasonable and necessary," and the consequential impact this has on beneficiaries, are

topics that have been discussed by scholars from various perspectives but have not been studied. In light of Medicare's vision for patient centeredness and equity to access to care, there is a dearth for research to address the challenges beneficiaries encounter from their perspective, especially when they are denied health care services that they believe are vital for their well being and recovery.

Rationale and Research Question

The optimal use of Medicare requires beneficiaries to be vigilant in monitoring the plans offered by Medicare and to select what best suits them based on their health care needs and their finances (DeJong, 2005; Medicare & You, 2011). This built-in component of flexibility that Medicare offers allows Medicare to make necessary changes to its plans as well as allows beneficiaries to change their coverage based on their health care needs and finances each year (Medicare & You, 2011). However, the onus of being self conscious of one's needs and deliberately agentic in using Medicare for one's benefit is the responsibility of the beneficiary (DeJong, 2005; Medicare & You, 2011).

In my preliminary study conducted to understand the navigational experiences of Medicare beneficiaries, participants (N=11) were found, irrespective of SES, gender and race, to depend on health care professionals and family/friends to assist them in navigating Medicare. This is proxy navigation, in contrast to independent navigation where participants make decisions based on their personal knowledge of Medicare. Proxy navigation, and attitudes such as doing things on a trial and error basis or 'going with the flow,' has been defined as passive consumerism (Adkins & Corus, 2009). Feelings expressed by beneficiaries about navigating Medicare indicated that participants

experienced a compromised self and lassitude (“dumb,” “powerless,” “do what you have to do,” “I am just an old codger”), when events were considered to be out of their control. However, they also expressed the view that life without Medicare was unthinkable due to the monetary benefit of having Medicare in this phase of their lives.

My preliminary study concurred with past studies which described clients’ agency within a hierarchical medical system to be predominantly passive and dependent on the advice of healthcare professionals and others (Adkins & Corus, 2009; Bann, et al., 2004, Harris-Kojetin et al., 2007; Hibbard et al., 1998). While Medicare focuses on being a good purchaser of health care for its beneficiaries at low costs, its lack of specific criteria to determine “reasonable and necessary” services puts the onus on providers to be gatekeepers and render essential services (Davitt & Choi, 2008; Guterman et al., 2005; Karlin & Humphreys, 2007; Mayes & Berenson, 2006). Providers practice strategies such as “gaming,” “dumping,” or applying the “improvement standard” to adhere to Medicare’s dictate of providing what is reasonable and necessary but at the same time to ensure their share of the health care market (Aday et al., 1993; Davitt & Choi, 2008; Estes & Linkin, 1997; Krausse, 2006). In such an environment, low health literacy and passive consumerism increase the likelihood of a denial of coverage going uncontested.

There is a need for qualitative research to examine beneficiaries’ interactions with Medicare in times of crises such as denial of services in order to have a better understanding of the beneficiaries’ perceptions of their health care insurance, the types of resources they utilize when in such a crisis, the types of interactions beneficiaries have with health care providers, and strategies beneficiaries and families utilize in response to such crises. Due to the complexity of Medicare, decision-making and the beneficiaries’

agency can have economic, psychological and social implications for beneficiaries and their families (Adkins & Corus, 2009; DeJong, 2005; Estes & Linkin, 1997). Estes and Linkin (1997), in light of the push for privatization and devolution of Medicare, predicted that denial of health care services by providers to manage their profit margins would result in a substantial burden to beneficiaries, their families, and communities.

Furthermore, there is a need to expose pitfalls beneficiaries are likely to experience in this climate of cost containment and rationing of health care. Findings of such an inquiry may increase the awareness of beneficiaries and policy makers of the current state of equity of access to health care. Exploring lived experiences of beneficiaries and their families when beneficiaries face the challenge of not qualifying for needed medical coverage can shed light on the nature of interactions that take place between Medicare and the respective beneficiaries and their families, and the impact of such experiences.

Therefore this research proposes to examine the lived experiences of beneficiaries and families when beneficiaries are denied or lack coverage. The specific research question of the study is:

How do beneficiaries who have been denied health care perceive their experiences and navigate Medicare?

Author's Perspective

Growing up in post colonial India and with the remnants of the caste system I realized the importance of inherited capital and social positioning in giving one's agency and life a boost and vice versa for those that lacked it. The very submission and challenges I saw people in lower ranks face in hierarchical systems of government institutions, religion, education and society in India, as a health care provider in the US I

saw with older adults, as they navigated a health care system that they had paid into and were dependent on to maintain their quality of life and health. My questions about what made people passive and powerless entities, and what may be avenues for their emancipation attracted me to Bourdieu's philosophy and theory of practice and symbolic violence. In this research Bourdieu's theory of practice and symbolic violence has provided me with a world view that mirrors my presuppositions about social phenomena and has guided my development of research questions and queries I have about human agency and the state of health care for the elderly.

Being a native of a third world country my experiences with health care for the elderly in the US has been both, enlightening and intriguing. It was enlightening because for the first time as a young adult I encountered a system (Medicare) where the government attempted to ensure health care for its older adult population. Its foundation in the great society program and the Civil Rights Movement, along with its strategy to share the risks and benefits of such an operation across the population rather than it being a personal and a family responsibility to me was a sign of good governance by a society for its well deserving older citizens. Furthermore, the fervor with which I found a majority of the older adults strive to maintain their autonomy and independence was awe inspiring and worthy of support.

At the same time, as a health care provider the insight I gained of the workings of the system puzzled me. Time and time again I found beneficiaries and families of beneficiaries in times of health crisis that could be described to feeling their way around a health facility seeking answers to numerous questions about their coverage. Denials of services by providers were observed to only further surprise them and disappoint them

with expressions of feeling powerless. While Medicare's restructuring promised older adults consumer choice, consumer direction, consumer power, quality care and greater control I observed it to empower providers and disenfranchise the beneficiaries who needed health care to maintain their quality of life. This thought that I later found to be discussed in scholarly journals dawned on me was a valid and an important topic to study (Davitt & Choi, 2008; DeJong, 2005; Estes & Linkin, 1997; Krausse, 2006; Oliver & Lee, 2009). On examination of the Medicare manual most of the queries were found to be referred to, but not explicitly explained. The literature review further clarified my doubts about the lack of compatibility that exists between beneficiaries and a technologically advanced system such as Medicare.

While my experiences in the health field and with Medicare in particular include a monetary benefit from caring for Medicare beneficiaries, it has also created a need in me to understand and research human agency of older adults as they strive to maintain their quality of life and their psychological well being in this modern culture. Questions that have intrigued me include: Why do older adults and their families not know their Medicare coverage? Why do proactive older adults and their families within the field of health care place implicit trust in health care professionals accepting them to be the power house of knowledge about Medicare and health? Do they believe health care providers who depend on Medicare for their pay checks are in a position to give them a valid understanding of their situation, their rights and their options? What is the intuition of the beneficiary when they are told that services have to be terminated or they do not qualify for services? How do beneficiaries manage when they are denied health care services?

The choice of theory and the method (Interpretive phenomenological analysis which will be elaborated in the methods section) in this inquiry is to call attention to the plight of beneficiaries and introduce a new angle of understanding of beneficiaries' interaction with Medicare. Although the trend in health services research is to use quantitative research to describe, analyze, and evaluate the structure, process and outcomes in medical care systems and with Medicare in particular, qualitative health services research can effectively engage in a macro-micro level of examination for a set of beneficiaries who may have a distinct set of experiences because of the specificity of their challenge (Aday et al., 1993; Smith, 2006; Swartz, 1997). The epistemological position of this research is to understand and link face to face interaction and socially constructed meaning of beneficiaries' experiences to the context in which they occur.

CHAPTER 2

METHOD

Interpretive Phenomenological Analysis

The philosophical underpinning of the Interpretive Phenomenological Analysis (IPA) method is to understand and highlight human experience by focusing on the conscious awareness of an individual's experience, but also drawing attention to what is normally hidden in human experience and relations (Solomon, 1987 as cited by Lopez & Willis, 2004). While phenomenological studies in general are interested in the subjective experience of human beings, the ontological and epistemological underpinnings of the descriptive and the interpretive approaches guide the respective research process and determine the research findings (Lopez & Willis, 2004; Smith, Flowers & Larkin, 2009). IPA's focus is to understand the meaning people assign to their experiences but it is also guided by the assumption that meanings are not always apparent to the participants and therefore the researcher, by engaging in an interpretive (hermeneutic) inquiry, interprets the narratives of participants in relation to specific, embedded contexts (Lopez & Willis, 2004). Expert knowledge is valued as an important component of this research method and is used throughout the research process from the formulation of the research question to producing useful knowledge (Smith et al., 2009). IPA is idiographic and committed to the detailed examination of each participant's narratives, examining the similarities and the differences that appear to exist within a small group of homogenous participants (Smith et al., 2009). The use of IPA helped this research generate culturally relevant knowledge, mindful of the convergences and the divergences of the social realities of

Medicare beneficiaries living within specific situations, by attempting to understand their meanings and interactions with others in their environments.

The assumptions of IPA had implications for sample selection, interviews and the analysis. IPA perceives people as being cognitive, linguistic, affective and physical beings and therefore assumes a connection exists between individuals' talk and emotional states (Smith, 2006). It also assumes that individuals are influenced by the world they live in, referred to as "life world" or "being in the world" (Heidigger, 1962 as cited by Lopez & Willis, 2004). Based on these assumptions, IPA lent itself to the analyses of narratives of Medicare beneficiaries' lived experiences while utilizing Medicare (Smith & Osborne, 2006; Smith et al., 2009).

IPA recognizes that although individuals are free to make choices, their freedom is circumscribed by the specific conditions of their daily lives (Heidegger, 1962 as cited by Lopez & Willis, 2004). Individuals are embedded in specific environments, and therefore their subjective experiences are inextricably linked with the social, cultural, and political contexts of their environment (Lopez & Willis, 2004). This phenomenon is referred to as situated freedom (Lopez & Willis, 2004). Based on this assumption, the researcher sifted and examined the meaning participants gave to their states of being, their events, and their experiences, but also interpreted what their meanings and their experiences implied as they occurred in their world as the researcher saw it (Lopez & Willis, 2004; Smith & Osborne, 2006). These assumptions of IPA required a detailed examination on a case by case basis of the homogenous sample in this study (Smith et al., 2009).

Participants

In order to provide a detailed and descriptive account of perceptions and understanding of participants' experiences, a small homogenous sample size was recommended, and was used by the researcher to engage in an in depth case by case analysis of individual transcripts (Smith, et al., 2009). The following criteria were used in selecting the participant's for the study: (a) Medicare beneficiaries who were 65 years and older; (b) who had experienced a functional decline due to an incident (illness/accident) and believe they needed health care services to recover their independence/functional ability; and (c) who had been denied health care services that they believe that they needed to functionally recover. Family and friends who navigated Medicare on behalf of the beneficiary were also eligible to be included in the study as proxy navigators.

One source of referrals was the facility where I worked as a full time occupational therapist. The administrator, after reviewing the study, approved the use of the facility for both recruiting and interviewing participants with a request for me to share the information with the administrative staff after the study was completed. The administrator also contacted her marketing staff and her social worker and advised them to make referrals as they saw suitable for this study. In addition, I contacted three nurse practitioners, and one physician assistant, and posted a flyer at a senior citizens center and in the offices of two physicians who work primarily with the elderly.

Nine of the referrals in the study came from the facility where I worked. These participants were informed of the study by either their nurse practitioners/physician's assistant or staff from the facility. All nine of the participants made contact with me

either at the facility, in person, or over the telephone. All of these participants agreed to be interviewed at the facility itself. One participant was referred to me by her granddaughter who worked as a certified nurse aide. She explained to me her grandmother's situation, and on being informed her grandmother qualified to be a participant in the study, she arranged for me to interview her grandmother in her home. Another participant who was visiting his wife at the facility asked me about my research and told me about his experiences with health care. When asked if he would like to participate in the study, he agreed and was interviewed at the facility. Another participant was referred by her daughter who was a colleague of mine. This participant lived in a town outside of Lubbock, and contacted me by phone. She agreed to be interviewed at her home.

Once initial contact was made with each of the participants that volunteered to be in the study, I described the study to each of the participants, the participants were asked to briefly narrate the type of service that was denied, the reason the beneficiary was denied health care services, and the location the event took place. This brief history from the participants about the experiences of the beneficiaries that were represented in the study allowed me to decipher the nature of the denial of service and the suitability to include the participant in the study.

The 12 beneficiaries represented in this study were all community dwellers prior to suffering an illness/accident that needed intensive and extended care. For their biographies, refer to Appendix D (actual names have been replaced with study names). The biographies also provide an account of how and why beneficiaries relied on proxy navigator's to help them navigate Medicare. Appendix E provides an overview of the

demographics of the participants in the study. Briefly, beneficiaries represented in this study ranged from 88 to 67 years of age, there were five male beneficiaries and seven female beneficiaries. Educational background of beneficiaries was: less than high school (2), high school and some additional education (6), bachelor's degree and some additional education (2), master's degree (2). Their past occupations were: real estate agent (2), soil chemist (1), professor (1), home maker (2), teacher (1), book keeper (1), hostess (1), registered nurse (1), farmer (1) and insurance agent (1).

Four of the beneficiaries represented themselves. Eight beneficiaries were represented by proxy navigators. Two of the male beneficiaries were represented by their spouses. Six of the female beneficiaries were also represented by family members, consisting of daughters (3), son (1), and daughter in law (1) and niece (1). The occupations of the proxy navigator's were home maker (3 -2 spouses +1 daughter), insurance agent (2), owner of an advertising company (1), bookkeeper (1) and pharmacist (1). Their education levels were less than high school (2), high school and greater (3), bachelor's degree (1), pharmacist (1), and master's degree (1).

The illnesses of the beneficiaries were varied. Ten of the 12 beneficiaries had an acute onset of illnesses ranging from transverse myelitis, two cerebrovascular accidents, back injury secondary to a motor vehicle accident (MVA), one with an unspecified diagnosis, multiple fractures due to a MVA, knee replacement secondary to rheumatoid arthritis, followed by an above the knee amputation, hip replacement with osteomyelitis secondary to degenerative joint disease, hip replacement due to a fall and hypoxia due to cardiac arrest. The other two beneficiaries represented in the study suffered from a history of Parkinson's, and a history of Gouty arthritis. Eight of the participants were

denied services due to a lack of improvement determination. One participant was denied due to a lack of improvement initially, and later was again refused by a Medicare hospice agency to provide her with rehabilitative services. Two participants enrolled in HMO's were denied services due to a lack of a qualifying diagnosis to continue to be treated in a SNF, but the family of one was also told by the HMO that she was not making improvement. Another participant's services were prematurely terminated in a hospital setting. Lastly, one was denied a pain pump, as the criteria as stated by the physician was for her to be on hospice care or on her death bed, additionally she was denied oral medication for pain, which she later received after her daughter intervened.

Eleven of the beneficiaries had to reconsider their original living arrangements following a denial/termination of services, and an inability to be independent with basic self care. Six of the beneficiaries were confined to long term care setting following denial of services secondary to a lack of improvement determination by HC professionals. Others moved in with their daughters (2), to skilled nursing or assisted living facilities (2), or lived at home (2); however one needed around the clock care. Insurance plans that the participants were enrolled in at time of incident were Medicare/Medicaid (1); Medicare alone and Veterans Affairs (VA) (1); Medicare with Medicare supplement (8); and Medicare Advantage Plans (HMOs; 2). For nine of the participants enrolled in traditional Medicare (Medicare and a supplemental policy/Medicaid), Medicare was the primary insurance policy for all of these Medicare beneficiaries; denial of Medicare services automatically cut off the involvement of their supplemental or their Medicaid policy.

Interview

At initial contact with participant, introductions were made, the topic of this study was touched on briefly, the Medicare card of the beneficiary was checked to ensure that Medicare was the primary insurance of the beneficiary, and eligibility for the study was confirmed. Rights of the participant were explained including the right to confidentiality, following which a consent form was signed by the participant, and the participant was given a token gift of \$20/family as an appreciation and a thank you for the time taken to participate in the study. Participants were also informed that they would be doing more of the talking and the researcher would interject as needed only to clarify a doubt, or when more information would be needed about a particular topic of interest that the participant touched on (Smith et al., 2009).

Semi structured interviews provided an opportunity for the participants to tell their stories freely. The interview schedule (Appendix A) was designed to facilitate an interaction with the participants, so although the schedule provided a frame work for the interview, the dialogue was co-determined. This dialogue between the researcher and the participant of the participant's experiences provided the researcher the freedom to modify questions and the order of questions based on the participant's responses. It also provided an opportunity to explore important and uncharted territories which arose in the course of the dialogue. The interview was recorded on a digital recorder and the interviewer (researcher) during the course of the interview made note of issues of interest that needed clarification, or needed to be explored in greater detail. Following the interview, the recording was given a code name before being sent electronically to the transcriber.

Analysis

As suggested by Lopez & Willis (2004) and Smith and Osborne (2006), the use of IPA helped understand the psychological world of the beneficiary by examining beliefs and constructs that were manifest or were suggested in the participant's narratives. The main aim of using IPA for this analysis was to understand the content and complexity of participant's experiences rather than measure their frequency of occurrence (Smith & Osborne, 2006; Smith et al., 2009).

With the assumption that assigned meanings may not be transparent in the narratives, the researcher engaged in an interpretive relationship with each transcript to capture and do justice to the embedded meanings in the texts to learn about the participant's mental and social world (Lopez & Willis, 2004; Smith & Osborne, 2006). This protracted process with the text of the narratives although was done initially on a case by case basis, included: (a) looking for themes in the first case, (b) connecting the themes in the first case, and (c) continuing this analysis with the other cases.

Looking for themes in the first case. After reading the transcript a number of times, the left hand column were used to annotate interesting or significant thoughts about what the participant said. With each additional reading of the transcript, I looked for new insights. My notes consisted of summarizing or paraphrasing parts of the text, associations or connections related to the text that come to mind, and preliminary interpretations. I then looked for emerging themes that were jotted on the right-hand margin, which moved the analysis from the initial notes (from the left hand margin) to a higher level of abstraction. Care was taken to make the themes transparent enough, to provide visibility to the initial response of the participant.

Connecting themes. The emergent themes were then listed in the order of the sequence they appeared in the text. The next step was to make sense of the connections between the themes and to organize them under super ordinate concepts. Clusters of themes were then checked against the transcript to ensure the connections made were relevant to the data with the actual words of the participant (primary source material). An identifier with a four digit code was used with the first two numbers representing the page and the latter two numbers representing numbers representing the line, and a key word was attached to each theme (EX: 01 08, will reflect page 1, line 8 and a key word). These identifiers served as an organizational tool and an easy access to locate the text. During this process themes were dropped depending on their relevance to the topic or the emerging analysis, as well as if they lacked the rich evidence within the transcript.

These super-ordinate themes reflected participants concerns about this topic. In the process of creating super ordinate themes I relied on my knowledge about the topic, the theoretical framework that guided this research, and the Medicare context within which this narration was set, and I used my interpretive resources to make sense of what the participant kept saying in the text. This process referred to as the double hermeneutic permitted me (the researcher) to try and understand the inner perspective, by attempting to make sense of what it may have been for the participant based on the my (researcher's) conceptions (Lopez & Willis, 2004; Smith et al., 2009).

Continuing the analysis with other cases. Subsequent transcripts were also analyzed using the first two steps of the analysis, while I kept an eye for repeating patterns, but also identified new issues that emerged with the analysis of each transcript. I continued to track similarities and differences looking for a convergence and a

divergence of trends. Following the analysis of all transcripts by the interpretive process, a final table of super ordinate themes was constructed. I then prioritized the super ordinate concepts and supporting data and reduced it based on the richness and the relevance to the topic.

Quality Issues

Smith et al., (2009) advocated the use of criteria suggested by Yardley (2000), as the suggested criteria was wide ranging and not prescriptive, and offered a range of ways good practices and quality could apply irrespective of theoretical orientations of qualitative studies. The four recommended criteria were: (a) sensitivity to context, (b) commitment, rigor, transparency and coherence, (c) impact and importance of the study, and (d) independent audit.

Sensitivity to context. According to Yardley (2000) sensitivity to context has many facets, which include: sensitivity to existing literature of the topic, the methodology used, the data generated from the study, and the researcher –interviewee relationship. This study was sensitive to the existing literature, with regards to the understanding created by previous investigators who employed similar methods and similar topics (Lopez & Willis, 2004; Yardley, 2000). The literature review, the rationale for this study, and the Theory of Practice and Symbolic Violence used as the world view for this study outlined the need for an IPA study, which focuses on sensitivity to context from the early stages of the research process (Smith et al., 2009). As recommended the relationship between the researcher and the interviewee were also addressed. The researcher looked to the interviewee as the expert in the field, and was cautious of how the expectations of the researcher would influence the interviewee.

In addition, an attempt was made to fit the study's findings to the extant beneficiary –Medicare literature. As recommended by Yardley (2000) and Smith (2006), sensitivity to the data was ensured in the analysis phase, and the unfolding discussion was further supported by the data collected from the participants. The data derived from participants was used to make a case for the discussion of the study, and simultaneously sensitivity to context was also maintained by attending to the socio-cultural milieu of Medicare within which this study took place. The attention to sensitivity to context influenced the conduct, the outcome and the relevancy of this study in relation to the current discourse the trajectory of Medicare has taken over the last two decades (DeJong, 2005; Estes, & Linkin, 1997; Krausse, 2006, Smith et al, 2009; Yardley, 2000).

Commitment, rigor, transparency and coherence. This criterion referred to the level of diligence engaged in data collection, analysis and reporting of research (Yardley, 2000). Yardley (2000) suggested establishing commitment by prolonged engagement with the topic, not just as a researcher, but in the capacity of someone with vested interests, with the development of competence and skill in the method used, and also the level of engagement of the researcher in the relevant data. The author's point of view stated earlier in this study refers to my intentions and my engagement with this clientele. This undertaking was a commitment to provide a voice to issues beneficiaries face and be an advocate for this clientele. Although this was my first attempt to utilize IPA, the guidance of a well accomplished mentor and the use of the recommended protocol for analysis by Jonathan Smith who developed this method; honed my skill in using this method to make a case for this study.

Rigor refers to the attention given to the completeness of data collection and analysis (Yardley, 2000). This component of the criteria refers to the adequacy of the sample in terms of its capability to supply all the information needed for a comprehensive analysis (Sandelowski, 1993), and the completeness of the interpretation which includes the variation and the complexity observed in the phenomenon being studied (Yardley, 2000, Smith, 2006). The data collected from 12 homogenous respondents was adequate to make a case. Furthermore, the use of the IPA protocol and Bourdieu's Theory of Practice and Symbolic Violence helped maintain a contemplative and an empathetic attitude throughout the study, and helped transcend commonsense and superficial understandings of this topic.

This study also strived to be coherent and transparent to make it meaningful to the reader. As suggested by Yardley (2006), maintaining a fit between the research questions, the philosophical perspective adopted, the method of investigation used and the analysis was addressed. Additionally Yardley (2009) and Smith (2006), encouraged the use of rhetorical persuasion by the researcher, to construct a meaningful version of reality of the participants, with clarity and logic to ensure it is meaningful for the readers (Smith, 2006, Yardley, 2009). The framework and the constructs of Bourdieu's Theory of Practice in conjunction with use of the IPA method provided the methodological congruence, and the philosophical underpinnings necessary to engage in the rhetorical persuasion necessary for logical reasoning to make this study coherent.

Furthermore, as recommended transparency was attempted by detailing every aspect of the data collection process, the steps in the data analysis, and the presentation of passages from the data so patterns in the analysis were identifiable (Yardley, 2000).

Additionally as suggested by Yardley (2000) and by Bourdieu (1993), reflexivity was engaged by the researcher wherever appropriate. My intentions, motivations, opinions and my assumptions as a researcher in developing the research schedule, my interaction with participants of the study during the interviews, and my intuition and my imagination as a researcher were made explicit in the study.

Impact and importance. According to Yardley (2000), the impact and the utility of a study is judged by the objectives of the analysis used in the study, the applications it was intended for, and the community for whom the findings were considered relevant (Yardley, 2000) . As recommended by Smith (2006), in attempting to present a novel and a challenging perspective of this topic, this study opened up new ways of understanding this topic. As mentioned earlier it seeks to get the attention of all stakeholders --policy makers, health care professionals, and Medicare consumers. The theoretical framework used in this study, provided this topic with a new perspective of the challenges agentic beneficiaries encounter in advanced technologically complex health systems, when subjected to symbolic violence.

In considering the socio-cultural impact of this study as recommended by (Yardley, 2000), this research has highlighted the impact complex systems like Medicare have on Medicare consumers by using medical authority as an avenue for control. In doing so, this study has provided visibility to an issue that has been under reported, and even passed undetected by some. The findings of this research are aimed at increasing the awareness of policy makers and health care professionals of the consequences of their actions, and to reconsider existing policies, in addition to empowering beneficiaries and

organizations such as AARP to examine Medicare's plans, and to understand the arbitrariness that exists in health care delivery.

Independent audit. Smith et al. (2009) believes that an independent audit is a powerful way of ensuring quality qualitative research. Maintaining an account of the whole study, from its inception to the final outcome to allow the reader to follow the chain of evidence compiled right to the final results (Koch, 2006; Yin 1989). To ensure validity of this inquiry, the dissertation contains a compilation of all the steps taken, through the analysis and the discussion. All initial notes on the research questions, the research proposal, the audio tapes, annotated transcripts, tables of themes and other devices used in the analysis, draft reports and the final report have been saved and are available for an independent audit.

Also, the supervision of students was recommended (Smith, 2006; Smith et al., 2009). This project being a dissertation was conducted with the supervision of my committee chair, who in the process of ensuring good practices was constantly engaged in the development of the inquiry in the form of mini audits and a questioning mind which clarified the logical reasoning of the decisions made throughout the research process. As recommended by Yin (1989) and Smith et al. (2009) this research attempted to be transparent so readers see a logical progression throughout the inquiry and comprehend the study the way they see it.

CHAPTER III

RESULTS

Overview

Of the five main topics and associated themes identified in the analysis of these interviews, there was consensus among respondents in four areas. These were the perception of Medicare at the time of enrollment, the use of Medicare resources, the consequences of denial of Medicare services, and the perceptions of Medicare following denial of services. The themes associated with these topics are described in the first section below. There were differences, however, in relation to the fifth theme, the actions taken in response to denial of services. Seven of the respondents narrated an essentially passive response to this denial, while five took a somewhat more active, agentic stance. These differences in resistance to denial of services are described in the second section below.

Perceptions and Experiences Common to All Respondents

These four topics and associated themes are summarized in Table 1. Although there were variations in how respondents talked about each of these topics, as indicated in the text, there was general consensus with regard to the themes.

Perception of self and Medicare at time of enrollment

A retirement health care benefit. Some of the respondents said that at time of enrollment they cared less about Medicare than their Social Security, based on a belief that good health care and youthfulness was a thing forever: “When you’re young you feel immortal.” Others were eager to enroll in Medicare due to neglected health care issues and inadequate health care insurance earlier in their lives. All respondents in the

Table 1: Perceptions and Experiences Common to All Respondents

Topics	Themes
Perception of Medicare at time of enrollment	A retirement health care benefit
Use of Medicare resources	Limited use
Consequences of denial of services	Physical impact Psychological impact Financial impact Impact on PN's
Perception of Medicare post denial of services	Doing Medicare as cumbersome Ambivalence regarding Medicare Medicare an unequal system Medicare not in sync w/ beneficiary's needs Beneficiary the ultimate loser

study viewed Medicare as a health care benefit for US citizens, which beneficiaries had paid into. The narratives indicated that beneficiaries without giving much thought to the mechanics and mode of delivery of care, did not anticipate Medicare to deny them health care when they needed it. They believed as citizens of a country such as the US, the government has taken on the responsibility to address its citizen's health care needs. A proxy navigator who was navigating Medicare on behalf of her mother had this to say:

I feel that the people, we pay enough into Medicare especially; I mean you know when you see that you work, you know that we put in you know for Medicare, I think that when someone gets sick they should have that. I mean you know, we are a country where there should be a way where people should get what they need, what they need.

Use of Medicare Resources

Limited use of resources. Although the Medicare manual is delivered to every beneficiary once a year and is available online, a third of the sample appeared surprised and initially claimed not to have seen a manual. One proxy navigator who was navigating Medicare on behalf of her husband and was herself a beneficiary had this to say:

P: I don't know if I ever had the manual, maybe I did. It is like having a drink at the fire hydrant everything comes at you so fast and I don't know. I truthfully cannot say I remember a manual.would that have been given to me at the hospital?

I: No. Medicare mails it to you once a year.

P: OK, I am thinking. Is that the one that has the white cover, or the red and blue?

I: Yes, you're right.

P: OK well, I know where it should be. I truthfully cannot say I read it.

A majority of the participants reported that the medical and legal jargon used in the manual was beyond their comprehension and therefore did not use the manual. The assumption of these participants that they would not understand the language used in Medicare media, created a situation where they did not attempt to even seek the manual to stay informed. Overall, there was a consensus with a majority of the sample that the Medicare manual lacked the ability to engage Medicare consumers and aid in their understanding of Medicare.

Similarly, aside from two proxy navigators, respondents did not attempt to use the Medicare website, referring to internet websites as being "ahead of their time." Regarding the Medicare hot line, about half of the group reported that they had used it, but often with limited success. Reports of long waits, a lack of human contact, an inability to stay in contact with one consistent person with the use of the hotline, and being redirected to

other offices served to discourage the use of the hotline. Only one beneficiary found the Medicare hotline to be a helpful resource.

Only two participants contacted the Department of Aging and Disability (DAD) office for assistance, one finding it helpful but the other reporting disappointment because they failed to help him understand his situation. Most respondents had not heard of the DAD's office. And none of the respondents had heard of the State Health Insurance Assistance (SHIPS) program designed to advise older adults about health insurance coverage.

In sum, most participants found Medicare media/resources perplexing, and therefore did not attempt to use them or even familiarize themselves with Medicare media/resources. Instead, they sought assistance from health care professionals to help them navigate Medicare. In the words of one beneficiary:

She is on Part D, Part B whatever one she is on. Which one she is on I would assume, that is what I kind of depend on the people here to guide us and tell us we need to do this and we need to be here and we need to make changes. I don't know those things, and I don't want to know those things. That is why I pay people or want people that specializes, 'cause I might think that I want something and it is not what I need. But if you know what you want and someone tells you what you want and what you need it is a service that is desperately needed for people that are ignorant to this program like I am. And, most of the people I talk to are in the same boat. Holy crap we got a whole boat full of stuff and don't understand any of it. It is not in laymen's terms that you can understand. If you want to send me a book in soil chemistry I can communicate with anybody, but, I don't know about the medical field, and I am not in the medical field.

Consequences of Denial of Services

All of the participants reported physical, emotional and financial consequences due to the denial of Medicare services. The consequences included physical limitations that resulted in an inability to function independently in the community, despite a longing

to return to their families, their homes and their community. The psychological impact ranged from having their hopes and dreams wilt away, and consequential feelings of being let down, and in some cases depression and anxiety about their situation and the future. The financial impact was also significant and in some cases involved large out of pocket expenses for beneficiaries and their families as they continued to be dependent on personally funded long term care.

Physical impact. Prior to their illness/accident for which Medicare services were eventually denied, all of the beneficiaries represented in this study were community dwellers. . Following denial/termination of services, most beneficiaries were confined to living in nursing homes, skilled nursing facilities, or assisted living. Two had to live with their daughters, and one beneficiary attempted to continue to live at home, while another returned home with around the clock care. Many respondents felt the outcome might have been different if Medicare services had not been denied. For example, one beneficiary, due to what the family viewed as a premature discharge from a SNF, had to live with her daughter as she was unable to take care of herself at time of discharge. Following discharge, adequate home care was not provided. At the time of the interview she continued to live with her daughter as she needed supervision when walking, and her daughter continued to work with her to help her recover. Another beneficiary who lost his leg reportedly due to a premature discharge from a hospital was in a SNF at the time of the interview. His future residence was not yet determined as his amputated leg had not yet healed, and he had contracted a serious gastrointestinal infection while in the facility.

The physical impact of denial of services is depicted in the following excerpt. This respondent and his wife were unable to live at home together due to his unaddressed

back pain and a lack of adequate rehabilitation in addressing his wife's physical and swallowing difficulties incurred following a stroke.

...with the way with her sitting up right now she can never come home because she can't get the therapy and pushed hard enough to be able to get well. The one thing I have seen around these nursing homes But I cannot bring her home and take care of her now simply because if she fell on the floor and needed to be lifted or helped I cannot lift that much right now. Here maybe, while I am working my tail bone off to get where I can do it or where if I could I would take her home and just take care of her myself, but I cannot do it right now.

Psychological impact. Every respondent spoke of feelings such as being “devastated as it was their only hope” to recover. Respondents expressed anxiety over the present situation, and their future with Medicare. Feeling “dehumanized”, “inferior”, “buried in a pit”, “wanting to cry”, “being led out to pasture”, and “being shelved” were some of the ways respondents described their feelings following the denial of services. The following excerpt from a proxy navigator gives a glimpse of a beneficiary's feelings when an insurance policy that was selected by her, failed to provide the services she needed. The beneficiary, who was enrolled in a Medicare HMO, had been injured in a motor vehicle accident:

I mean she was very independent her whole life. And she worked very hard her whole entire life if she could, but then all of a sudden (husband) passes away and she has heart trouble and she has back trouble, she was in an accident, and now she can't even go to the bathroom by herself. And now people are questioning her judgment saying well you are stupid you don't, you are just old and stupid you don't know what you are doing. And she couldn't navigate the telephone, the stupid cell phone to call these people back because she couldn't see. You know she couldn't see the numbers, she didn't, it was very, the whole situation was somewhat dehumanizing for her. And it certainly took away her independence and her confidence in herself, the whole situation. Not just being here and her physical part of it, but the fact that she felt like she couldn't manage her affairs. She couldn't take care of any of the stuff. And she is a mother, and her children at this point are not willing, the boys don't want any part of it

and the only person that will help her out is her daughter-in-law and that is it. All of these things were hard, a burden for her.

The magnitude of the problem, the complexity of the system they were dealing with, and the unexpectedness of such a situation made beneficiaries feel dependent on assistance, a burden on their families, and most of all unwanted. The psychological impact of such an experience was not just limited to the beneficiary who was denied services, but their families as well. Proxy navigators reported feeling stressed and anxious as they attempted to make the right choices to ensure a life of dignity for their family members.

Financial impact. For those residing in nursing homes (aside from one beneficiary who had Medicare-Medicaid as a result of using all assets to support their care), the cost of staying in a long-term care setting was >\$5000/month. One proxy navigator had to depend on her children to fund her husband's stay in a nursing home. Two respondents a beneficiary and a proxy navigator, who were both well off prior to being served with the denial of services, expressed fear and anxiety of not being able to support their spouses and themselves in the future at the rate they were spending to maintain the beneficiary in long term care. The following excerpt exemplifies the financial challenges, in this instance of a beneficiary who was attempting to recuperate in a SNF.

It's bad in both ways. See, I had... I'm an insurance broker and I was brokering insurance through another agent, and missing out of a lot of business there, you know where I get paid, but, that was... what's today, the second or third? That was 65 days ago and basically all I've got is Social Security. So, basically, that is all I've got is Social Security. And then, my wife works up at (church). She doesn't make a lot of money, but she does have a job up there. I basically pay the house payment, the insurance, got a little That I pay, and it leaves about \$100 a month is all it leaves out of it. So, financially its hurting bad. Emotionally, when I get out of here, I've got to either try to get some help somewhere or to find a job that I can do.

Costs incurred by families to maintain family members in health care institutions were a source of remorse. Medicare consumers in this sample viewed the beneficiaries' dreams of retirement and leaving an inheritance for their families as declining due to the costs of maintaining them in health care institutions. One proxy navigator expressed resentment at the thought of his mothers' hard-earned money going towards maintaining health care institutions and health care professional's lavish lifestyles. The out of pocket expenses incurred due to the denial of services was a source of remorse, stress, and anxiety about their future for all the Medicare consumers in this study.

Impact on proxy navigators. Proxy navigators, in taking on the role of navigating on behalf of a beneficiary, were automatically engaged in navigating multiple related fields for the beneficiary, themselves and their families. They described their life as juggling and neglecting, their duties such as their jobs, their families, the affairs of the beneficiary they are assisting and in trying to accommodate the schedules of health care professionals who are in charge of the beneficiary's care. A woman who was a proxy navigator for her aunt explained:

Well it is about to wear me down. I am running two households because you see she still has a home. And I am taking care of all her stuff at home and she has pets and a yard and so I am taking care of all that stuff. Taking care of her mail and bills. You know everything. I do her laundry, I bring her laundry, I take care of her laundry and come every day to see her and take her, when she goes to doctors' appointments I go with her, you know whatever she has to have done. Yesterday we had a meeting, her care plan meeting and that so I am up here quite a lot and I can't work. I worked for and I can't work now because there is just too much stuff to do. There is just no way I could get my work in, so I am not working. You know so I don't have any income coming in except my social security. You know. But the most important thing is taking care of her, so I just have to put first things first. It has been a struggle.

One proxy navigator who took on the job of taking over the care of her mother following the death of her step father, attributed the death of her step father to the stress, and energy he put into in attempting to get the care her mother needed from Medicare, and she had this to say:

I think probably, physically, I think created his early death, because he was the caregiver at that point in time. He was coming up here on a daily basis. He felt that that was his duty to do that. To be sure that she was taken care of. She was getting the therapy that she should have. The marriage, I am sure there was not much left once the partner has left to go the nursing home and the other stays at home. That was a strain on, it was strain on him, and it has been a strain on our entire family.

While the experiences are varied, the underlying issue with all proxy navigators was that they were neglecting their health, their lives and their families in an attempt to attend to the needs of the beneficiary.

Two thirds of the beneficiaries represented in this sample were solely represented by family to assist them navigate Medicare. The beneficiaries that represented themselves were dependent on assistance from their families. Families were seen to contribute financially, monetarily and emotionally. One respondent, who was a retired RN, reported she would not have survived this experience without her daughter's assistance to navigate the health care field/Medicare. Another proxy navigator, in relaying her mother's experiences of transition through multiple facilities, termination of services from a SNF and discharge to home, attributed her mother's survival to the support she and her siblings, were able to provide their mother.

Perceptions of Medicare Post Denial/Termination of Services

Participants acknowledged the vital need for Medicare and expressed gratefulness of what Medicare has done for the older adults and continues to do, but were

nonplussed when denied services. Termination of Medicare services caused all respondents to be stranded, and left with the only option of personally funding their maintenance and their health care needs at that point. An analysis of the meaning they gave to their experiences and their current view of Medicare as their health insurance policy was revealing of a yearning for a system that was more nurturing and helpful in their hour of need.

Doing Medicare –“A cumbersome system.” The complexity of the system, the inability to understand Medicare media, the lack of sensitivity and timely responsiveness of health care providers and Medicare, the decisions of a system that were not in synchrony with their needs, the unexpected gap in coverage, and the resultant out of pocket expenses were all issues that made doing Medicare a cumbersome system for these respondents. One beneficiary spoke of the existence of collective ignorance of Medicare, and he felt that assistance in navigating Medicare was a service that was desperately needed. Another proxy navigator who was navigating Medicare on behalf of his mother expressed the challenges of staying informed as follows:

I pay Medicare part A and part B. I don't know one from the other. It's got me confused. I mean... this is a great example. That's a great question. These are the things that weren't covered. And here's why... Medicare takes... and then I get something like this... and you start getting 30 or 40 of these and you just kind of go calf rope! I give up. I mean think about it. I mean, here's a deal, charged \$10,858, co-insurance was \$877. I'm responsible for all \$877 of it. The next one is... these aren't good examples. Some of them I get, I'm responsible for \$13. And you're going, how did I go from \$800 to \$13? So, I'm totally confused by it. I don't know Medicaid... Medicare part A form part B. I probably should, but it just... it wears me out just thinking about it.

Even the three respondents, who were familiar with the health care system because of their professional experience, reported feelings of lack of control, helplessness

and loneliness when seeking services and information needed to understand and engage in Medicare. One of these respondents reported not surviving this experience without help from a family member. Another felt it was very unfair for Medicare to leave this vulnerable population with navigating such a complex system, which included privatized HMO's, and felt 100% alone trying to understand Medicare and HMO's in particular. The third respondent reported the need for an advocate to help her connect the dots and see the bigger picture when navigating such a complex system.

Three of the respondents depended solely on insurance agents to advise them to keep up with the changes Medicare makes with regards to its plans. Two of these beneficiaries enrolled in HMO's based on the advice they got from insurance agents. Following their denial of services, they found out that those that were around them in a SNF who had enrolled in traditional Medicare received comparatively a much more generous benefit than they did. While one proxy navigator/pharmacist felt compelled to take over her mother-in-law's care to assist her in re-enrolling with traditional Medicare, the other at the time of the interview and a year after the incident, is still figuring out the system.

Other proxy navigators in this sample had similar experiences. Issues such as a lack of knowledge of their rights, lack of understanding of the medical hierarchy, and reluctance to contact the Medicare offices, echoed through the narratives and created a situation where respondents relied on health care providers for information and guidance to navigate Medicare. Most respondents reported incidences where they had to bear the brunt of decisions made by health care professionals. Many reported lack of consideration by health care professionals/Medicare towards their time constraints and

their schedules. All of these issues made doing Medicare cumbersome and a tough reality not just for beneficiaries but for their proxy navigators.

Ambivalence regarding Medicare. Although some respondents referred to Medicare as doing “more good than harm,” they also simultaneously saw Medicare as failing beneficiaries because of their experiences with the denial /premature termination of services. All of the respondents viewed Medicare as the only service they have to help them with their health care needs. They appeared appreciative of the help and the coverage they have had, but felt disappointed with the current situation and viewed their future with Medicare apprehensively based on their current experiences. Two of the respondents believed they had to abide with the authority of the health care professionals and hoped they made the right decisions. One of them said she just had to have faith that she would get the help she needed. As mentioned earlier, while a couple of respondents claimed they did not expect Medicare to help in the future, a majority of the respondents appeared anxious about their future with Medicare based on their experiences, but for now they believed they just had to “go with the flow.”

Medicare an unequal system. Lack of equal accessibility to needed services was an issue that most of the respondents addressed in their narratives. One aspect of this was that, due to differences in resources, some people have greater knowledge of and access to services than do others. Most participants expressed a need that all beneficiaries should have equal access to all services and should be equally informed about the availability of the various services. Beneficiaries and proxy navigators also expressed their frustration with Medicare’s mode of delivery of care which is dependent on qualifying for Medicare services. A failure to qualify for Medicare services inactivates

their supplemental insurance/Medicaid services, and therefore they are left without any coverage. This gap in coverage was the greatest challenge all beneficiaries in this study had to face in different forms. To make up for this gap in coverage, they used a combination of strategies including paying out of pocket, pooling family resources, and waiting, hoping they would qualify for care at some point.

Respondents also questioned the inequity in the system that favors those on Medicare/Medicaid, but neglects the care of “hard working citizens”. The respondents who expressed this sentiment appeared resentful that this system neglected their needs despite their contributions to both Medicare and the country. The majority expressed a yearning for a fairer, more equal system that addresses all issues related to health care for all beneficiaries, rather than categories of people.

Medicare not in sync with beneficiaries’ needs. Overwhelmingly the narratives of the respondents portrayed an experience of dealing with a system that was not in sync with beneficiaries’ needs. The issues that they addressed were primarily centered on an inability to navigate the system, the time frame and the qualifying criteria set for recovery, and Medicare’s economic rationality that failed to consider the beneficiaries’ well being.

As described earlier, beneficiaries and proxy navigators sought or planned to seek assistance of family members, lawyers, insurance agents and health care professionals to navigate Medicare. Their dependence on advice from these professionals and failure to independently use the system was due to a feeling of an inability to fathom the way Medicare works, or comprehend its literature. Medicare consumers view this mismatch not just in terms of choosing benefits, but also thereafter with their interaction within the

health care system. Second, respondents reported that the qualifying criteria and time frame set for recovery was not in sync with the recovery processes of beneficiaries. A number of respondents discussed this with respect to the transition of the beneficiary from one medical setting to another, when insufficient time in a setting was problematic for recovery. Another aspect of this theme was the termination of interventions when beneficiaries and family members believed that the beneficiary was making progress and that continuation of these interventions was critical for recovery.

Third, a few respondents commented that lack of synchrony of beneficiary's needs with Medicare services was not only working against beneficiary's recovery, but also economically disadvantageous for the system. A beneficiary based on his experiences and that of his wife had this to say:

But I am not a medical, but I am not a medical or therapy, but if they would have continued some type of a maintenance program we probably wouldn't be starting over again. Now, we are back to where we were before. So how did we save money by shutting off a decent program that ya'll had initiated. Why don't they listen to ya'll, and say ya'll tell them we have reached the point that we don't need to go five days a week. But we think we might go one day a week and maintain the program, then it saves Medicare/Medicaid a lot of money and we don't start all over again. Every time we get something accomplished we start over again.

Beneficiary “the ultimate loser”. Medicare consumers viewed the denial/termination of services by the health care system as a final verdict of being on their own from hence forth till they qualified for more services. One beneficiary, who was recovering in a SNF, spoke collectively for beneficiaries around him in the facility.

I was thinking the other day. There's a woman down here and that's really a shame because I am... I'll be 68 on September 18th. There's a lady down here that's 65 with, I guess, Alzheimer's, or whatever. Other than that, the closest person in age to me around here is probably 73-74 years old, and they range to nearly 100. And those people, it's just not fair to them. I mean, I'm at the bottom

of the barrel that I can see right here. Medicare is okay, but it's sure not taking care of what needs to be done.

Feelings of sympathy for the beneficiary, and the beneficiary being the ultimate loser, echoed through each one of the narratives.

Agency Differences among Respondents

Differences among respondents occurred in relation to the fifth topic area of the analysis, reaction to denial of services. These differences are broadly characterized as a passive narrative (seven respondents) and an active or more agentic narrative (five respondents). In the passive narrative two beneficiaries represented themselves, while the other five beneficiaries were represented by proxy navigators. The active narrative consisted of two beneficiaries who represented themselves, and three of the beneficiaries were represented by proxy navigators. Group differences will be described for each of the two themes in this topic area, interaction with health care providers and contest denial of services (Table 2).

Interaction with Health Care Providers

Passive narrative. The health care professionals that respondents dealt with consisted of health care practitioners and health care providers. These respondents described themselves as patient and compliant when interacting with health care professionals, even when they viewed health care professionals as failing to consider their time constraints, their right to be informed about decisions, and their right of choice. All respondents relied on medical authority for guidance, both with regards to their medical condition and explanation of their benefits. Within this narrative, some respondents viewed health care providers as the authority and therefore believed it was

their duty to accept decisions and advice rendered to them. One proxy navigator, who was also a beneficiary, had this to say:

I guess it is a given, will I understand what they are telling me? It is a thing um.., depression babies, I don't know, I guess we were told to accept what we have, and you didn't question it and went on from there and that is just the sort of, I guess...

Others expressed to professionals that they wanted to have a say in their care, but they felt ignored. A proxy navigator, who was disappointed with the way his mother was discharged from rehabilitation services without being informed, reported the following:

P: Yes. I mean... on the first day... we were out of town for four days. On the first day I came back I said, what's wrong with you? I mean, she hadn't even said a word to me and I knew something was not right. And I said, 'are you tired from working out?' Because I thought she was just exhausted and she said, I don't work out anymore. I went what? That was the first I'd heard of it. Now, there that was a problem, a communication mistake on their part. I think I darn sure should have been notified when they changed some of my mom's drugs and when they changed her therapy.

I: So no one informed you?

P: I was never informed. I had to go ask them. And then they went, oh oops. So, I wasn't real happy about that.

Respondents found they did not have a voice as health care professionals did not consider their point of view, their time, or their well being. However, they felt that they needed health care and therefore had to yield to health care providers' actions. These respondents viewed the disregard health care providers had for beneficiaries' rights and their families with disdain, but in the end gave into their authority.

Table 2: Reaction to Denial of Services

	Passive narrative (7 respondents)	Active narrative (5 respondents)
Interaction with health care providers	Implicit faith in health care professionals watching out for them, viewed health care professionals as authority, believed they have no other choice, no voice in the system, did not have the knowledge to question health care providers	Questioned health providers and the system. Monitored the care vigilantly and were persistent with demands.
Contest denial of services	Belief it is a Medicare decision, belief health care professionals looking out for them, belief authority of health care professionals/Medicare requires deference, a waste of their time trying to contact Medicare, a lack of knowledge to question judgment of health care professionals.	Did not officially contest Medicare decision, but attempted to work the health system to achieve their goals.

Active narrative. These respondents recognized that they were dependent on health care professionals to provide the care they needed, but they talked of the importance of monitoring their care and attempting to negotiate the care they needed. One proxy navigator had this to say about negligence she believed her mother and her family experienced in an ER, despite her attempt at monitoring and having a say in her care.

And the doctor still says no. But, I did the research on it and what she described as having the... what she was feeling the exact side effects of that medication. But it was like very rare that that would happen, but it

happened to her. But she was doing fine until then. When I took her to the heart hospital and told them that she was not breathing, they didn't let me go back there with her because they didn't have a bed for her. They put her in the hallway. I feel that they put her in the hallway and forgot about her, and they wouldn't let me go back there, and I kept asking "how is my mother?" And "how is my mother?" "Well she is doing ok." By the time we went in she was already in a room. She was intubated, they had her on a respirator breathing for her, she had already blue coded and everything and we didn't even know anything about that.

Following this experience, this proxy navigator stayed close to her mother to monitor the care she received and demand the care she needed.

The nurse did not find it. I did, When I touched it I said "oh no" I mean, that is when I said ok, I called you know, told her we need to get her checked out and that is when the Dr.'s came and everything. I feel like if I hadn't been there.... Like people that don't have anyone, I don't know. I don't know. It is too easy....I mean you know, first of all, If you don't have someone there to be there with you, you are the one that is sick, how are you going to be able to tell somebody if you are not able to express yourself, like okay my mother. Let's say she didn't have anybody how is she going, she was going to do whatever they told her to do that's all. Do you hurt? Yes. Where do you hurt? Okay. But as far as okay. Why? Why are you doing this? What is next? There is no way, I think my mom would have passed away by now.

These five respondents did not entirely trust the health care professionals/system.

They reported that they had to be persistent and vigilant about the care they received or needed. Despite these respondents being vocal, they too bore the brunt of health care professionals' decisions that did not work in their favor. Their response to such interactions was increased vigilance and persistent demands in the care of the beneficiary. A beneficiary, who was also a retired RN, said she no longer had the energy to fight for her care, but used her daughter to demand the care she needed:

Then they tried to get me back we go searching, they try to get me another doctor and another doctor "not taking any patients". If I was dying or if I

was on hospice, yeah they could probably get me somebody to put this pump in, but I do not want to have to be on hospice or dying to get the pump I just want to live out a few more years comfortable. This is very, very painful. So I kept saying why can you not have the same drug because they make it in a pill form where you can take it by pill and I could not get anybody to listen to me. Finally after my daughter got very irate and she went to pieces on them they decided to try me on the pill medication.

Contest Denial of Services

Passive narrative. When informed of denial of services, these respondents believed health care professionals were following Medicare rules or guidelines to make the decision. Additionally some believed they lacked the knowledge to question Medicare and the judgment of health care providers. As one proxy navigator reported:

P: But again, I don't know all the ins and outs. You know, I'm not a doctor. I'm not in the system, and I don't know... I mean you can definitely look at her now. She has less energy. She has less skin color. She has less skin tone. If that's not regressing I don't know what is now. The nurse here, I don't know her name. The little blond-headed girl, she says it's got to be certain things.

I: When she says certain things, what did she say?

P: I'm trying to remember. You know, she said well, it's got to be a bowel movement. I said well, you had gotten her to the point where she was going to the bathroom all the time. Now, like then, she had gone back to it. That kind of nullifies what you just said there.

I: Right

P: But, she was holding to her guns and saying, you know, there is a criteria that we have to meet. I can't remember what all it is, because.

I: Right.

P: You know, I mean...regression is regression to me.

A prominent theme with these respondents was a lack of faith in Medicare supporting them and assisting them. One proxy navigator who was navigating Medicare on behalf of her mother, and was also a supplemental policy insurance agent had this to say:

I: Have you not tried to call Medicare to see if?

P: Oh, Forget that!!! (Laughs aloud)

I: Why?

P: Oh my Lord. I mean it is one eight hundred go fly a kite if you have got half a day to sit on the phone. And, I mean I guess I could. I could if I thought it would help. It has not been my experience before that it helps. Perhaps I should try that. They are not user friendly to deal with. They are not. Good luck, with my experience with them in the past you never get the same person twice. And so you are just liable to get one answer at one time and another answer the next second. It hadn't crossed my mind to do that.

Respondents' experiences and perceptions that Medicare had the last word, and therefore there was not any point in contacting Medicare echoed in these narratives. For the most part, the respondents did not contest the denials, and passively accepted the decision.

Active narrative. These respondents when faced with the consequences being denied/terminated services reacted and developed a strategy to get the attention and care they needed. One proxy navigator and one beneficiary who were familiar with the health care system were better enabled to work the system to their benefit. The proxy navigator/pharmacist took the time to study Medicare's mode of delivery of care and transferred her mother-in-law to traditional Medicare at the end of the year, and also got her a supplemental insurance. The beneficiary who was a retired RN, realized with the help of her daughter she had to put up a fight until she received what she needed and had this to say:

Then I got home and we tried to get them to give me the pill for, and that took my daughter like six weeks later and she was so irate, irate to think that they would not give them to me. She just kind of got very upset with them. They decided to try it and I have to tell you that I have only been on it now for a week and a half but I have, but I can move, move almost freely.

However, it was not just those who had worked within a medical setting who took an active role regarding health services. A proxy navigator reacted in the following way:

When they came here, what they did here was nothing compared to what she was getting over there and I saw her take a big ole step back. I was really frustrated with that. I tried to do my best with what I could. When that was over, when they said ok this is all we can do I said ok. She is not at where she needs to be what else is there. They told me you can take her to a facility every day. So I said ok so let's arrange it so that is when I started taking her to that Out Patient Today. That is when they started working with her there. I saw a little progress, but then Medicare would not pay for all of that. Every time that she would go she would have to pay \$30. Every time she went they wanted her to go three times a week. That was a lot. I said ok from here what is going to happen, that is what I asked the therapist. He said we have another facility that you can become a member and you can go as many times. I said is there someone there that can help us to tell us what we can do, what direction to go. They said yes we will send all information over there. I was the one that made the decision once we are stopped here lets go over there. So now we are going every day. We get up at 5 a.m. every morning and we go to physical therapy there and we do tread mill and the pool.

This navigator persisted until she was able to find resources in the community to help her mother. At the time of the interview, a year after her mother's discharge from the SNF, she was still working with community resources to help her recover.

An additional example is a beneficiary who had always been represented by a proxy navigator and was confined to a nursing home for approximately four years based on a lack of improvement determination. She was placed on Medicare hospice by her daughter, following the death of her husband, who was an avid supporter of her receiving rehabilitative services to help her recover and return home. Although Medicare hospice was required by law to provide rehabilitative service, the hospice agency informed the beneficiary's proxy navigator that the beneficiary would not be provided these services. The beneficiary then opposed her daughter's decision to be on Medicare hospice and

convinced her daughter to change plans so she could receive the services she needed.

Despite the beneficiary's and the daughter's lack of awareness that hospice was required by law to provide rehabilitative services for Medicare hospice beneficiaries, the crisis of not having her needs met prompted the beneficiary to become active on her own behalf.

CHAPTER IV

DISCUSSION

This study points to challenges in accessibility to health care experienced by some Medicare consumers. It highlights their sense of helplessness as they attempt to navigate a complex hierarchical system and the social and institutional processes that serve to constrain and enable them. It also draws attention to differences among consumers in their transactions with the health care system.

Perceptions and Challenges of Consumers When Denied Services

Disillusionment with the System

Study participants felt disappointed and let down by Medicare, when denied services. They believed it was the duty of a nation to take care of its older adults. Despite the current debate about the place of social insurance programs to support older adults at the expense of future generations, these Medicare consumers believe that a country of such a stature should afford its hard working citizens a comprehensive coverage (Brown, 1999; Oliver & Lee, 2009). Further, as has been reported by others (Basanta, 2007; DeJong, 2005; Medicare & Me, 2011), Medicare's ongoing rhetoric about health care being consumer directed and choosing one's plans to avoid gaps in coverage was influential for some respondents in their belief that they would receive needed care as needed. Experiencing gaps in coverage and its consequences, despite attempts to play by the rules and enroll in plans as recommended by Medicare, was a source of disillusionment with the system.

Consequences of Service Denial

The physical, psychological, and financial impact of service denial on beneficiaries and their families was substantial. For example, over 80% percent of the beneficiaries were dependent on their families for some form of material, physical and monetary assistance, and over 90% of the respondents reported a psychological impact to the beneficiary, which left them feeling unwanted. According to Sparrow (2008) such issues when not reported remain invisible and the scope of such issues remains unknown. Although there is a push to protect Medicare beneficiaries from harm due to fraudulent practices in health care, harm inflicted on beneficiaries and their families due to Medicare's policies and health care professionals' interpretation of eligibility has not been recognized as a serious issue (Davitt & Choi, 200; Krausse, 2006).

Barriers to Contesting Denial of Services

First, despite Medicare consumer rights to contest decisions they are not in agreement with, such incidents are underreported due to the lack of awareness of their rights (Olson et al., 2010), as was the case in this study. Other factors that played a part were, an assumption that Medicare would not support them and that Medicare had the last word. Such perceptions of consumers indicate an underlying problem of lack of power and a taken for granted acceptance of their situation commonly seen in hierarchical systems (Swartz, 1997). Gaps in the safety net of coverage and a lack of adequate care faced by these consumers is contrary to and undermines Medicare's mission to provide equitable access to care and to be patient centered (Aday et al., 1993; Basanta, 2007; Guterman et al., 2005; Krausse, 2009).

Second, Medicare resources are not user friendly. Others have proposed that there is a structural mismatch between an advanced system such as Medicare and its beneficiaries, creating a challenge for Medicare consumers to access Medicare information (DeJong, 2005; Fiucane et al., 2002; Harris-Kojetin et al., 2007; Hibbard et al., 1998). Medicare's attempts to make it a consumer driven health care system has had limited success. This study concurs with Hibbard et al. (1998), that only a very small segment of beneficiaries/Medicare consumers are able to use its literature as intended. This study found over 80% of the respondents primarily relied on oral information and 75% made no attempt to seek Medicare media/resources. Their primary reason for not seeking Medicare literature was their underlying assumption that they would not be able to understand medical and legal jargon. These participants sought human contact (primarily health care professionals) rather than interaction with a machine, delayed responses, and the expectation that information obtained by such means would be unclear and inconsistent.

Schilling and Mellor (2007) view such responses to be a natural preference to use culturally embodied ways of dealing with systems, as opposed to communicating with technology that is characteristically used by complex systems. As suggested by Tsouka's (1997) the use of "objectified, commodified and decontextualized" (p.827) information used in advanced systems isolates consumers. Medicare's use of non standardized plans and its strategy to market its services as commodities, along with its use of technology to market its services have only served to increase the complexity of the system and isolate its consumers (DeJong, 2005; Svihula, 2008). These strategies have served to promote a greater reliance on health care professionals for guidance. With the transformation of

health care in America, reliance on health care professionals has been reported to be a source of concern, and this study exposes the continued existence of such patterns in the Medicare health care field (Starr, 1982).

Medicare at Odds with Beneficiaries' Needs

Following their experiences with denial of services, the consumers in this study saw Medicare's length of stay and other eligibility criteria to be at odds with their recovery and their well being. Gibson, Zitzelsberger & McKeever (2009) refer to such experiences as those of futureless persons who are marginalized because their needs/recovery follows a different trajectory from what is expected. The inadequacy they express in their health insurance meeting their needs, according to scholars is more a function of Medicare's strategies to provide services in a cost effective way (Aday et al., 1993; Davitt & Choi, 2008; DeJong, 2005; Estes & Linkin, 1997; Svihula, 2008).

The uses of the discretionary clause by health care professionals to determine the need for health care services is liable to vary as various health care professionals work within a unique set of constraints (Davitt & Choi, 2008; Karlin & Humphreys, 2007; Mayes & Berenson, 2006). Consumers are not privy to such information and therefore what goes on in the determination process can be likened to a black box. Evidence of such practices was found in this study with the experiences of Medicare consumer's enrolled in HMO's and with the premature termination of a hospital stay that caused a respondent to lose his leg to an amputation. The consumers in this study were accepting of health care professionals' determination despite their contrary belief to the benefit of the denied/terminated services to them because of their acceptance of the dominant time

culture and the authority commanded by health care professionals (Conrad, 1992; Estes and Binney, 1989; Gibson et al., 2009).

Passive and Active Narratives

Medicare consumers in this study were faced with the social reality of navigating an unfamiliar and complex system whose rules were not always explicit. Over half of the participants (7) told an essentially passive narrative; they were apprehensive about the future when denied services but did not question or challenge Medicare decisions as conveyed to them by health care professionals. However, other consumers in this study (5), when faced with denial, told a more active narrative. None officially contested Medicare denial, but they adopted an active consumerist strategy to have their needs met.

Passive Narrative

Current Medicare practices promote passive consumerism. Passivity is an almost inevitable outcome of a complex system where decisions are for many reasons opaque to consumers (Adkins & Corus, 2009; Swartz, 1997). Medicare works in collaboration with medical professionals to determine who is worthy of receiving health care goods (Conrad, 1992; Estes & Binney, 1989). Yet these professionals often fail to clearly communicate the bases for denial to consumers. Furthermore, via the inaccessibility for many of its policies, Medicare has essentially distanced itself from Medicare consumers (Karlin & Humphreys, 2007; Preston et al., 1997). This strategy used by Medicare according to Pinker (2011) is a practice which serves to protect the health care system from taking responsibility for its actions. Medicare consumers, by passively conforming and accepting the dictates of the medical establishment, accept the repercussions of dependence, believing they have no recourse.

Active narrative

This narrative speaks of the potential of consumers to engage in an active form of agency to have their needs met when faced with a crisis. These respondents engaged in gathering information about their situation following the denial of services and rebounded with assertiveness and a will to have their needs met. Although Medicare's mode of delivery of care continued to be a challenge, these respondents sought, observed, and persistently attempted to understand their choices from multiple sources and manipulated the system to get the attention and services they believed they needed.

Béhague et al. (2008) viewed this kind of resistance to medical authority as having the potential for positive change. Adkins and Corus (2009) view such action as active consumerism, where consumers use their skills to gather the necessary information to make health choices. Additionally, they also suggest that it is the focus on having their health care needs met at all costs, that prompts them to interact with health care professionals to make an effective decision that benefits them. In this study, two of the more active respondents did have past experience in the health care system, but the others did not have any apparent past experiences or skills that might account for their more agentic stance in response to service denial. The only commonalities among these consumers were a perception that their needs were being disregarded and a determination to be persistent in challenging medical decisions.

Theoretical Connections

According to the theory of practices and symbolic violence (Bourdieu, 1977), Medicare is a relatively autonomous field where beneficiaries and their proxy navigators vie for health care goods and services, while Medicare works under a set of rules

basically unknown to the beneficiaries (Mayes & Berenson, 2006). Medicare publicly espouses the idea that the delivery of high quality health care and cost effective care can be best addressed by consumers determining the care they need, but it covertly collaborates with health care providers to engage in cost conscious medical practices (Aday et al., 1993; Basanta, 2007; DeJong, 2005; Mayes & Berenson, 2006; Oberlander, 2007). Bourdieu (1977) views struggles for services by consumers to be a result of dealing with a system characterized by unequal power distribution and hidden structures unavailable to consumers.

Structural mismatch. The discrepancy between Medicare's aspirations to be a technologically advanced consumer driven health care system and the realistic probabilities of Medicare consumers accessing and navigating Medicare independently is viewed by Bourdieu as a structural mismatch (Swartz, 1997). Beneficiaries' limited use of Medicare's resources, their limited knowledge of their benefits, and their reliance on health care professionals to guide them in navigating Medicare as evidenced in this study, is a contradiction to Medicare's objective of making it a consumer driven health care system. DeJong (2005) questioned the use of such a system by even the best educated. The structural mismatch limits the symbolic power of Medicare consumers, in an already unequal hierarchical system (Bourdieu, 1993; Swartz, 1997). In this study, the consequences of interacting with such a system had psychological implications of feeling incompetent, frustrated and stressed.

Class habitus. Bourdieu (1993) refers to systematicity seen in consumers' practices such as a tendency to depend on health care professionals, and failure to contest denial of needed services as a class habitus, despite disagreement with the determination.

He compares such practices to “a conductorless orchestration, (p.105)” because of the orderliness, unity and regularity of a class of people who are exposed to the same life chances (Swartz, 1997). Despite variations in their personal styles of accessing resources and attempting to interact with health care professionals, participants in this study shared a common sense of their position in the system, the deference to health care providers’ decisions, and the futility of reversing a health care decision they were not in agreement with. The authority of health care providers within the realm of Medicare was taken for granted, and their social control accepted. Consumers reported bearing the brunt of the decisions of health care professionals not just with the determination of denial/termination of services, but over the course of navigating Medicare.

Symbolic violence. Medicare’s actions of collaborating with health care providers and making them the gate keepers of the system has far reaching implications for consumers, as the disguised symbolic power taken for granted as medical authority impacts not just their health but also their benefits (Aday et al., 1993; Bourdieu, 1977; Conrad, 1992; Estes & Binney, 1989; Swartz, 1997). Medicare’s action legitimizes the power differential in this field, and in doing so it has elicited the consent of both the dominant health care professionals and the dominated Medicare consumers who view this power differential as natural (Swartz, 1997). Consumers’ actions of deference to Medical authorities despite not being in agreement with their decisions, highlights the impact hierarchical systems have on the less powerful. This misrecognition of the unequal power relations that exist in the Medicare field is viewed by Bourdieu (1977) as symbolic violence exerted against Medicare consumers who accept their own condition and the consequences of their domination.

Lack of transparency in the mode of delivery of care, and the lack of knowledge of the power vested in health care professionals in determining their coverage, created a situation where consumers viewed themselves as being incompetent in navigating the system independently and in understanding the criteria used by Medicare for recovery. Such features of a hierarchical system that only a segment of the system is privy too are viewed as hidden structures that create the misrecognition in the system (Swartz, 1997). In examining the experiences of consumers it was such misrecognition, in part, that also created the unpredictability and the unforeseen gaps in coverage that they experienced. The consequences of use of such hidden structures and arbitrary rules in hierarchical systems have been discussed as being dire to consumers in past studies of health care systems, and are evident in this sample of Medicare consumers' narratives (Araújo et al., 2009; Béhague et al., 2008; Moore, 2004).

Transformative agency. This study also points to the possibility that consumers can to some degree resist the system, despite social and institutional structures that shape their class habitus. While habitus is viewed as practical and pre-reflective rather than conscious, transformative agency is viewed as an innovative capacity of habitus (Swartz, 1997). The five participants who engaged in an active narrative following the denial/termination of services is indicative of the potential of human agency to strategize in unexpected ways to have their needs met. This was an important finding in this study as it confirmed the interplay that exists between habitus and the field, and the potential such an interaction has to stir up the habitus to engage in nonconforming ways (Béhague et al. 2008). In this study the transformative agency respondents engaged in appeared to

materialize primarily due to an unmet need and the awareness that it was up to them to have their needs met.

Limitations

This study, in drawing attention to the difficulty beneficiaries experience accessing resources and navigating Medicare and the challenges they face with unanticipated gaps in Medicare coverage, has exposed a problem. Being the first of its kind in using qualitative research to explore this issue in a bottom up fashion, it has told part of the story. The pervasiveness of this issue is an implication that this study was not designed to address but that needs to be understood.

Participants in this study had a variety of health care plans. Although they all experienced denial/termination of services, their benefits varied; those that had traditional care were envious of those that were dually eligible believing they were better covered. Those that were on HMOs found traditional Medicare to be more expensive, but when dealing with the uncertainties of health they reported traditional Medicare provided a more comprehensive plan. Studies addressing such comparisons are needed in order to provide policy makers with data that addresses the efficiency and effectiveness of plans and to provide beneficiaries with information that can help them stay informed and make choices as needed.

The respondents in this study were primarily those that had been denied rehabilitation services from Lubbock and its surroundings. Medicare purchases health care services and goods for Medicare consumers from various entities (Aday et al., 2004; Karlin & Humphreys, 2007). Denial of services can take on various forms such as surgeries, organ transplants, medication, equipment and ageist attitudes, all of which

should be included in future research. Representativeness of samples in future research could be expanded in other ways, for example, geographical location and the type of support available to the beneficiary.

Health care professionals who represent Medicare were not interviewed, and therefore the conclusions of this study are based on the consumers' narratives, the researcher's understanding of the Medicare structure based on my professional experience, and the extant literature. For a more thorough understanding of this topic, interviews that included health care professionals that denied the service would have provided a more comprehensive understanding of health care professionals' interpretation of policy and the institutional and social processes that served to enable and constrain their delivery of health care.

Implications

This research falls within the realm of health services research that is concerned with generating knowledge about the impact the Medicare structure and its policies have on Medicare consumer in terms of efficiency, effectiveness and equitable access to care (Aday et al., 2004). It illustrates the potential of qualitative research to provide a more in-depth view of Medicare consumers' experiences than is provided by large survey studies. It has made visible the consequences to beneficiaries and their families of unanticipated denials of service. Denial of services can take many forms due to Medicare's extensive use of various entities to provide health care services. The complexity of Medicare and its policies has far reaching implications for its consumers. With the emphasis being on cost containment, Medicare's focus has been on policy and engaging in cost effective practices (Krausse, 2006). There is a dearth of research on the range of implications

Medicare's policies and health care professionals' practices have on beneficiaries and their families. A more comprehensive understanding of these issues is needed because of their potential consequences for consumers. Such research can inform future policies that better inform, protect, and empower Medicare consumers.

Interpretive Phenomenology (Lopez & Willis, 2004) was a useful framework for elaborating consumer's experiences of denial of services and the meanings they gave to these experiences. Use of this framework has a place in health services research because of its potential to highlight issues based on experiences of beneficiaries within the Medicare context. It provides the means of making a case embedded in Medicare consumers' experiences to policy makers regarding the significance of a problem that consumers face. It also has the potential to provide a rationale for evaluating the impact existing policies have on practices of all the various entities that are assigned with the responsibility of providing adequate and necessary care to beneficiaries.

Bourdieu's theory served to highlight the symbolic violence and the impact it had on beneficiaries' sense of agency. Although violence has been documented to be on the decline over the ages, violence in an advanced technologically complex world has taken on other forms other than just physical violence (Bourdieu, 1993; Pinker, 2011). The consequences of symbolic violence are real (Bourdieu, 1993; Swartz, 1997). Like physical violence, it has the potential to overpower and subject unassuming consumers into acceptance of the status quo without consideration of the physical, financial and psychological harm they are subjected to. (Araújo et al, 2009; Béhague et al., 2008; Bourdieu, 1993; Ming-cheng & Stacey, 2008; Pinker, 2011; Swartz, 1997). Use of this theory helped this research make the macro-micro link and unearth hidden structures such

as Medicare policy that was responsible for the unequal power, the misrecognition and symbolic violence that was experienced by the Medicare consumers in this study. Use of this theory is helpful and recommended in understanding consumers' experiences in bureaucratic and hierarchical systems whose policy is focused on driving pricing, quality and, service, but also need to understand the impact their actions have on the consumer.

Bourdieu's concept of transformational agency provides a foundation for change (Swartz, 1997). Béhague et al. (2008) view it as "a form of social practice that arises from the possibilities that the ruptures and conflicts in the social structure enable," and is reported to have the power to cause institutional changes. There is a need for future research to understand the conditions under which disappointed expectations have the potential to turn into effective vehicles of change so programs can be implemented to aid Medicare consumers establish their legitimacy in the Medicare system and be better able to negotiate such conflict in having their needs met (Swartz, 1997).

In sum, the common perceptions and experiences that emerged in this study irrespective of type of plan enrolled in, social background or diagnosis suggest the probability that other beneficiaries are experiencing similar situations. Medicare consumers' experiences of denial of services and their needs not being met is an indication that Medicare's mission of right care for everyone, equitable access to care, and promoting a consumer driven health care system are failing older adults. As anticipated by some scholars, the policy innovations of Medicare over the past decade may have served to undermine the social contract Medicare had with its consumer and its humanitarian mission. Examination of the prevalence of denial of needed services in its

various forms, and the harm incurred by beneficiaries, need recognition and further examination.

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APPENDIX A

Interview Questions for Beneficiaries

1. Thank you for being willing to talk with me about your experiences with Medicare. I am doing this study because we don't know much about people's experiences when Medicare benefits have been denied. So, I'd like to begin by asking you to tell me the whole story of what happened. Why don't you start with the beginning of your health problem, and go from there. (This will be their story, with only clarifying questions. After they have told their story, follow up or review questions will cover the following.)
 2. Who informed you that your benefits had been denied?
 3. How did you feel when you were told about benefits being denied?
 4. Did you try to do anything about that? If so, tell me about what you tried.
 5. If you didn't try to do anything, tell me why you didn't.
 6. If it happens again, would you do anything differently?
 7. What impact is this having (did this have) on you -emotionally, physically, financially?
 8. What impact is this having (did this have) on your family?
 9. Do you think your life would have been different had you received the coverage? If so, how?
10. How do you feel about Medicare? -The services it offers, health care providers, the aging and disability office, meeting your health care needs.
11. If you could talk to people who run Medicare about changing how they do things, what would you say?

12, How do you stay informed about the types of changes Medicare makes with its plans?

–get the information you need, discuss concerns, type of media (hot line, website) you utilize to communicate with Medicare?

13. Are you doing anything now to make sure you do not have another experience of denial of services you need?

14. Is there anything else you would like to add about anything we have talked about?

15. Now I'd like to get some basic information about you and your health plan.

-Age, marital status and how you live (alone, spouse, w/ children)?

-Why and how did you enroll in Medicare? – How old were you?

-What type of health insurance coverage do you have? – Traditional Part A & B, part A only, managed care, Part D. -Why did you select such a plan?

-Do you have supplemental health insurance coverage in addition to Medicare?

Please tell me about that.

Interview Questions for Family Members

Thank you for being willing to talk with me about your experiences with Medicare on behalf of your (family member). I am doing this study because we don't know much about people's experiences when Medicare benefits have been denied. So, I'd like to begin by asking you to tell me the whole story of what happened. Why don't you start with the beginning of your (family member's) health problem, and go from there. (This will be their story, with only clarifying questions. After they have told their story, follow up or review questions will cover the following.)

2. Who informed you that the benefits had been denied?
3. How did you feel when you were told about benefits being denied?
4. Did you try to do anything about that? If so, tell me about what you tried.
5. If you didn't try to do anything, tell me why you didn't.
6. If it happens again, would you do anything differently?
7. What impact is this having (did this have) on (the beneficiary) -emotionally, physically, financially.
8. What impact is this having (did this have) on you and other family members?
9. (a) Do you think (beneficiary's) life would have been different had she/he received the coverage? If so, how?
- 9 (b) what was your role in helping (beneficiary) during the illness.
10. How do you feel about Medicare? -The services it offers, health care providers, the aging and disability office, meeting your health care needs.
11. If you could talk to people who run Medicare about changing how they do things, what would you say?

12, How do you stay informed about the types of changes Medicare makes with its plans?

–get the information you need, discuss concerns, type of media (hot line, website) you utilize to communicate with Medicare?

13. Are you doing anything now to make sure you do not have another experience of denial of services needed by (beneficiary)? What about for yourself—does this affect your plans for health coverage, now or in the future?

14. Is there anything else you would like to add about anything we have talked about?

15. Now I'd like to get some basic information about (beneficiary) and her/his health plan.

--Age, marital status and where living (alone, spouse, w/ children).

-Why and how did she/he enroll in Medicare? – At what age?

-What type of health insurance coverage does he/she have? – Traditional Part A & B, part A only, managed care, Part D. -Why did you select such a plan?

--Does she/he have supplemental health insurance coverage in addition to Medicare? Please tell me about that.

APPENDIX B

Consent Form

We are asking you to be a Respondent in a research project called: “Older Adults Navigating Health Care: When Benefits are Denied.” Dr Nancy Bell and Karen Aranha in the Department of Human Development and Family Studies at Texas Tech University are in charge of the study. Dr. Nancy Bell’s phone number is (806) 742-3000, and Karen Aranha’s phone number is (806) 283-3488. Their emails are nancy.bell@ttu.edu and karen.aranha@ttu.edu.

The purpose of this project is to find out about the experiences of Medicare beneficiaries when they are denied the health care coverage that they believe is essential for their recovery and well being. Your participation in this research will involve a tape-recorded interview of 1-2 hours in length. The interview will be conducted in your home or another place of your choice, at a time convenient for you. In the interview you will be asked questions about what services were denied by Medicare and about how this denial has affected you.

Participation is completely voluntary, and you may withdraw from the study at any time. You will not be asked to talk about any topics that are uncomfortable for you.

No one other than those directly associated with the project will have access to the interview information. The tapes and the interview transcripts will be kept in a secure place. Your name will not be linked to the transcribed interviews, and any use of this material in reports or publications will never be associated with the names of individuals.

As a way of saying thank you, you will receive \$20 at the conclusion of the interview. Participation is completely voluntary, and you may withdraw from the study at any time. You will not be asked to talk about any topics that are uncomfortable for you. If you wish to stop the interview at any time, you will still receive the \$20.

We do not see any risks to you from participating in this research. As mentioned above, you will be free to stop the interview or request a change in topic should you feel uncomfortable with any aspect of the discussion.

Nancy Bell or Karen Aranha will answer any questions you have about the study. For questions about your rights as a subject or about injuries caused by this research, contact the Texas Tech University Institutional Review Board for the Protection of Human Subjects, Office of Research Services, Texas Tech University, Lubbock, Texas 70409. Or you can call (806) 742-3884.

Signature of Respondent

Date

This consent form is not valid after May, 2012.

APPENDIX C: Flyer Used to Recruit Participants

Attention Medicare Beneficiaries

If you have been denied Medicare benefits in hospitals, skilled nursing facilities, in doctor's offices and through home-health for:



-not having a qualifying diagnosis

-not making progress

-being too sick to participate

-or being too old for treatment

This is an opportunity to participate in an **important research study**.

To participate you must be a Medicare beneficiary 65 years of age and older and must have been denied services/coverage, or you can be a family member or a close friend who has assisted a beneficiary when they were denied coverage.

We would love to get your opinions and hear about your experiences.

The interview will take about 1-2 hours and will be confidential.

Respondents will receive a **thank you gift of \$ 20/-**

Place: at any location at your convenience.

To find out more about the study, please email:

Karen Aranha at karen.aranha@ttu.edu

or call 806 283 34 88,

or email Dr. Nancy Bell at nancy.bell@ttu.edu

Please remember that if you or a close family member has been ever denied health care coverage as a Medicare beneficiary we would like to hear from you.

APPENDIX D

Biographies of Respondents

Respondent 1 -Hill family: Mr. Hill is a 78 year old beneficiary who suffered from transverse myelitis four years ago while on a cruise with his wife, son and his son's family in the Caribbean. Mr. Hill reported within a matter of minutes he was completely paralyzed and had to be flown to a medical facility by Aero Care for medical help. Prior to his illness, he was gainfully self employed as a broker and had rental properties. Mr. Hill and his spouse are both Medicare beneficiaries, and their supplement and part D coverage is through AARP. His rehabilitation in the past four years has been intermittent because of the determination of lack improvement made by health care professionals in a long term care setting. He is eager to return home, maintain an active lifestyle, and provide for himself and his wife as he did in the past. He believes he has made great progress considering his starting point, and feels he needs rehabilitative services to progress and prevent a physical decline.

He has been in a long-term care setting for the past four years and was not clear about the type of coverage he had or his experiences when he first fell ill. To fill in the gaps in his narrative, his wife was also interviewed. Denial of services has impacted him in multiple ways. Mr. Hill has been paying >\$5000/month to stay in a LTC setting. His wife, who was unprepared to be the provider, finds it a strain handling her husband's business and their health care, despite input from her husband and her son. Although Mr. Hill says he is strong emotionally and is doing the best he can to get on with his life, he has expressed anxiety about the future and has expressed feeling helpless at the moment.

He likened his current situation to a childhood experience where a friend of his had buried him in a sand pit with only his head and neck exposed.

Respondent 2- Garrison family: Mr. Garrison is an 80 year old beneficiary who was in a car accident and suffered a back injury. At the time of the injury, he had and continues to have Medicare part A and a supplemental policy. He was a soil chemist and had his own business. Following the accident, on the day he was scheduled to have his back surgery, he learned that Medicare was not going to pay for the surgery, citing the third party as responsible for the costs. As Mr. Garrison lacked the funding to undergo the recommended back surgery, in consulting with his physician, he opted to do physical therapy to be relieved of the pain he was suffering. Although he was getting relief from his physical therapy sessions, he subsequently was denied coverage secondary to a lack of improvement determination by health care professionals. Because of the relief and the benefits he saw in receiving physical therapy services, he took the advice of the treating physical therapist and has been paying out of pocket to engage in a local wellness program.

His wife, following a stroke, was recuperating in a long term care setting. His initial plans were to recover from his back injury and take his wife home to care for her. He believes the denial of physical therapy has limited him in many ways, but in particular he has not able to take his wife back home because of his untreated back problems. He is in constant pain and reports that housekeeping is difficult for him. He has limited income as his wife needs a nursing home placement. Additionally, her qualifying for Medicaid has limited his earning potential and his options to deal with his wife's condition as well

as his. Emotionally, he reports being frustrated and angry with Medicare because of the limits imposed on his wife and himself. Mr. Garrison also has experienced reaching the “doughnut hole” with his Medicare part D coverage, and due to the high cost of his cardiac medications, has not been taking his medications.

Respondent 3: Anthony Family: Mr. Anthony was 87 years old, and prior to his illness was living at home with his wife. He was independent with his basic activities of daily living. He participated with family and community events along with his wife, and she reported that they always made joint decisions. Mr. Anthony was an engineer and a professor for 60 years. The only signs of decline his wife reported prior to the precipitating event were minimal cognitive limitations, primarily with his memory. They were both Medicare beneficiaries, and had traditional Medicare and Blue cross Blue shield as their supplementary insurance. At the time of the interview, Mrs. Anthony reported being confused about Medicare part D and was not sure what plan she and her husband were on. On the day of the admission to hospital, he called his wife, saying he was having trouble standing. His wife reports that the hospital staff referred to his case as an “altered mental status” from which he did not fully recover. She has no idea what went wrong, but from then on she was responsible for navigating his health care. When she was informed that he would have to be moved from the hospital, she attempted to find a suitable SNF. He was denied admission secondary to not having a skillable diagnoses. In the mean time, the hospital moved him to a psychiatric facility. Following a short stay, he was finally admitted to a SNF. In this facility he had difficulty participating in rehab because of his altered mental status and lack of posture control.

Within a short time he was discharged from rehabilitation secondary to a lack of improvement determination. He was placed in the most advanced dementia unit in the facility despite the fact that his altered mental status was only a recent event and that the physicians had not found a definitive cause for his condition. Navigating multiple fields including Medicare has been a strain on his wife. Denial of rehabilitation services crushed Mrs. Anthony's hopes of taking her husband home. Because Mr. Anthony had been confined to a wheel chair since the termination of services and had developed contractures in bilateral knees. the family has been paying >\$5000/month to maintain Mr. Anthony in long-term care. Mrs. Anthony has been dependent on children for monetary assistance to pay for her husband's care and to manage their affairs. Mr. Anthony died in the month of August'11 in the nursing home where he lived.

Respondent 4 –Sox family: Ms Sox is a 76 year old beneficiary who is a retired RN. She initially was diagnosed with Rheumatoid Arthritis and was treated for it but found no relief. She has traditional Medicare and Blue Cross Blue Shield as her supplemental insurance. At first she attempted to manage by herself in her home town in Massachusetts. Due to her inability to get the Medical care and the assistance she needed in the community, she accepted her daughter's invitation to live with her. Once with her daughter, Ms Sox found out that she had Gouty Arthritis and realized all along she had been treated for the wrong disease. A symptom of this disorder is debilitating pain that she believed needed to be managed, possibly with a pain pump. After numerous attempts to get the help she needed to relieve her pain, she was informed that she would only be given a pump if she qualified for hospice care. Ms Sox and her daughter, after multiple

hospital visits and conflicting opinions, finally got oral medication to treat her pain. Ms Sox believes if not for her daughter she would have been dead. She viewed the denial of the pain pump a Medicare determination and so never contested the denial. Denial of the pain pump and alternatively oral medication subjected Ms. Sox, in her view, to undue pain and emotional stress. Additionally she feels the emotional burden of being forced to depend on her daughter, who besides having her own family and responsibilities, now has to assist her mother with her health needs.

Respondent 5: Odessa Family: Initially, Mrs. Odessa, who was 84 years old, made her decisions with her daughter's support. Due to the increasing frequency of medical issues, particularly in the past year, Mrs. Odessa's daughter gradually took over and navigated the health field for her mother. Mrs. Odessa's daughter was interviewed on behalf of the beneficiary as she has been the primary responsible party for her mother and has navigated the system on her mother's behalf. Mrs. Odessa has been on multiple medications and would not have been able to participate in the interview. According to her daughter, Mrs. Odessa was enrolled in traditional Medicare and Blue Cross Blue Shield of Texas as her supplementary insurance. She has had a series of hospitalizations due to a hip surgery that developed complications and finally became infected. She experienced termination of services due to the lack of improvement determination made by health care professionals in skilled nursing facilities. The last time that Mrs. Odessa was faced with a lack of improvement determination she was being rehabilitated for removal of a replaced and infected hip joint but was also fighting other infections. Her daughter was interviewed the week her mother's services were terminated. The impact of

denial of services included the strain the her daughter was experiencing with handling her mother's finances, her medical bills and the emotional experience of her mother's Medicare benefits being terminated the very day she was informed that her mother had another infection. This proxy navigator was an insurance agent for Medicare supplemental policies, and she had little faith in Medicare supporting or helping Medicare consumers.

Respondent 6-Tripp family: Mrs. Tripp, a 72 year old female and a real estate agent, met with a motor accident and sustained multiple lower extremity fractures and required extensive medical care and rehab in a SNF. Mrs. Tripp died before she could do the interview, but her daughter-in-law, who had assisted her, agreed to be interviewed. Initially, Mrs. Tripp had confidence in that she had selected a good plan for herself but was shocked to learn that approximately 60 days into her stay at the SNF her HMO had decided to terminate coverage. Initially this beneficiary attempted to deal with the HMO herself, but due to personal limitations such as limited eyesight making it difficult for her to use a cell phone and poor customer service of the HMO; she handed over the management of her health care needs to her daughter-in-law. Her daughter-in-law was a pharmacist and was able to study Medicare and change her mother-in-law's plan to traditional Medicare with a supplemental policy. Mrs. Tripp resented the out of pocket expenses she had to pay to stay in a nursing home and receive rehabilitation services (>\$5000). Her daughter-in-law reported that Mrs. Tripp's experiences with the HMO were a dehumanizing experience; she lost all faith in the system she believed she had paid into to be cared for, in her old age.

Respondent 7- Straw family: Mrs. Straw was 88 years old and lived by herself with a little assistance from her niece until the day she was found on the floor with a broken hip. Following surgery, Mrs. Straw had an altered mental status, and was discharged to a SNF where she underwent rehabilitation. Her niece, who initially helped her with buying groceries and taking her for doctors appointments prior to her fall, became the sole responsible person to navigate Medicare and the health care field on the beneficiary's behalf following the fall. The beneficiary was enrolled in traditional Medicare and had a supplemental insurance. Ms. Straw was dependent on health care providers to make her decisions for her as she lacked an understanding of how the health care system and Medicare in general worked.

Mrs. Straw was discharged from rehab secondary to a lack of improvement determination. Although her niece was not in agreement with the decision of termination of services, she perceived the termination of services to be a Medicare decision and therefore believed she had no other options. The impact of denial of services caused the beneficiary to be dependent on nursing home care at a cost of >\$5000/month. Neglect of beneficiary's functional status following discharge from rehab, caused Mrs. Straw to develop contractures in her lower extremities. Her niece found it an emotional strain to witness her once independent and autonomous aunt languish and deteriorate in a nursing home. Her niece had to give up her job to attend to her aunt's needs and affairs, despite her aunt being placed in a nursing home.

Respondent 8 -King family: Mrs. King was a 79 year old beneficiary whose son, her proxy navigator, likened her to a house on fire prior to suffering a severe stroke in Nov. 2010. As a result of the stroke, Mrs. King was aphasic, had dense hemiplegia and a very poor activity tolerance. Her family and Mrs. King hoped she would recover so she could return home. Following six months of rehab, she was cited for showing a lack of progress and was discharged from rehabilitation services. Her son, who was not informed of his mother's discharge from rehab, was unhappy with the way the facility handled the transition. He believed she was responding well to rehabilitation and should have been given a chance to recover at her pace considering the intensity of the stroke and the acute onset. Mrs. King's husband was reported to have dementia and was having difficulty coping with his wife not being at home. Their son took charge of their affairs and is currently helping both parents.

Mrs. King continued to be aphasic, and therefore her son agreed to be interviewed. He reported that, due to the termination of rehabilitation services, his parents have been denied their hopes of spending their retirement years together and are also now faced with the prospect of losing their life's savings with the costs of long term care. Their son also reports his mother has gotten increasingly quiet and forlorn. Although the nursing staff has attributed her demeanor to depression, and has since doubled her depression medication, he attributes his mother's emotionality and loneliness to the termination of services and the loss of hope of being able to recover and return home. He has realized that he is going to need a lot of money to support both of his parents and is working hard at increasing their revenue potential to maintain themselves.

Respondent 9-Twist family: Mr. Twist is a 77 year old farmer who was diagnosed with Parkinson's disease and has been experiencing a steady functional decline over the years. Due to his decline and multiple hospitalizations, his wife has been navigating the health care system on his behalf. His wife therefore was interviewed for the study. Due to the chronic degenerative nature of the beneficiary's disorder, he has needed ongoing physical therapy to help him maintain his functional skills to stay at home with his wife. On multiple occasions he has been denied Medicare benefits secondary to the determination of lack of improvement or most recently a lack of a qualifying diagnosis. Due to a denial of rehabilitation services, the beneficiary has been reported to be having a physical decline with multiple falls. His wife reports they have had increasing costs due to the 24 hour care he needed at home and ultimately were forced to find him an assisted living facility where he could get the assistance and the supervision he needed. His wife reports that the entire experience has been difficult in many ways.

Respondent 10-Shriver family: Mrs. Shriver is an 82 year old beneficiary who suffered a severe stroke approximately four years ago. Following a stint with rehabilitation, her Medicare benefits were terminated due to a lack of improvement determination. Over the years she has developed multiple secondary issues that have incapacitated her and confined her to a nursing home. Mrs. Shriver's husband and daughter were not happy about the decision to terminate rehabilitation but were persuaded with the promise from the facility that Mrs. Shriver would be on a restorative program that would help her maintain her skills. Her husband was eager to take her home and therefore on several occasions attempted to get his wife on a rehabilitation program to help her recover.

According to her daughter, the consequences of the termination of rehab services resulted in an end to her mother's and step father's marriage, and subsequently contributed to his death. She believes the strain of navigating the health care system caused him to neglect his own health. The financial burden consisted of the beneficiary losing all of her assets and ultimately needing to apply for Medicaid. The daughter also feels that her mother's confinement to a nursing home has caused a strain on all of her children who contribute monetary assistance to take care of her needs and navigate the system for her. Following the death of her step father a few months ago, the daughter took over her mother's care and enrolled her in Medicare hospice. Mrs. Shriver noticed she had had a physical decline and repeatedly asked for physical therapy services from the hospice company that she had enrolled in, but was denied these services. Mrs. Shriver persuaded her daughter to switch her to traditional Medicare to have her rehabilitation needs met.

Respondent 11- Barclay family: Beneficiary was a 67 year old male who had been dealing with a diagnosis of rheumatoid arthritis for a major part of his life. While working as an insurance agent, he noticed he could not put weight on his right leg and had trouble walking. After consultation with the doctor it was determined he needed a knee replacement. Three days after the knee replacement he was moved from an acute care hospital to a sub acute hospital. At the sub acute facility, Mr. Barclay reports that the staff ignored his and his wife's repeated requests to have the hospital staff contact his orthopedist to report the excessive bleeding he was experiencing and to seek direction with his care. At the end of the week, Mr. Barclay was transferred back to an acute care setting secondary to excessive bleeding accompanied with pain. He was diagnosed with

an infection in the joint, and a few days later had to undergo an above the knee amputation. In retrospect, he believes he was discharged too soon from the hospital following the surgery, but at that time did not express his thoughts as he believed it was a Medicare protocol that was being observed. Both he and his nurse practitioner in the SNF believed and verbally voiced their concern of having been discharged before the surgery site had stabilized.

At the time of the interview, Mr. Barclay was in a SNF undergoing rehabilitation following the amputation of his leg. He was concerned about his future as he needed to support his wife and himself. His insurance consisted of Medicare part A and veterans affairs (VA) benefits. Due to a lack of a supplemental insurance, Mr. Barclay was responsible for paying a 20% deductible per day (\$114) for the SNF that Medicare part A and VA benefits did not cover. Mr. Barclay reports this whole experience has been a strain on himself and his wife who has had to continue to work to bring in the needed income to support his medical expenses and pay personal bills. The question of finances weighed heavily on the beneficiary at the time of the interview. Additionally, although this is a consequence he did not list the day of the interview, he had acquired an intestinal infection known to be an issue in hospitals and medical settings, at the SNF. Three days later he was admitted to an intensive care unit for medical attention.

Respondent 12- Rodriguez family: Ms. Rodriguez is a proxy navigator for her 87 year old mother who is Spanish speaking only. Her mother had a cardiac arrest in a hospital emergency response center which left her with moderately severe neurological deficits. Prior to the event, the beneficiary lived by herself and was independent. She had enrolled

in Medicare Advantage (HMO) based on advice from a friend. Ms. Rodriguez, along with the support from her siblings, was there for her mother through the ER experience, ICU, acute care, sub acute care, and SNF stay. Her mother progressed physically and mentally, and continued to have the potential to progress as per her therapists. However, due to a determination that her condition did not warrant a SNF stay, payment for these services was terminated. She was not yet independent enough to return home alone, in fact the day before her discharge she had fallen. Her daughter, after assessing her mother's condition, decided to take her home to live with her. The HMO communicated with Ms. Rodriguez through the admissions coordinator of the SNF and did not return her calls in a timely manner. Since time of termination of services from the SNF, Ms. Rodriguez has attempted to fill in for the skilled care her mother has needed.

Ms. Rodriguez believes that if it were not for her support and dedication to her mother's well being and recovery, her mother would not have survived this ordeal. Termination of services has put an added burden and a strain on the daughter who not only has had to manage her household but has also had to care for her mother. Ms. Rodriguez has had to be vigilant about beneficiary's health and to constantly demand needed care for her from the managed care company. Her mother has also reached the doughnut hole with her prescriptions and has been managing with physician's samples and monetary assistance from the rest of her siblings. The siblings are contributing towards supporting beneficiary's medical needs as well as her other personal needs. Financially, the family has teamed up to support their mother on numerous instances as the HMO she belongs to does not provide comprehensive coverage.

APPENDIX E

Table 3. Demography of Beneficiaries and Proxy Navigators

Beneficiary	Age	Medicare plan	Beneficiary's profession	Reason for termination of services	Interviews		Proxy navigator's profession	Residence of beneficiary at interview	Education of beneficiary proxy navigator
					Beneficiary	Proxy navigator			
Hill	79	A, B, D	Real estate broker	Lack of improvement	yes	yes	Home maker	LTC	HS/HS
Garrison	80	A, B, D	Soil chemist	Lack of improvement	yes	yes	-	Home	>BS
Anthony	87	A, B, D	Professor	Lack of improvement	-	yes	Home maker	LTC	MS/>HS
Sox	76	A, B, D	Registered nurse	Denial pain pump & oral medications	yes	-	-	Lives w/ daughter	BS RN
Odessa	84	A, B, D	Book keeper	Lack of improvement	-	yes	Insurance agent	LTC	HS/>BS
Tripp	73	Managed Care (HMO)	Real estate agent	Condition did not warrant SNF rehab/ Lack of improvement	-	yes	Pharmacist	Home w/ 24 hour care	HS/ Pharm. D.
Straw	88	A, B, D	Home maker	Lack of improvement	-	yes	Clerk	LTC	HS/HS
King	80	A, B, D	Teacher	Lack of improvement	-	yes	Advertising	LTC	MS/MS
Twist	76	A, B, D	Farmer	Lack of improvement/	-	yes	Home maker	ALP	>HS/HS
Shriver	82	A, Medicaid, D	Hostess/home maker	Lack of improvement / Medicare hospice denied rehab	-	yes	Insurance agent	LTC	<HS/>HS
Barclay	67	A, VA	Insurance agent	Premature termination of hospital stay post surgery	Yes	-	-	SNF	>HS
Rodriguez	87	Managed care (HMO)	Home maker	Condition did not warrant SNF rehab.	-	yes	Home maker	Lives w/ daughter	<HS/HS