EXAMINING RURAL VS. URBAN DISPARITIES IN COMMUNITY-BASED HELPER
SUPPORT AND RESIDENTIAL CARE TRANSITIONS AMONG MEDICARE
BENEFICIARIES WITH DEMENTIA AND FUNCTIONAL LIMITATIONS

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ABSTRACT

Tandrea Sharrell Hilliard: Examining Rural vs. Urban Disparities in Community-Based
Helper Support and Residential Care Transitions among Medicare Beneficiaries with
Dementia and Functional Limitations
(Under the direction of Peggye Dilworth-Anderson)

Strategies to afford elders with dementia the opportunity to remain in their homes or
other community dwelling places are often desirable among various stakeholders. Informal
care in the community has been shown to delay nursing home entry. Rural elders in general
are particularly vulnerable for institutionalization due to reduced access to adequate
community-based support. Less is known regarding geographic disparities in community-
based helper support networks over time for people with dementia and functional difficulties
and the direct impact of such support on residential care transitions from community
dwellings to nursing facilities (i.e., skilled nursing facilities (SNFs), nursing homes, and
assisted living facilities).

Using a retrospective cohort of community-dwelling Medicare beneficiaries in the
Medicare Current Beneficiary Survey (MCBS), this study aimed to examine the presence,
magnitude, and sources of community-based helper support over time for Medicare
beneficiaries age 65 and older with dementia and ADL/IADL limitations living in rural and
urban residences, as well as to determine whether and how such support impacts residential
care transitions.

Gaps in support for functional limitations (i.e., the absence of reported help for a
reported functional difficulty) were found among the full sample; however, the presence of

the support gaps for functional limitations did not statistically differ across geographic areas. Compared to persons living in an urban area, persons with dementia and functional limitations who lived in a rural area adjacent to a metropolitan or micropolitan area were, on average, less likely to transition to both short- and long-term care nursing facilities. Rural-urban residence and community-based support were not associated with time-to-transition. Age and number of co-morbidities were significantly associated with time-to-first nursing facility transition.

In conclusion, this study did not find evidence of geographic disparities in residential care transitions. However, differences in the composition of support networks of older persons in the community with dementia who are managing functional limitations across rural and urban communities were found. Widespread access to well-supported community living for persons with dementia or their family members who desire this option should remain a policy priority given the perpetual impact of this disease.

To my praying grandmother, Mrs. Conella Jones Hilliard; my grandparents in heaven, Joe Henry Hilliard and Ruth and Nathaniel Nicholson; my exceptional parents, Charlene and Daniel Nicholson; a host of family, friends, loved ones, and generous supporters; and every child in Halifax County, NC, with a dream.

God's timing is perfect.

Jeremiah 29:11

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LIST OF ABBREVIATIONS

AD   Alzheimer's disease

MCBS   Medicare Current Beneficiary Survey

ADL   Activities of Daily Living

IADL   Instrumental Activities of Daily Living

SNF   Skilled Nursing Facility

HHA   Home Health Agency

R, N   Rural, Not Adjacent to Metropolitan or Micropolitan Area

R, A   Rural, Adjacent to Metropolitan or Micropolitan Area

U   Urban Area

ACA   Affordable Care Act

SD   Standard deviation

GLM   Generalized Linear Model

GEE   Generalized Estimating Equation

CHAPTER 1. INTRODUCTION

Alzheimer's disease (AD), the most common form of dementia (accounting for an estimated 60–80% of cases), is the fifth-leading cause of death among those age 65 and older in the United States (Alzheimer's Association, 2014; Murphy, Xu, & Kochanek, 2013). Approximately 5 million older Americans are affected by this disease—one in nine people age 65 and older and close to one-third of people 85 and older have AD (Alzheimer's Association, 2014). Many older adults who develop dementia also experience loss of independence due to activities of daily living (ADL) or instrumental activities of daily living (IADL) limitations. The presence of functional limitations is often used as a marker of dementia severity and signifies an advanced disease state among affected persons (Moore, Zhu, & Clipp, 2001). Functional loss is typically the impetus for formal (i.e., professional) and/or informal long-term care, services, and supports, either in the community or in institutions (CDC, 2013).

Consequently, the tremendous burden of AD and other dementias on the older adult population is shouldered not only by those with this disease and their healthcare providers but also the more than 15 million Americans who provide unpaid care, often over long periods of time, for a person with AD or other dementias (Alzheimer's Association, 2014; based on data from the 2009 Behavioral Risk Factor Surveillance System (BRFSS), 2013 U.S. Census data, and the 2009 National Alliance for Caregiving Survey). The overwhelming majority of AD caregivers or helpers are family members who devote countless hours to providing home-based care and ensuring the best quality of life for their loved ones battling

this disease. For rural elders who may have less access to adult children as helpers (Glasgow, 2000; Glasgow, 2003) and who may be isolated from more formal sources of support, assistance with ADLs/IADLs may be provided for by other members of their informal support networks such as neighbors or friends. Less is known regarding the longitudinal stability of helper networks among community-dwelling Medicare beneficiaries with AD or other dementias and who need help with basic daily activities. This is especially true among those living in rural areas where, in addition to informal support challenges, there are often access barriers to formal care due to fewer health professionals locally, a lack of community or medical services, or transportation issues.

Although strategies to delay or prevent nursing home placement are desirable due to increased costs, loss of independence, preferences to remain in community dwellings, and other reasons (Kane & Kane, 2001; Eckert, Morgan, & Swamy, 2004; Reinhard, 2010), the transition to a nursing home or other nursing facilities is common for older adults with dementia (Arrighi, Neumann, Lieberburg, & Townsend, 2010). No previously identified studies have assessed rural vs. urban differences and disparities in community-based helper support for ADLs/IADLs among persons with dementia and limited functional capacity, as well as associations between residence, community-based support, and the occurrence and timing of residential care transitions from the community to nursing facilities.

Given increasing interest in and commitment to helping older persons with chronic care needs, such as persons with dementia and functional limitations, continue living in their communities for as long as possible among various stakeholders including health policymakers, an examination of geographic disparities in community-based helper support for these individuals as well as transitions into nursing facilities is warranted. This study will

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directly inform policy efforts and community-based initiatives that seek to provide accessible

and supportive community-based care options for older persons with impairments and create

a more sustainable healthcare system by reducing costly and potentially avoidable

institutionalizations.

CHAPTER 2. LITERATURE REVIEW

Community-Based Informal Caregivers

Informal caregivers, typically family members, are the first-in-action to provide care and support for older persons with dementia. In fact, the majority of older people with dementia are cared for in the community by family or others (Moore, Zhu & Clipp, 2001; Schulz & Martire, 2004). The prevalence of these informal caregivers (e.g., family, friends) far exceeds the number of paid direct-care workers in the United States (Institute of Medicine, 2008). It is estimated that 60–70% of older adults with Alzheimer's disease (AD) or other dementias live in the community in non-institutionalized settings compared to 98% of older adults without this disease (Met Life Mature Market Institute, 2012; Alzheimer's Association, 2014; Medicare Current Beneficiary Survey, 2008 Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011). Of those with dementia who live in the community, an estimated 75% live with someone while 25% live alone (Alzheimer's Association, 2014; Medicare Current Beneficiary Survey, 2008. Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011).

Dementia onset is often mild, but over time, persons with this disease develop limitations in basic functional activities and become increasingly unable to care for themselves. Persons affected by dementia increasingly rely on help from others to manage and supervise mental and physical tasks (Moore, Zhu, & Clipp, 2001; Alzheimer's Association, 2014). Because there is no cure for dementia (Alzheimer's Association, 2014),

eventually people with dementia reach a level of disability that requires constant care, which is often provided by their informal support networks (Moore, Zhu, & Clipp, 2001). Unpaid caregivers, who are typically family members, other relatives, or friends, provided an estimated 17.7 billion hours of unpaid care, valued at over $220.2 billion, to loved ones with dementia in 2013 (Alzheimer's Association, 2014). Informal care provided by children in particular reduces Medicare expenditures on long-term care and inpatient care (Van Houtven & Norton, 2008) and is considered a cost-saving alternative to institutionalization.

The care provided by family caregivers to loved ones with dementia is extensive and often includes assisting with instrumental activities of daily living (IADLs) such as grocery shopping and meal preparation; medication assistance; personal activities of daily living (ADLs) such as bathing, dressing and feeding; mobility assistance and supervision; decision making; service identification and use; and other key life tasks. Compared to non-dementia caregivers, dementia caregivers have been found to spend significantly more hours per week providing care and also report greater impacts related to employment issues, strain, mental and physical health problems, time constraints, and family conflicts (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz & Martire, 2004). Dementia caregivers also tend to provide care for a longer time, on average, than caregivers of older persons with other serious conditions and are more likely than caregivers of other older people to assist with any ADL (Alzheimer's Association, 2014).

The challenges of dementia caregiving are great and numerous studies have documented the overwhelming psychological and physical impacts on family caregivers of people with AD, which include depression and lower subjective ratings of physical health and well-being (Schulz, O'Brien, Bookwala, & Fleissner, 1995; Covinsky, Newcomer, Dane,

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Sands, & Yaffe, 2003; Siegler, Brummett, Williams, Haney, & Dilworth-Anderson, 2010).

Having a higher income, larger social network, more positive appraisals of caregiving (i.e.,

feeling useful, appreciated, or finding more meaning in life), religious beliefs and practices,

and strong ties to religious organizations have been associated with fewer depressive

symptoms and better mental health among caregivers (Williams, 2005; Hebert, Dang, &

Schulz, 2007). Despite the numerous challenges that informal caregivers encounter, the

invaluable support provided by spouses, adult children, relatives, friends, and neighbors

continues to serve as the first line of consistent care for elders living with this disease.

Although these home- and community-based informal caregivers are the primary providers

of long-term care for older adults with AD, as this disease advances and becomes more

complex care provision across different settings is often required.

Transitions into Institutional Care

Care transitions, which The Care Transitions Program at the University of Colorado

Denver defines as "the movement patients make between healthcare practitioners and

settings as their condition and care needs change during the course of a chronic or acute

illness," for older adults are often numerous and complex (Coleman, Min, Chomiak &

Kramer, 2004; Sato, Shaffer, Arbaje, & Zuckerman, 2010). Residential transition patterns

(i.e., between community settings and facilities including hospitals, skilled nursing facilities

(SNFs), and other long-term care institutions) have been found to be remarkably stable and

consistent across years among Medicare beneficiaries in general; the most frequent transition

pattern observed was a transition to the hospital and back (Sato et al., 2010). Although

transitions were relatively stable for the general older population of Medicare beneficiaries

(Sato et al., 2010), transitions to nursing facilities from the community are common among

older persons with dementia. Transitioning to a nursing home is expected by age 80 for 75% of AD patients, compared with only four percent of the general population (Arrighi, Neumann, Lieberburg, & Townsend, 2010; Alzheimer's Association, 2014).

Older persons with prevalent or incident dementia have been shown to have greater Medicare- and Medicaid-funded nursing facility use, greater hospital and home health use, more residential care transitions (i.e., transitions between home, home with healthcare, nursing facility, and hospitals) per person-year follow-up, and more mean total transitions than people who were never diagnosed (Callahan et al., 2012). Among beneficiaries with dementia, 74.5% of transitions to nursing facilities were transfers from hospitals. At the time of death, nearly half (46%) of persons with dementia were at home, compared to 35% in the hospital and 19% in a nursing facility (Callahan et al., 2012).

Care transitions are often tied to complex informal and/or formal network dynamics (Allen, Lima, Goldscheider, & Roy, 2012). Because older persons with dementia, and particularly those with functional difficulties, are more prone to experiencing residential care transitions, it is important to examine such transitions over time among this patient population as well as to determine whether and how their support networks are connected to them. The reduction of costs due to skilled nursing facility stays is also a relevant Medicare policy priority because short-term skilled nursing facility stays are covered by Medicare following a qualifying hospital stay. Nursing homes provide care to residents with chronic health care needs who require long-term care, and although admission to a nursing home could be due to the need for short-term rehabilitation services, this move is often a permanent one (Metlife, 2009). Although Medicaid is the primary payer for long-term nursing home

care, Medicare beneficiaries who enter long-term care facilities such as nursing homes rely heavily on Medicare to cover medical care costs (Jacobson, Neuman, & Damico, 2010).

Assisted living is a long-term residential care option that often bridges the gap between home care and nursing homes to assist persons in need of assistance but not at the level provided by nursing homes (Metlife, 2009). Assisted living residence is not covered by Medicare; although many states now cover some assisted living services under Medicaid programs (e.g., waivers), there is much variation across states in terms of eligibility and funding amounts (ALFA, 2013). As such, much of assisted living care is privately financed. Although nursing homes constitute the majority of long-term facility use, it is also important to examine assisted living facilities in the context of long-term residential care transition settings. Specific attention needs to be given to geographic variation in transitions between community and institutional settings to identify care patterns and disparities in care and to assess whether efforts to create a more balanced system of care for vulnerable older persons are having the desired effects in both rural and urban communities.

Rural vs. Urban Divides in Informal and Formal Support

The chronic care needs of persons with dementia are often great, particularly among individuals who are unable to independently perform daily functional activities. An older person living in a rural community with dementia and functional limitations may experience considerable challenges and risks if adequate support is not available or readily accessible. As a result of many younger people migrating out of rural areas, the support networks of impaired rural elders may be considerably less stable than persons with better access to kin support (Buckwalter, Davis, Wakefield, Kienzle, & Murray, 2002). Rural community-dwelling older residents tend to have fewer paid helpers and less access to adult children than

urban older residents who are more likely to co-reside with or have adult children living nearby (Dwyer & Miller, 1990; Goins, Spencer, & Byrd, 2009). Inadequate or distal kin support among rural older adults often results in greater reliance on friend and neighbor networks compared to urban older people (Glasgow, 2000; Glasgow, 2003).

Geographic proximity of caregivers is particularly important in discussions of adequate support systems for rural elders with functional limitations. Although the definition of "long-distance caregiver" varies (e.g., living more than 50 miles away from an aging parent (Schoonover, Brody, Hoffman, & Kleban, 1988); living more than two hours away from the care recipient (Koerin, & Harrigan, 2003)), a commonly applied definition of a long-distance caregiver is "living one hour or more away from the care recipient" as proposed by Wagner (1997). Based on this common definition, an estimated 2.3 million people are long-distance caregivers (Alzheimer's Association, 2013; Unpublished data analyzed under contract for the Alzheimer's Association by the National Alliance for Caregiving and AARP, 2009). Approximately 25% of rural caregivers live in the same household as the person for whom they provide care; 60% live within a one-hour drive; 4% live between a one- and two-hour drive away; and 11% live more than a two-hour drive away (National Alliance for Caregiving & AARP, 2004; based on Family Caregiving In The U.S.: Findings from a National Survey, National Alliance for Caregiving and AARP, 1997).

Caregiver proximity has been found to play a significant role in determining care transitions among older adults. Compared to those with no children nearby (i.e., greater than 30 miles away), older adults with at least one child living with or near them before the onset of ADL limitations had lower odds of transitioning to a nursing home and were less likely to depend on formal care after the onset of new ADL limitations (Choi, Schoeni, Langa, &

Heisler, 2014). Lack of proximal support could significantly impair the ability of older

persons with dementia and functional limitations to remain in community settings versus

transitioning to nursing facility. However, many older adults with dementia rely on informal

support from persons who live at a significant distance away. Approximately nine percent of

unpaid caregivers of people with dementia live more than two hours away from the person

for whom they provide care, and another six percent live one to two hours away (Alzheimer's

Association, 2013; Unpublished data analyzed under contract for the Alzheimer's

Association by the National Alliance for Caregiving and AARP, 2009).

Given informal and formal support challenges in rural areas, implementing efforts to

shift the use of long-term care services away from costly institution-based care in these

communities may prove difficult (Coburn & Bolda, 2001). Formal home- and community-

based support programs and services (e.g., transportation assistance, support groups, respite

services) for rural older adults and their informal caregivers may or may not be present in

rural areas depending on fiscal resources and infrastructure (Berger, 2012). Unavailability of

services, unawareness of services, and affordability issues are primary access barriers to

home and community-based services among rural older adults and their caregivers (Li,

2006). There is also a larger supply of nursing homes in rural areas. Estimates published in

2002 showed that the distribution of certified nursing home beds per 1,000 population aged

65 and over was 51.9 in metro areas and 66.7 in non-metro areas (Silberman, Rudolf, D'alpe,

Randolph, & Slifkin, 2003; Dalton, Van Houtven, Slifkin, Poley, & Howard, 2002; The

National Advisory Committee on Rural Health and Human Services, 2004; Berger, 2012).

Forty percent of nursing homes are located in nonmetropolitan counties and these

nonmetropolitan facilities serve about 35% of the nursing home population (Braddock &

Parish, 2001; Seekins et al., 2011). Due to poor access to home- and community-based services that would support community living among older adults with functional limitations and a generally larger supply of nursing homes in rural areas, nursing homes tend to be the only available option in these areas for seniors as they become increasingly unable to care for themselves (Coburn & Bolda, 2001).

To better grasp and understand the differences in long-term care needs that may exist for rural elders compared to urban elders, greater understanding of the family and social support characteristics of elders in rural and urban communities is needed (Coburn & Bolda, 2001). Despite the overwhelming impact of this disease on older Americans and persistent geographic divides in care access and quality, research examining geographic disparities in the presence and stability of community-based helper support and how such informal support affects nursing facility use among older adults with dementia has lagged. Greater knowledge and understanding of this issue may help the system better prepare to meet the demands for formal long-term care while concurrently developing supportive policies and community-based interventions for older adults living with dementia and functional impairments and their informal helpers or caregivers.

Purpose and Contributions to the Literature

The purpose of this retrospective, longitudinal, cohort-designed dissertation study is to descriptively and analytically examine geographic disparities in the presence (co-occurrence of reported help, helpers, and/or use of special equipment (ADLs only) for reported ADL/IADL limitations), magnitude (number of helpers), and sources of reported community-based helper support for ADL/IADL functional limitations (i.e., relationships of helpers to beneficiaries) over time among non-institutionalized rural and urban Medicare

beneficiaries age 65 and older with dementia and functional difficulties. Rural vs. urban comparisons are of primary interest; however, rural, not adjacent vs. rural, adjacent to metropolitan or micropolitan area differences are also assessed. Additionally, this study examines the effects of rural vs. urban residence and community-based helper support on the likelihood and timing of transitions into nursing facilities among Medicare beneficiaries with dementia and functional impairments residing in the community at baseline. This includes skilled nursing facilities or shorter-stay nursing facilities as well as nursing homes or assisted living facilities, which are traditionally longer-stay nursing facilities.

Improving care access, quality, and delivery for Medicare beneficiaries while concurrently controlling program costs is a consistent challenge for the healthcare system. There is considerable health policy interest in developing effective and sustainable solutions to assist older adults with dementia and/or disabilities with remaining in community settings, because this is often a preferred care option over institutionalization. Concerns about the current and future economic viability of the healthcare system have spurred numerous efforts to foster a shift in which institutionalization remains an important aspect of long-term care but is accompanied by a broader range of care options for persons in need of long-term services or supports (LTSS) for disabilities and/or debilitating chronic conditions (Reinhard, Kassner, & Houser, 2011). These LTSS specifically provide assistance with ADLs or IADLs to older persons or other adults with disabilities and include but are not limited to direct human assistance; assistive technologies, devices, or environmental modifications; health maintenance tasks, information, care, or service coordination; and supports for caregivers (Reinhard, Kassner, & Houser, 2011).

With the goals of increasing quality of life and well-being among such persons who have functional limitations due to chronic disease, illness, injury or other causes of disability, the Affordable Care Act (ACA) of 2010 vastly increased the availability of such services (Reinhard, Kassner, & Houser, 2011). In 2012, the Administration for Community Living at the U.S. Department of Health and Human Services was specifically created to improve access to community supports for persons with disabilities and older adults with unique needs, such as seniors with dementia, who desire to remain in community dwelling places (U.S. Department of Health and Human Services, 2012). Despite these efforts, significant variation in the availability of these services exists due to the optional nature of many key provisions. Decisions regarding the provision of these supports are largely made at the state level and many states choose not to fully invest in LTSS, greatly limiting the care choices of many persons in need (Reinhard, Kassner, & Houser, 2011). To achieve a rebalanced system with adequate home- and community-based support for older persons with functional impairments and other disabilities, continued efforts to identify and address inequities in support are necessary. This includes consistent monitoring of informal helper support systems, because informal care provided by family and other community members remains a critical factor in the effectiveness of home- and community-based options.

Overall, this study will contribute to the literature by examining geographic disparities and variation in reported community-based helper support for functional difficulties and its link to residential care transitions over time among older persons with dementia, a serious chronic illness requiring extensive support. Although dementia onset is mild, persons with dementia become less able to care for themselves as time progresses and increasingly rely on others to manage mental and physical tasks, eventually requiring

constant care (Moore, Zhu, & Clipp, 2001). Individuals who require assistance with basic needs such as ADLs represent an advanced stage of Alzheimer's, where their ability to function in daily life has been impaired by the cognitive and behavioral effects of AD (Alzheimer's Association, 2014). Providing assistance with such limitations constitutes a large portion of informal dementia caregivers' task load, which tends to be more extensive than caregivers of older persons with other conditions (Alzheimer's Association, 2014). Medicare beneficiaries included in this study report functional impairments at baseline and thus represent a segment of the dementia patient population that is more progressed in the disease. Given the aforementioned challenges associated with informal dementia caregiving, which often involves providing functional impairment assistance to persons in later stages of AD, it is critically important to longitudinally examine and describe the support networks of this segment of the dementia patient population. Findings from this research may identify additional areas in which LTSS are needed augment the support networks of beneficiaries with dementia and inform the development of more targeted policies that increase dementia care options for older persons while addressing geographic-specific determinants.

There remains a limited body of research examining the role of rural residence on caregiving processes and outcomes (Goins, Spencer, & Byrd, 2009). Although there is evidence in the literature of the role of help in the community in averting long nursing home stays among the disabled elderly (Boaz & Muller, 1994; Van Houtven & Norton, 2004; Choi, Schoeni, Langa, & Heisler, 2014), a dearth of studies exists in the literature that examine the role of community-based helper support in shaping residential care transitions specifically among older persons living in the community with AD or other dementias and identified functional limitations. There is also a great need for additional research that accounts for

differences that may exist between different types of rural communities, particularly in research that relates to access to care or support, as this study does. Barriers in access to care are persistent issues in rural communities in general. However, persons living in communities more adjacent to urban areas may have different care experiences than those living in more remote rural areas. Differences within rural communities with respect to health care have been found. Persons living in rural, non-adjacent to metropolitan or micropolitan areas visit their health providers less often than residents of other areas (i.e., urban or rural, adjacent to urban communities) (Larson & Fleishman, 2003). A non-dichotomous definition of rural and urban residence may reveal hidden variation in nursing facility use that may help policymakers, clinicians, and researchers identify specific areas where disparities in access and service use exist (Larson & Fleishman, 2003; Hall, Kaufman & Ricketts, 2006). In an effort to uncover variation that may exist across rural communities, in addition to differences between rural and urban areas, this study includes a three-category definition of rural-urban residence (i.e., rural, not adjacent to a metropolitan or micropolitan area (R,N); rural, adjacent to a metropolitan or micropolitan area (R,A); and urban (U)).

Further, many existing studies of rural caregiving have key methodological limitations (e.g., lack of underlying theory in research design, failure to provide operational definitions of key variables, overreliance on self-report data, and underuse of objective measures) and tend to be cross-sectional as opposed to longitudinally designed (Goins, Spencer, & Byrd, 2009). This study contributes to the literature by examining the presence of and changes in helper support over time among older adults affected by dementia and with functional limitations, especially those living in rural areas. Characteristics of this study that will fill critical gaps in the literature and address key limitations identified of previous studies

include (Goins, Spencer, & Byrd, 2009): 1) conceptualization in theory; 2) a longitudinal

study design; 3) operationalization of key variables of interest; and 4) the inclusion of

objective measures from Medicare claims data to support many self/proxy-reported

measures.

Study Aims and Hypotheses

The relationships of interest in this study were examined via the pursuit of three

specific aims:

Aim 1a: To describe rural vs. urban group differences and temporal trends in the

presence (i.e., co-occurrence of reported help, helpers, and/or use of special

equipment (ADLs only) for reported ADL/IADL limitations), magnitude (i.e.,

number of reported ADL/IADL helpers), and sources of community-based helper

support reported for ADL/IADL functional limitations (e.g., spouses, adult children)

among the study sample.

This aim is descriptive. Therefore, no hypotheses are stated.

Aim 1b: To examine rural vs. urban disparities in community-based support for

ADL/IADL functional limitations among the study sample over time, controlling for

key demographic, socioeconomic, and health status factors.

H1: Controlling for key demographic, socioeconomic, and health status predictors,

rural residence will be associated with gaps in support for functional limitations.

Aim 2: To examine the effects of rural vs. urban residence and community-based

helper support for ADL/IADL functional limitations on the likelihood of any

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residential care transition out of the community to nursing facilities (i.e., SNFs, nursing homes, or assisted living facilities) during the study period.

H2: Based on evidence that adequate help in the community reduces the risk of permanent nursing home residence (Boaz and Muller, 1994) and that rural elders in the community may have less access to adult children as informal helpers (Glasgow, 2000; Glasgow, 2003), it is hypothesized that rural residence and limited community-based helper support (i.e., single source of community-based support vs. multiple sources) will be associated with an increased likelihood of transition to a residential nursing facility.

Aim 3: To examine the effects of rural vs. urban residence and community-based helper support for ADL/IADL functional limitations on the length of elapsed study time to the first residential care transition to a nursing facility.

H3: On the basis of existing literature demonstrating that informal care provided by adult children delays nursing home entry (Van Houtven & Norton, 2004) as well as evidence of reduced access to adult children as caregivers among rural elders (Glasgow, 2000; Glasgow, 2003), it is hypothesized that rural residence and limited community-based helper support (i.e., single source of community-based support vs. multiple sources) will be associated with fewer elapsed days-to-first transition.

Theoretical Framework

To guide the proposed research, a theoretical framework adapted from the Andersen and Newman Behavioral Model of Health Service Use (Andersen & Newman, 1973; Andersen, 1995) was developed. This model suggests that health services use is determined

by environmental factors such as societal and health services system factors and individual factors (Bradley et al., 2002). Individual factors are categorized as need and enabling and predisposing factors. Need includes perceived and evaluated functional capacity, symptoms, general state of health; enabling factors include family and community resources, and accessibility; and predisposing factors include age, sex, marital status, education, race/ethnicity, and occupation as well as attitudes, knowledge and beliefs (Bradley et al., 2002). As described in Phillips, Morrison, Andersen, & Aday (1998), this model is useful for understanding the context of healthcare use and has been cited as a critical theoretical approach to nursing home use (Culbert, 2009). The Behavioral Model of Health Service Use is applicable to this study given the focus on the effects of contextual factors on transitions to formal residential care settings.

The model applied in this dissertation research was adapted to best meet the goals of this study and include the best available measures while attempting to maintain the model's core integrity. The adapted theoretical model guiding this research is illustrated in Figure 1. This adapted model includes relevant variables in the following major categories: healthcare system environment; population characteristics including predisposing factors, enabling resources, and need factors; and the outcome variables reflecting health service use—likelihood and timing of residential care transitions out of community dwellings to nursing facilities. The primary factors of interest in this study are rural vs. urban residence and informal community-based ADL/IADL helpers.

Having a regular source of care is included in the model as an indicator of healthcare system environment. Variables such as having a usual source of care help measure the context within which usage occurs (Phillips et al., 1998). Predisposing factors examined in

this study include key demographic characteristics (i.e., age, sex, race/ethnicity, marital status, income, education, and living situation (i.e., lives alone vs. lives with others)) (Luppa et al.,2010). Although rural vs. urban residence could be considered an enabling factor because it may influence the ability to engage in health services, rural vs. urban residence also affects the propensity to use health services (i.e., predisposing factor) and may directly determine enabling factors included in this study, such as the level of support received in the community. For these reasons, it is modeled as a predisposing factor.

Community-based ADL/IADL support, as measured by the reported number of ADL/IADL helpers and the relationships of those helpers to the beneficiary, is modeled as an enabling factor because such support and assistance represents a personal, familial, or community resource that may facilitate or impede healthcare use among older persons (Toseland, McCallion, Gerber, & Banks, 2002; Luppa et al., 2010). In Aim 1, the quantity and relationships of reported ADL/IADL helpers for reported ADL/IADL limitations are described. In Aims 2 and 3, a dichotomous indicator of having a single (i.e., only one type of helper as measured by reported helper relationships) vs. multiple (i.e., having more than one type of helper as measured by reported helper relationships) sources of community-based ADL/IADL support is included in the regression models as a predictor.

Informed by evidence in the literature of: 1) less access among rural community-dwelling older adults to adult children for support as compared to their urban counterparts; 2) informal support provided by adult children in the community delaying institutionalization; 3) a larger supply of nursing homes in rural areas; and 4) gaps in access to home- and community-based services in rural areas, several central hypotheses for this longitudinal

research study are proposed. Compared to urban-dwelling persons with dementia and functional limitations, rural-dwelling elders will:

- Have gaps in support for specific ADL/IADL limitations;

- Report fewer helpers for ADL/IADL limitations;

- Report more non-kin helpers;

- Have an increased likelihood of transition to a nursing facility during the follow-up period; and

- Have fewer elapsed days to the first residential care transition to a nursing facility during the follow-up period.

It was my expectation that rural vs. urban, and potentially rural, not adjacent vs. rural adjacent disparities in the presence, magnitude, and sources of community-based helper support for ADL/IADL limitations would be identified and that community-based support would be significantly associated with the residential trajectories of older adults with dementia and functional assistance needs.

Figure 1. Theoretical framework.

Environment	Individual Characteristics			Outcome
Health Care System	**Predisposing Characteristics**	**Enabling Resources**	**Need**	**Use of Health Services**
• Usual Source of Medical Care	• Age • Sex • Race/Ethnicity • Rural vs. Urban Residence • Marital Status • Income • Education • Living Alone	• Community-based ADL/IADL Helpers	• Functional Limitations (ADLs/IADLs) • Co-morbidities • General Health Status Rating	• Community-to-Nursing Facility Transitions

Study Significance & Innovation

Significance

This research is significant in several ways. First, this study is timely and relevant because it deals with a very serious and highly prevalent disease (i.e., AD) greatly affecting older Americans today. Alzheimer's is a burgeoning epidemic in America. Advanced age is the greatest risk factor for AD (Alzheimer's Association, 2014; Gauthier, Wu, Rosa-Neto, & Jia, 2012), and with the Baby Boomers reaching the age of greater dementia risk, the cognitive stability of America's older adult population is threatened. Projections in 2008 from the U.S. Census Bureau indicate that in 2030 nearly one in five U.S. residents is expected to be age 65 and older (Vincent & Velkoff, 2010; U.S. Census Bureau 2008 Projections). By 2050, the number of persons age 65 and older is projected to increase from 38.7 million in 2008 to 88.5 million in 2050 (Vincent & Velkoff, 2010; U.S. Census Bureau 2008 Projections). Due to the rapid increase in the number of Americans over age 65, the annual incidence of AD or other dementias is expected to double by the year 2050 (Alzheimer's Association, 2014; Hebert, Beckett, Scherr, & Evans, 2001).

The good news is that Americans are living longer. The nation has experienced significant gains in life expectancy over the past century, which is largely attributable to significant improvements in the prevention and control of the chronic diseases of adulthood (Shrestha, 2006). However, Americans are also accumulating more diseases and disabilities with age (American Geriatrics Society, 2011; Hung, Ross, Boockvar, & Siu, 2011), and with no current disease-modifying therapies available to slow or stop the progression of AD worldwide (Alzheimer's Association, 2014; Hong-Qi, Zhi-Kun, & Sheng-Di, 2012), increased longevity comes at a price for many older Americans.

Second, a focus on community-based support and residential care transitions to facilities is critical given the economic impacts of AD on the healthcare system. Controlling nursing facility expenditures is a consistent priority in public policy, particularly because a large portion of nursing home costs are covered at the public's expense by Medicaid (Levine, Halper, Peist, & Gould, 2010). In 2014, aggregate payments for health care, long-term care, and hospice from all sources for persons with AD and other dementias totaled $214 billion; this number is projected to increase to $1.2 trillion (in 2014 dollars) in 2050 (Alzheimer's Association, 2014; The Lewin Group, 2004; Medicare Current Beneficiary Survey, 2008. Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011). This projected increase is expected to result in a six-fold increase in government spending under Medicare and Medicaid, as well as a five-fold increase in out-of-pocket spending among beneficiaries (Alzheimer's Association, 2014).

This is a serious cause for concern for the already strained programs Medicare and Medicaid. Twenty-nine percent of older persons with dementia also have Medicaid coverage, compared to 11% of older persons without dementia (Alzheimer's Association, 2014; Medicare Current Beneficiary Survey, 2008. Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011). Average Medicaid payments per person for Medicare beneficiaries age 65 and older with dementia were 19 times greater than average Medicaid payments for beneficiaries without dementia ($10,771 per person for those with dementia vs. $561 for those without dementia); it is not specified whether these figures are age-adjusted (Alzheimer's Association, 2014; Medicare Current Beneficiary Survey, 2008. Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011). Although Medicaid is the primary payer for nursing home care,

beneficiaries admitted to long-term care facilities rely heavily on Medicare to cover medical care costs (Jacobson, Neuman, & Damico, 2010). With a substantially larger older adult population, sustainability concerns for Medicare are elevated, particularly given the consistent rise in Medicare spending associated with care for chronic conditions.

Third, this project answers the Alzheimer's Association's call for additional research on geographic disparities in dementia care (Alzheimer's Association, 2012b, p. 53). The demography of America is rapidly changing, creating an urgent need for additional research in this area. This study seeks to identify whether disparities in community-based helper support and institutionalization exist among rural and urban older Americans with compromised health and functioning. This is a critical initial step in identifying areas where locale-specific behavioral and policy interventions are needed to bridge gaping divides in care.

Innovation

This study is innovative in several ways. First, this study focuses on a novel hypothesis—rural residence and limited community-based helper support are associated with an increased likelihood of and less elapsed time to transition to a nursing facility. Additionally, the examination of longitudinal trends and gaps in community-based assistance for functional limitations and rural vs. urban differences specifically among older persons with dementia is innovative and offers a unique contribution to the literature. To my knowledge, an examination of the effects of rural vs. urban residence as well as community-based helper support on the likelihood and timing of institutionalization has not been previously pursued among older adults with dementia.

Second, the use of the MCBS to longitudinally examine and quantify effects and patterns of helper support among Medicare beneficiaries with dementia and ADL/IADL difficulties sets this study apart from others in this area of research. Much of the previous work on care transitions specifically has been cross-sectional. The MCBS provides a unique opportunity to study access to helpers in the community, as well as other key contextual factors, and residential care transitions across time concurrently.

Third, rural vs. urban disparities in community-based helper support for ADL/IADL limitations will be directly examined and quantified, if present. This is consistent with previous research examining unmet needs with regard to assistance with functional limitations among older adults. Previous research has found that many older persons with reported ADL/IADL difficulties have unmet needs in this area; older persons lacked needed assistance and often experienced negative consequences as a result of those unmet needs (Desai, Lentzner, & Weeks, 2001). This study examines potential unmet needs with regard to community-based helper support for functional difficulties specifically among those with dementia and functional impairments. Reported ADL/IADL difficulties were compared to the reported receipt of any help, reported helpers for those functional difficulties, and use of any special equipment for ADLs only and assessed for incongruence. Such incongruences are referred to as "support gaps" and this measure is assessed over time for rural and urban elders with dementia. To my knowledge, this study uniquely uses the MCBS to measure ADL/IADL-specific community-based support gaps among rural and urban older persons with dementia and functional limitations.

CHAPTER 3. DATA SOURCES

Medicare Current Beneficiary Survey

The Medicare Beneficiary Survey (MCBS) offers a unique opportunity for studying longitudinal relationships between helper support, contextual factors, and residential care transitions by nature of its study design. To my knowledge, no previous study has examined all of these concepts concurrently in a longitudinal fashion using MCBS data, despite the data set's offerings.

All aims of this dissertation used data from the MCBS from 2000–2009. The MCBS is a continuous, multipurpose survey of a sample of institutionalized and non-institutionalized Medicare beneficiaries. This survey was designed to aid the Centers for Medicare and Medicaid Service's (CMS) administration, monitoring, and evaluation of the Medicare program. The central goals of the MCBS are to determine expenditures and sources of payment for all services used by Medicare beneficiaries, including co-payments, deductibles, and non-covered services; to ascertain all types of health insurance coverage and relate coverage to sources of payment; and to trace processes over time, such as changes in health status and spending down to Medicaid eligibility and the specific impacts of program changes, satisfaction with care, and usual source of care.

Medicare beneficiaries represent the unit of analysis in the MCBS. The sample design is a multi-stage stratified random list sample. The survey design is a rotating panel; a new panel enters the MCBS annually. Each panel includes approximately 4,000 people and is followed for

an additional three years following the enrollment year, for a total of four years of data (one baseline year of data, plus three follow-up years of usage data). For this reason, longitudinal changes may be assessed with annual observations for each beneficiary, as available. In each year of data, there are four overlapping sample panels with staggered entry into the survey, meaning that one panel is contributing data to the MCBS for the first time while the others are supplying data for the second, third, and fourth time (Briesacher, Tija, Doubeni, Chen, & Rao, 2012). Additionally, in each year of data, the last panel from the prior year will have been replaced with a new sample panel to ensure that the total MCBS sample provides an accurate reflection of the current Medicare population (Briesacher et al., 2012). The MCBS typically has three rounds of data collection per year, with each panel followed for up to 12 interviews. However, most questions in the MCBS are only asked once per year in the fall round. Generally, the MCBS is designed to provide a view of what happened during the entire year. People under age 65 (disabled) and age 85 or older (oldest old) are oversampled to increase the precision of estimates for these groups (Briesacher et al., 2012). All interviews are conducted in person with computer-assisted personal interview technology (Briesacher et al., 2012).

The MCBS releases two data modules annually: Access to Care and Cost and Use. The Access to Care module contains three continuing panels (from previous years), plus the one new panel for that year for a total of approximately 16,000 beneficiaries (i.e., four panels with approximately 4,000 beneficiaries in each) enrolled in a given year. The Cost and Use module only contains the three continuing panels (i.e., participants do not appear in the Cost and Use module the first year in the study) for a total of approximately 12,000 beneficiaries enrolled in a given year. There is overlap between the two modules because of the continuing panels. However, there are also some differences in who appears in which module: the Access to Care

module contains the "always enrolled" population (i.e., participants that were enrolled/alive for the entire study year), whereas the Cost and Use contains the "ever enrolled" population (i.e., participants will still appear even if they die mid-year) (Ferraro & Liu, 2005; Mann, 2012). The two modules are created from the same survey population. The Cost and Use and Access to Care files may be linked using the unique beneficiary identifier called the "BASEID" that is contained in both modules (Mann, 2012). Two types of interviews are conducted: 1) Institutionalized persons complete a "facility" interview; and 2) non-institutionalized persons complete a "community" interview, because they reside in community dwellings as opposed to facilities.

The Access to Care module contains survey-reported information (i.e., either self- or proxy reported) on beneficiaries' access to healthcare services, satisfaction with care, and usual source of care and is released within one year of the survey (CMS, 2012a). The Access to Care module also includes survey information on functional limitations among beneficiaries as well as their "helpers" or individuals who provide help with these limitations and other activities. Helpers include spouses, adult children, immediate relatives, friends, and others providing support, as reported by community-dwelling beneficiaries or their proxies. Conventional descriptions in the literature typically use the term "caregiver" to describe persons in this role. However, there may be a difference in meaning between the terms "helper" and "caregiver" due to the potential for differences in interpretation regarding the level of support provided. Caregivers may be helpers, but helpers may not necessarily be caregivers, particularly in terms of the primary support role (Milller & Guo, 2000). No studies that formally examined potential differences in meaning or interpretation between these terms were identified. Because the MCBS used the term "helper" and not caregiver, this study retains that terminology in an attempt to maintain the fidelity of the original questions. Although the context of this study is caregiving,

persons assisting with ADL/IADL functional limitations included in this study were referred to as helpers rather than caregivers. Despite this potential difference in meaning, this study is well-connected to issues concerning informal and community-based caregiving for older persons in the United States due to the type of support under study (i.e., assistance with functional limitations).

The Cost and Use module, which is released after the Access to Care module (i.e., within two years of the survey), combines survey-reported data (e.g., information on the use and cost of all types of medical services as well as information on supplementary health insurance, living arrangements, income, health status, and physical functioning) with Medicare claims data (e.g., use and cost information on inpatient hospitalizations, outpatient hospital care, physician services, transitions between settings such as skilled nursing homes, and other medical services, diagnoses, and procedure codes, etc.) to provide a more comprehensive view of health services used, amounts paid, and sources of payment (CMS, 2012a). Each year of the MCBS may be used separately for cross-sectional analyses or linked together over multiple years for conducting longitudinal analyses (Briesacher et al., 2012), as this study does.

The present study includes a pooled sample of panels entering the MCBS in 2000 through 2006 as well as their linked follow-up usage data, creating a longitudinal design; follow-up data are available through 2009.

<div align="center">**Area Resource File**</div>

To obtain a richer description of rurality, beneficiaries' county codes were linked to the Urban Influence Code (UIC), which was developed by the Economic Research Service (ERS) of the U.S. Department of Agriculture (USDA) (USDA, 2012). These UICs were obtained from the Health Resources and Services Administration's 2012–2013 Release Area Resource File (ARF)

(recently renamed the Area Health Resources File), which was accessed online (U.S. Department of Health and Human Services, 2013) and linked to MCBS data using the Social Security Administration's (SSA) Office of Research, Evaluation and Statistics Beneficiary State and County Codes.

The 2003 UICs, rather than the 2013 UICs, were deemed appropriate for this study given the specific years of interest. MCBS captures one state/city for the year (i.e., as of December 31st). The 2003 UICs divide U.S. counties into twelve total categories (two groups of metropolitan counties and ten groups of nonmetropolitan counties) (USDA, 2012). Similar to Stearns, Slifkin, and Edin (2000) and Jaynes (2004), these individual UICs were collapsed into fewer categories indicating rural vs. urban status due to the limited sample size to maximize power of the analyses. For this study, the UICs were collapsed to create three distinct categories: a) urban (UICs 1 & 2); b) rural, adjacent to a metro or micro area (UICs 3–7, 9 & 10); and rural, not adjacent to metro or micro area (UICs 8, 11, & 12). This method allows for the identification of key differences or heterogeneity within the rural group and represents a more nuanced approach to understanding rural vs. urban disparities. The ARF was also the source for the individual level county characteristic variables that were tested as instruments in Aim 2's instrumental variables analysis.

Inclusion and Exclusion Criteria

Because the Access to Care module includes data collected in the year of entry into the MCBS, unlike the Cost and Use module, and it includes individuals enrolled during the entire study year, this module was used to identify the sample cohort. MCBS sample entry panels from 2000–2006 were combined to create a cohort with follow-up data extending through 2009. Continuing panels included in the 2000 MCBS data were excluded because they joined the study

prior to the 1999 Supreme Court ruling in *Olmstead v. L.C.* ((98-536) 527 U.S. 581 (1999)), which mandated the provision of long-term care service options in the community for aging and disabled populations (Kasper, 2005). The baseline study cohort was limited to community-dwelling individuals (i.e., sample persons who completed "community" interviews; meaning that they were community residents rather than facility residents) with an enrollment year age of 65 years or above who also had a self- or proxy-reported and/or claims-identified dementia diagnosis *and* who reported at least one ADL/IADL difficulty. Aim 1 includes all eligible beneficiaries included in the MCBS for at least one study year. Aims 2 and 3, which examines movement into nursing facilities beyond the baseline study year, were limited to beneficiaries who remained in the MCBS for at least two study years.

Beneficiaries who were eligible for Medicare due to End-Stage Renal disease were excluded from analyses because they represent a smaller and unique subpopulation of Medicare (Kautter, Khatutsky, Pope, Chromy, & Adler, 2006). Thus this study includes persons Medicare-eligible due to age or disability. The study was limited to fee-for-service or "traditional" Medicare beneficiaries. Beneficiaries with group health plan participation or Medicare managed care during the enrollment year were excluded from the study, because Medicare Advantage plan providers receive capitated payments from Medicare and do not process claims through CMS. As such, CMS Medicare claims data that would include service use and diagnosis information are not available for these beneficiaries. Claims that supplement the MCBS are for fee-for-service beneficiaries only. Some usage information used in this study was obtained from Medicare claims data only. Therefore, persons not enrolled in fee-for-service Medicare for all or part of the study years were excluded from analyses due to potential incomplete usage data. Data for Puerto Rico residents were excluded from analyses given key differences in Medicare in Puerto Rico

versus the mainland states. This includes lower Medicare reimbursements to Puerto Rican hospitals and beneficiaries enrolled in premium-free Medicare Part A not being automatically enrolled in Medicare Part B, which covers outpatient services (Elliott, Haviland, Dembosky, Hambarsoomian, & Weech-Maldonado, 2012).

This longitudinal study examined outcomes among prevalent dementia cases (i.e., transitions to a facility following a dementia diagnosis). Incident cases were not included in the study given attrition among the sample over time, which increased the potential for incomplete follow-up utilization data among cases identified in later study years. Persons were identified as having a dementia diagnosis during their MCBS enrollment year if the following criteria applied:

1. A self-given or proxy "yes" response to the following MCBS question, "Has a doctor ever told you that you had AD or dementia?" For proxy respondents, the MCBS question asked is, "Has a doctor ever told you that (your relative) had AD or dementia?"

2. At least one Medicare claim (inpatient, outpatient, or physician) in the enrollment year that included a diagnostic code for AD or other dementia. The diagnostic codes used to identify AD and other dementias were obtained from the 2006 ICD-9 codebook (Bynum, 2009). The diagnostic codes used to identify survey participants with AD and other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11 (Bynum, 2009).

Beneficiaries were included in the study if they self/proxy-reported dementia, had at least one claim with one of the dementia codes or met both criteria, *and* if they self/proxy-reported having at least one of six ADLs (i.e., bathing or showering, dressing, eating, getting in or out of

bed or chairs, walking, and using the toilet) or six IADLs (i.e., using the telephone, doing light housework, doing heavy housework, preparing meals, shopping for personal items, and managing money/paying bills).

Table 1 illustrates the application of the sample exclusion criteria and the resultant number of unique eligible Medicare beneficiaries (N= 720) for the study cohort. The inclusion criterion of a diagnosis of dementia is solely based on a self/proxy-reported diagnosis for the majority of beneficiaries included in the study sample (74%). Overlap between self/proxy-reported dementia and claims-identified dementia was minimal; nine-percent of the sample had both a Medicare claim with a dementia diagnosis code and self/proxy-reported dementia. The Medicare claims data that accompany the MCBS data modules only include data for beneficiaries included in the respective module and for that particular file year (CMS, 2013a). Medicare claims on historical or future events for past or current participants are not included in the standard release (CMS, 2013a). Therefore, the claims diagnosis is based on whether an applicable claim was identified during the beneficiary's first MCBS enrollment year. Claims prior to the MCBS enrollment year were unable to be examined. The inability to examine claims data from prior years may have resulted in the under-identification of dementia claims, particularly among persons who self/proxy-reported dementia. In addition, dementia diagnoses may be underreported in claims due to clinicians not associating the services provided at the time of contact with that particular diagnosis. Another potential explanation is that self/proxy-reported cases may have associated age-related memory loss or memory loss due to other conditions with dementia. The distinction between age-related forgetfulness and dementia is largely the interference with daily functioning. Once an individual's memory loss and/or deficits in terms of

thinking or reasoning reaches a level that affects their ability to perform daily activities, it is more likely that the individual has reached the state of dementia.

In fact, functional impairment is often indicative of a more advanced state of dementia (Moore, Zhu, & Clipp, 2001). By limiting this study to persons with dementia who also have functional impairments, the sample under study represents individuals in a more advanced state of disease and is not representative of all persons affected by this condition. However, the presence of such impairments suggests that the memory loss experienced has advanced beyond age-related changes. Further, the purpose of this analysis is to examine levels of community-based support among beneficiaries with dementia and impaired daily functioning to determine if these individuals are in fact receiving the help that they need with home-based care (CMS, 2014).

As shown in Table 1, 85% of eligible beneficiaries identified as having dementia, also reported at least one functional limitation. Functional limitations are highly prevalent among the beneficiaries identified in the sample as meeting the criterion of having dementia. In addition, at baseline, the total number of reported ADL/IADL difficulties is significantly higher among those with only a self/proxy report of dementia compared to beneficiaries identified through claims only (Table 2). Similarly, persons with both self/proxy-reported dementia and at least one dementia claim report a significantly higher number of total ADL/IADL difficulties than persons identified through claims only. Although overlap of claims identification and self/proxy-reported dementia is low, the burden of functional difficulty is high among persons with only self/proxy-reported dementia suggesting that these beneficiaries are truly affected by dementia and are in an advanced state of disease. Given the high burden of functional difficulty among those identified

as having dementia, studying ADL/IADL-specific support among beneficiaries *with* reported difficulties in this sample is a relevant pursuit.

All inclusion and exclusion criteria are based on beneficiaries' status during their enrollment year into the MCBS (i.e., enrollment in entering panels from 2000 to 2006). See Appendix 1 for a complete list of inclusion and exclusion criteria. The total number of eligible beneficiaries per MCBS entry year is indicated in Table 3. After the enrollment or entry year, each MCBS sample panel is followed for an additional three years. Therefore, participants may be enrolled in the study for a total of four years, consisting of one enrollment year plus three follow-up years in which healthcare use data are obtained. Follow-up data were merged in for the identified eligible sample cohort and duplicate observations were excluded. The number of beneficiaries remaining in the study longitudinally is illustrated in Table 4. All eligible beneficiaries were community-dwelling in Study Year 1. Fifty-three percent of community interviews at baseline were conducted with a proxy, rather than with the sample person (R,N: 52%; R,A: 45%; and U: 55%). The majority of proxies were adult daughters (37%), followed by spouses (30%). As shown in Table 4, some remaining beneficiaries in follow-up years were institutionalized and completed facility interviews.

The MCBS includes a survival indicator that provides information on how many beneficiaries survived during the calendar year as of the end of the calendar year (December 31st). As previously mentioned, the Access to Care module only includes data for persons who survived during the study year (up to the fall round interview). Documented deaths provided in the Access to Care data reflect beneficiaries who died post the fall round interview and prior to the next interview (on or before December 31st of the calendar year). There were a total of 57 documented deaths at the end of Study Year 4 (Table 5).

As Table 5 illustrates, not all missing interviews across study years are accounted for in the number of documented deaths, indicating non-death attrition. The MCBS does not include an indicator providing information on the trajectories of those who are lost to follow-up, nor their reasons for discontinuation in the study (Hubbard & Edwards, 2010). Most non-death attrition in the MCBS occurs after the baseline Access to Care interview and the first Cost and Use interview (i.e., second-year) (Hubbard & Edwards, 2010). Such is the case in this study.

Different attrition rates for the MCBS sample have been reported using earlier releases of MCBS data. Using two combined MCBS panels (panel 1: 2005 entry and 2008 exit combined with panel 2: 2006 entry and 2009 exit and excluding attrition due to death), Hubbard and Edwards (2010) report an attrition rate of 26% (1,639 left with 4,771 remaining in year 4 out of 6410 at baseline). Using three pooled entry MCBS panels (panel 1: 1997 entry and 2000 exit; panel 2: 1998 entry and 2001 exit; and panel 3: 1999 entry and 2002 exit), Kautter et al. (2006) report an attrition rate of 62% (8,878 left with 5,437 remaining in year 4 out of 14,315 at baseline). The total attrition rate for this study is 63.3% (Table 5), which is consistent with Kautter et al. (2006).

This study distinctively includes a sample of older beneficiaries diagnosed with dementia and reporting existing functional limitations. This is a highly vulnerable group of beneficiaries, and as such, continued study participation may prove challenging for this population. In that the decision of whether or not to continue in the study is likely not random, this attrition may represent a form of selection bias. Greater attention to the movement of beneficiaries with dementia in and out of the MCBS is needed and direct efforts within the MCBS to track such movement and provide justifications for missing interviews, which are not currently available,

would prove most beneficial to researchers interested in this subpopulation of Medicare beneficiaries.

Table 6 includes the total years of participation per beneficiary across study years. This table shows that of those who completed interviews at baseline, 32% remained in the MCBS only one year, 18% remained in the study two years, 15% remained in the study three years, and 35% of the original sample remained in the study for a total of four years. The mean length of follow-up among the baseline sample was 2.5 study years (SD=1.3) and ranged from one to four study years. Results from an imputed (i.e., uses imputed data from Aim 1b due to missing values for covariates) logistic regression model examining differences in key demographic characteristics at baseline between those who did not remain in the study all four years and those who did are presented in Table 7. Age and total number of ADL/IADL difficulties were positively associated with increased probability of attrition while Medicaid participation was associated with reduced probability of leaving the study.

Table 1. Eligible MCBS Sample Cohort

Imported data from years 2000-2006 of Access to Care module RIC K (Key Record) (i.e., baseline years) Began with 46,879 beneficiaries		
Limited to MCBS entry panels (i.e., incoming first year beneficiaries) in years 2000–2006; excluded continuing panels from 1997, 1998 and 1999 included in 2000-2002 data (-11,591) Result: 35,288		
Limited to community-dwelling beneficiaries, excluding persons in facilities during the enrollment year (-2,156) Result: 33,132		
Limited to beneficiaries with a self or proxy report of dementia and/or an inpatient, outpatient, or physician claim for a dementia diagnosis code (-33,097) Result: 1,061		
Self/Proxy-reported dementia only 794 (74.8%)	Claims-Identified dementia only 194 (18.3%)	Both Self/Proxy-reported and Claims-Identified dementia 73 (6.9%)
Limited to beneficiaries with at least one self- or proxy-reported ADL or IADL functional limitation (-155) Result: 906		
Limited to Fee-for-service or "traditional" Medicare beneficiaries, excluding persons with some group health participation during the year (-109) Result: 797		
Limited to Aged & Disabled Medicare population, no End-Stage Renal Disease (-8) Result: 789		
Limited to Aged Medicare population age 65 and older (52) Result: 737		
Excluding beneficiaries residing in Puerto Rico (-17) **Result: 720 unique eligible beneficiaries in enrollment years 2000-2006**		
Self/Proxy-reported dementia only 534 (74.2%)	Claims-Identified dementia only 125 (17.4%)	Both Self/Proxy-reported and Claims-Identified dementia 61 (8.5%)

Table 2. Functional Limitations by Self/Proxy Reported vs. Claims Identified Dementia at Baseline

(Mean [SD], N=720)

	Total Number of ADL/IADL Limitations	Total Number of ADL Limitations	Total Number of IADL Limitations
Self/Proxy-Reported Dementia Only **n=534**	6.8 (3.5)	4.1 (1.9)	2.7 (2.1)
Claims-Identified Dementia Only **n=125**	4.6 (3.1)	2.6 (1.8)	2.0 (1.7)
Both Self/Proxy-Reported and Claims-Identified Dementia **n=61**	7.0 (3.0)	4.5 (1.7)	2.5 (1.9)
Total *p*-value	6.4 (3.5) **Test of association:** *p<0.001* **Test of direction of association:** Self/proxy report only vs. Claims only *p<0.001* Claims only vs. Both Self/proxy report and Claims *p<0.001*	3.9 (2.0) **Test of association:** *p<0.001* **Test of direction of association:** Self/proxy report only vs. Claims only *p<0.001* Claims only vs. Both Self/proxy report and Claims *p<0.001*	2.6 (2.0) **Test of association:** 0.002** **Test of direction of association:** Self/proxy report only vs. Claims only 0.001**

Table 3. Eligible Beneficiaries by MCBS Entry Year, N (%)

2000	82 (11.4)
2001	102 (14.2)
2002	93 (12.9)
2003	106 (14.7)
2004	115 (16.0)
2005	110 (15.3)
2006	112 (15.6)
Total	720 (100)

Table 4. Eligible Beneficiaries by Longitudinal Study Year and Type of MCBS Interview, N (%)

	Study Year 1	**Study Year 2**	**Study Year 3**	**Study Year 4**
Community Interview	720 (100)	408 (85.7)	265 (74.2)	182 (68.9)
Facility Interview	0	68 (14.3)	92 (25.8)	82 (31.1)
Total	720	476	357	264

Table 5. Documented Deaths during the Year by Longitudinal Study Year and Type of MCBS Interview, N (%)

	Study Year 1		Study Year 2		Study Year 3		Study Year 4		Total Observations
Community Interview	No	27 (3.8)	No	13 (3.2)	No	4 (1.5)	No	3 (1.7)	47 (3.0)
	Yes	693 (96.2)	Yes	395 (96.8)	Yes	261 (98.5)	Yes	179 (98.4)	1,528 (97.0)
Total		720		408		265		182	1,575
Facility Interview	NA		No	1 (1.5)	No	7(7.6)	No	2 (2.4)	10 (4.6)
			Yes	67 (98.5)	Yes	85 (92.4)	Yes	80 (97.6)	232 (95.4)
Total				68		92		82	242
Community + Facility Interview Total		720 (All Community)		476		357		264	1,817
Community + Facility Documented Deaths Total		27		14		11		5	57
Missing Interviews in Next Study Year (Non-death attrition percentage)				217 (31.3%)		105 (22.7%)		82 (23.7%)	
Total Non-death Attrition from Study Year 1 to Study Year 4 (not including Study Year 4 deaths)								60.5%	
Total Attrition from Study Year 1 to Study Year 4 (not including Study Year 4 deaths)								63.3%	

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Table 6. Total Years of Participation per Beneficiary across Study Years, N (%)

	Study Year 1	Study Year 2	Study Year 3	Study Year 4
Participated in MCBS Only 1 Year	233 (32.4)			
Participated in MCBS 2 Total Years	129 (17.9)	123 (25.8)	6 (1.7)	
Participated in MCBS 3 Total Years	106 (14.7)	101 (21.2)	99 (27.7)	12 (4.6)
Participated in MCBS All 4 Study Years	252 (35.0)	252 (52.9)	252 (70.6)	252 (95.5)
Total	720	476	357	264

Table 7. Demographic Predictors of Attrition: Not Participating in the MCBS for Four Years

	Average Marginal Effects (Bootstrapped Standard Errors)
Rural vs. Urban Residence	
R,N	-0.075
	(0.062)
R,A	-0.016
	(0.047)
First year in MCBS	0.005
	(0.011)
Age	0.007^{**}
	(0.003)
Male	0.056
	(0.039)
African American	-0.052
	(0.061)
More than 1 Race	-0.043
	(0.061)
Other Race	-0.216
	(0.115)
Hispanic or Latino Ethnicity	0.043
	(0.084)
Lives alone	-0.009
	(0.045)
Marital Status	
Married	0.049
	(0.048)

	Average Marginal Effects (Bootstrapped Standard Errors)
Divorced	0.077
	(0.071)
Separated	-0.0070
	(0.179)
Never Married	-0.143
	(0.117)
Income $25K or less	0.050
	(0.044)
High School Diploma or Greater	-0.023
	(0.038)
Medicaid Participation	-0.131**
	(0.046)
Number of ADL/IADL difficulties	0.023***
	(0.005)
Number of Co-morbidities	-0.015
	(0.017)
General Health Status Rating	
Excellent	0.069
	(0.066)
Very Good	-0.097
	(0.058)
Fair	0.054
	(0.047)
Poor	0.083
	(0.051)
Observations	720

Notes. Uses multiple imputation data from Aim 1b due to missing values for covariates (i.e., multiple imputation using chained equations): Rural vs. urban residence (3 missing values); Income $25,000 or less (8 missing values); High School Diploma or Greater (16 missing values); and General Health Status (3 missing values).

Referent categories are Urban, White, Widowed, and *Good* General Health Status rating.

[*] $p < 0.05$
[**] $p < 0.01$
[***] $p < 0.001$

Study Variables and Measures

Table 8 provides a comprehensive list of variables and measures that were included in this study. Details on the variable, measure, type, and associated aim(s) are included. Empirical models are tested in all study aims, where the key independent variables of interest are rural vs. urban residence (aims 1–3) and community-based helper support (aims 2 & 3). Covariates are similar across aims. Some categorical variables were collapsed in aims 2 and 3 regression models.

Table 8. Study Variables and Measures

Variable	Measure	Type	Aim(s)
Dependent Variables			
Any ADL/IADL support gaps	1=at least one occurrence where an IADL or ADL functional limitation was reported, but no corresponding help, helpers or special equipment (for ADLs only) were reported representing a gap; 0= no gaps	Binary	1b
Any ADL support gaps	1=at least one occurrence where an ADL functional limitation was reported, but no corresponding help, helpers or special equipment (for ADLs only) were reported representing a gap; 0= no gaps	Binary	1b
Any IADL support gaps	1=at least one occurrence where an IADL functional limitation was reported, but no corresponding help or helpers were reported representing a gap; 0= no gaps	Binary	1b
Any residential care transitions to nursing facilities (i.e., SNF, nursing home or assisted living facility)	1=at least one residential care transition to a facility; 0=no residential care transitions to a facility	Binary	2
Transition category (Ever transitioned to…)	1=SNF only; 2=Both SNF and Nursing Home or Assisted Living facility; 3=Nursing Home or Assisted Living Facility only; 4=No transitions	Categorical	2
Time-to-first nursing facility transition	Elapsed days from first community interview to first nursing facility start date	Continuous	3

	Independent Variables		
	Environment		
Usual Source of Care	1=Has a usual source of care; 0=no usual source of care	Binary	2
	Pre-disposing Characteristics		
Age	Number of years	Continuous	1,2,3
Sex	1=male; 0=female	Binary	1,2,3
Race	1=White; 2=African American; 3=More than one race; 4=Other Race (Asian, Native Hawaiian or Other Pacific Islander; American Indian or Alaska Native; Other race)	Categorical	1,2,3
Ethnicity	1=Not Hispanic or Latino; 0=Hispanic or Latino	Binary	1,2,3
Geographic Location (Rural/Urban Residence)	1=Rural, not adjacent to metro or micro area (R,N); 2=Rural, adjacent to metro or micro area (R,A); 3=Urban (U)	Categorical	1,2,3
Marital Status	1=Married; 2=Widowed; 3=Divorced; 4=Separated; 5=Never Married	Categorical	1,2,3
Income	1=Income $25,000 or less; 0=Income greater than $25,000	Binary	1,2,3
Education	1=High school diploma or greater than high school diploma; 0=Less than high school diploma;	Binary	1,2,3
Medicaid Participation	1=Some Medicaid participation for the year 0=No Medicaid participation for the year	Binary	1
Living situation	1=lives alone; 0=lives with others	Binary	1,2,3
	Enabling Factors		
	Community-based ADL/IADL Helpers		
Reported Number of ADL/IADL Helpers	Count of reported helpers for ADLs/IADLs	Continuous	1

Sources of Support (Helpers) for ADLs/IADLs: Relationship of Reported ADL/IADL Helper(s) to Beneficiary (Reports receiving help from…)	1=spouse only; 2=adult child only; 3=other kin relative(s) only (e.g., female/male relatives); 4=non-kin only (e.g., friend, neighbor); 5=multiple helper relationships	Categorical	1
Single vs. multiple source(s) of community-based ADL/IADL support	1=Has only 1 type of informal helper as measured by reported helper relationships; 0=Has more than 1 type of helper as measured by reported helper relationships (includes persons with informal helpers and formal home health)	Binary	2,3

Need

Functional Limitations	Number of reported ADLs or IADLs	Continuous	1,2,3
Co-morbidities	Number of co-morbid reported chronic conditions (i.e., high blood pressure, heart disease, stroke, cancer, diabetes, arthritis, lung disease)	Continuous	1,2,3
General Health Status Rating	1=Excellent; 2=Very Good; 3=Good; 4=Fair; 5=Poor	Categorical	1,2,3

CHAPTER 4. A DESCRIPTION OF COMMUNITY-BASED HELPER SUPPORT, GAPS, AND DISPARITIES AMONG MEDICARE BENEFICIARIES WITH DEMENTIA AND FUNCTIONAL LIMITATIONS

Introduction

Many older adults prefer to remain in their homes and outside of institutions as they age (Kane & Kane, 2001). Such 'aging in place' often occurs among older adults and has become a preferred approach, because it promotes elder care service delivery outside of institutional settings (Bookman, 2008). Aging in place has also been associated with improved quality of life among older adults with functional impairments (Szanton et al., 2011). Persons with dementia who are limited in their ability to perform basic daily tasks may also be limited in their ability to age in place or remain in their community residences without adequate community-based support for those impairments.

In general, more than one-third of the Medicare population receives help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs); walking, getting in or out of bed or chairs, and bathing are the highest reported ADL difficulties and doing heavy housework, shopping, and doing light housework are the highest reported IADL difficulties (CMS, 2014). However, there is significant variability in the prevalence of support for such limitations. Among Medicare beneficiaries reporting ADL/IADL difficulties, the percent of beneficiaries receiving help with those ADLs/IADLs ranges from 20–90% depending on the difficulty (CMS, 2014). These figures illustrate that many older persons in need of functional support do not report receiving it.

With significant demographic shifts on the horizon in which the older adult population will dramatically increase as well as projected informal and formal caregiver shortages (Zarit & Reamy, 2012), examinations and discussions of potential unmet functional needs among older persons are needed (CMS, 2014). Research regarding geographic variation in the presence, magnitude, and sources of community-based help for functional limitations as well as the longitudinal stability of helper networks, specifically among elders with dementia and self-identified functional impairments, is limited.

The purpose of this chapter is two-fold: 1) to provide a description of community-based support provided by reported helpers over time among rural and urban elders with dementia and functional limitations; and 2) to quantify the potential presence of rural and urban disparities in community-based support over time by examining ADL/IADL support gaps. The overall goal of this part of the study is to identify potential unmet functional needs among a highly vulnerable segment of the Medicare population. By expanding knowledge of this issue, more gap-filling programs and policies focused on home- and community-based dementia care may be developed.

Specifically, the objectives and associated hypotheses for this part of the study are:

Aim 1a: To describe rural vs. urban group differences and temporal trends in the presence (co-occurrence of reported help, helpers, and/or use of special equipment (ADLs only) for reported ADL/IADL limitations), magnitude (i.e., number of reported ADL/IADL helpers), and sources of community-based helper support reported for ADL/IADL functional limitations (e.g., spouses, adult children) among the study sample.

This aim is descriptive. Therefore, no hypotheses are stated.

Aim 1b: To examine rural vs. urban disparities in community-based support for

ADL/IADL functional limitations among the study sample over time, controlling for

key demographic, socioeconomic, and health status factors.

H1: Controlling for key demographic, socioeconomic, and health status predictors,

rural residence will be associated with gaps in support for functional limitations.

<div align="center">

Methods

</div>

Aim 1a Methods

This aim's descriptive analyses provide important information regarding geographic

variation in the expansiveness of and shifts in informal helper networks among beneficiaries

with significant healthcare needs. Specifically, I describe the co-occurrence of reported

helpers for reported ADL/IADL limitations, the magnitude of reported help for functional

difficulties (i.e., number of helpers), and sources of support, which refers to the relationships

of reported helpers to beneficiaries (i.e., spouses, adult children, other kin relatives, non-kin,

or multiple helper relationships) among rural and urban community-dwelling dementia elders

with functional impairment. Analyses were limited to beneficiaries who completed

community component interviews (rather than facility component interviews) and reported at

least one ADL/IADL limitation across all four study years; helper questions included in the

Health Status and Functioning Questionnaire were only posed to community-dwelling

respondents reporting functional limitations.

For each of the six ADLs (i.e., bathing or showering, dressing, eating, getting in or

out of bed or chairs, walking, and using the toilet) and six IADLs (i.e., using the telephone,

doing light housework, doing heavy housework, preparing meals, shopping for personal

items, and managing money/paying bills), the MCBS assesses whether the beneficiary

reports difficulty with the ADL/IADL and documents all reported helpers for each reported difficulty. Specifically, the MCBS asks, "You mentioned that (you receive/sample person receives) help with (IADL). Who gives that help?" Questions regarding helpers in the MCBS refer to individuals the respondents identified as helpers for each specific limitation. All reported helpers and helper relationships are respondent-identified. There may be one, several, or no reported helpers per respondent (CMS, 2012a). These helper questions are designed to capture informal help received in the community. Reported helper relationships overwhelmingly refer to informal helpers in the MCBS. These reported relationships were collapsed into five mutually exclusive categories to indicate sources of help or support for beneficiaries: spouses only, adult children only, other kin relatives (e.g., female/male relatives) only, non-kin (e.g., friend, neighbor) only, or multiple sources of help (i.e., any combination of helper relationships; specific combinations were not assessed). Because beneficiaries were not limited in the types of helpers they could report, nurse or nurse aides, which could represent formal paid home health care, were reported as helpers by five respondents in the present sample. Given this limited number, these respondents were included in the non-kin helper relationship category.

In a separate question, the MCBS assesses whether the beneficiary received one or more paid home health agency (HHA) visits during the year. As such, the receipt of paid home health care is not directly tied to the ADL/IADL helper questions. The limited number of respondents who reported nurses or nurse aides as helpers for specific tasks suggests that the paid home health assistance received was not as recurrent (the measure captures at least one HHA visit during the year) as support from informal helpers and, thus, respondents did not factor in such assistance when asked who helps them with daily tasks. As such, although

paid home healthcare workers typically provide similar support, the sources of community-based support for ADL/IADL limitations measure described in this aim refers specifically to the reported informal helper information associated with each assessed ADL/IADL difficulty because that is the focus of this study aim. In that respondents were not limited in the types of helpers they could report and because a small number of respondents did report nurse or nurse aides as helpers, help from paid home health workers is indirectly captured in the ADL/IADL helper assessment variables. Because they represent a very small fraction of reported helpers among the sample and all other relationships refer to non-formal support, reported ADL/IADL helpers in this aim overwhelmingly represent "informal" or unpaid community helpers.

Means and Proportions

Baseline and pooled means and proportions are described for reported functional limitation and support outcomes across rural and urban residence categories (i.e., total number of ADL/IADL difficulties, number of ADLs, number of IADLs, number of reported ADL/IADL helpers, presence of support for each ADL/IADL limitation, and specific sources of support for ADLs/IADLs).

Transition Frequencies for Ever-Reported Support

Transition frequencies for the presence and sources of community-based support for ADL/IADL limitations were also generated. These frequencies refer to the count and percent of those who *ever* reported receiving support for an ADL/IADL limitation (i.e., among those who continued to report the limitation over time) or those who *ever* reported a specific source of support for the limitation in one study year who also reported receiving that support in the next study year. For support for ADLs and IADLs, these figures apply to those who also

reported having the difficulty in the subsequent time period. These transition frequencies were generated by examining the change in the categorical ADL/IADL support variables from one observation to the next period (Cameron & Trivedi, 2010; StataCorp, 2013a). Transitions are not counted for values that change from non-missing to missing or from missing to non-missing (StataCorp, 2013a). Although no statistical tests are associated with these descriptive frequencies (Cameron & Trivedi, 2010), these figures provide additional descriptive information on the stability of helper support across time in this longitudinal sample of older adults with dementia and functional limitations.

Bivariate Tests

Baseline differences between R,N; R,A; and U residence groups were tested via bivariate one-way analysis of variance (ANOVA) tests and Chi-square, or Fisher's exact tests as appropriate for expected cell counts less than five, and are described. The Bonferroni correction (i.e., multiplied unadjusted p values from pairwise tests by the total number of pairwise tests (three in this case) and compared to alpha=0.05), which controls the family-wise error rate, was implemented for post-hoc multiple pairwise comparisons (McDonald, 2009; McDonald, 2013). Although pooled group means and proportions are also provided across rural and urban residence categories, statistical tests of bivariate associations were not applied for pooled values because these tests ignore the time-dependent structure of the data by assuming independence and do not account for correlation across observations.

Multivariable Regression Models

A key goal of this longitudinal study was to assess the presence of temporal trends. Accordingly, descriptive analyses using multivariable generalized linear models (GLMs) using a generalized estimating equation (GEE) approach were applied to describe

associations between rural vs. urban residence and functional limitation and community-based support outcomes over time. Average marginal effects are reported. GEE was applied rather than pooled regression models with post-estimation adjustment for clustering for efficiency gains (Hanley, Negassa, Deb Edwardes, & Forrester, 2003). In a pooled regression approach, models are estimated ignoring any clustering, and post-estimation sandwich standard errors that control for clustering are computed. GEE accounts for the correlation structure while fitting model parameter estimates (Cameron & Miller, 2010). Unlike the bivariate tests, these models examine associations while accounting for the repeated measures study design and correlation across observations.

For the outcomes *total number of ADL/IADL difficulties (range: 1-12,* and *number of ADLs (range: 0-6), number of IADLs (range: 0-6)*, multivariable GLMs using a GEE approach with Gaussian distribution and identity link were used to assess temporal trends for rural and urban residence categories. Deviance goodness-of-fit tests conducted post-estimation of pooled Poisson regression models with standard error adjustment for clustering for the count variables *total number of ADL/IADL difficulties, number of ADLs,* and *number of IADLs* strongly rejected the null of Poisson distribution (i.e., *p*<0.001) (Rodriquez, 2007). Therefore, these three continuous measures were modeled via a Gaussian distribution. The statistical model estimated for these outcomes is depicted in Equation 1. Main and interaction effects for rural vs. urban residence and time (i.e., study year) in these linear models were examined. No additional covariates were included in the models because the purpose of these regressions was to describe temporal relationships between rural-urban residence and the outcomes. Regression coefficients in these models represent average marginal effects, or the average expected change in the mean per unit change in the predictors. Linear predictive

marginal means for each outcome were graphed over time (i.e., study year) to illustrate change in the mean number of difficulties for each residence group.

Equation 1: $E(Y_{it}) = X_{it}\beta$, where

Y_{it} represents the continuous outcomes of *total number of ADL/IADL*

difficulties, number of ADLs, and number of IADLs as separate models were

run for each outcome;

i=individual;

t=time;

X_{it}' represents the predictors rural vs. urban residence, study year

(continuous), and the interaction of rural-urban residence and time; and β

represents the coefficients for the predictors in X_{it}'.

The deviance goodness-of-fit test of the null hypothesis that the *number of reported*

ADL/IADL helpers (range: 1-8) was Poisson-distributed following a pooled Poisson

regression with standard error adjustment for clustering was not rejected ($p>0.99$)

(Rodriguez, 2007) and, as such, this measure was modeled as a count outcome using a GEE

approach with Poisson distribution and log link. The statistical model estimated for this

outcome is depicted in Equation 2. Similarly, main and interaction effects for rural vs. urban

residence and time (i.e., study year) in this log-linear count outcome model were examined.

Here, regression coefficients represent the average expected change in the log of the mean

per unit change in the predictors. Exponentiated linear predictive marginal means for each

outcome were graphed over time to illustrate change in the mean number of reported helpers

over the study period within each residence group.

Equation 2: $\log(E(Y_{it}))=(X_{it}\beta)$, where

Y_{it} represents the count outcome of *total number of reported ADL/IADL*

helpers;

i=individual;

t=time;

X_{it} represents the predictors rural vs. urban residence, study year (continuous),

and the interaction of rural-urban residence and time;

and β represents the coefficients for the predictors in X_{it}.

Correlation Structure

For all GLMs using a GEE approach in this aim, a compound symmetry or "exchangeable" correlation structure was applied. This correlation assumes that the correlation between observations on the same unit, individuals in this case, is the same across all time points. Although the unstructured correlation assumption does not place restrictions on the nature of the association among observations over time, this correlation structure estimates a larger number of parameters (i.e., it estimates all correlations separately), whereas the exchangeable correlation assumes the same correlation across all observations and uses fewer degrees of freedom (Hanley, Negassa, Deb Edwardes, & Forrester, 2003). Comparisons of the quasi-likelihood under the independence model criterion (Pan, 2001) for all models of an exchangeable correlation versus an unstructured correlation revealed no significant improvement in model fit using an unstructured correlation. Given these findings along with the modest sample size, the exchangeable correlation was implemented. In addition, the covariance matrix was modified to be robust (Pan, 2001), or allow for proper estimation in the event that the selected correlation matrix is incorrect, via the application of

Huber-White robust standard errors (Edwards, 2000; StataCorp. 2013b). As such, the exchangeable correlation with robust standard errors was applied for all GLMs using a GEE approach.

Results were considered statistically significant at the 95% significance level. Data for all study aims were analyzed using StataCorp 12.

Aim 1b Methods

This aim directly examines rural vs. urban disparities in community-based helper support for ADL/IADL limitations by examining the presence of ADL/IADL support gaps. As in Aim 1a, Aim 1b analyses were limited to beneficiaries who completed community component interviews (rather than facility component interviews) and report at least one ADL/IADL limitation across all four study years because helper questions included in the Health Status and Functioning Questionnaire were only posed to community-dwelling respondents who reported functional limitations.

Defining Support Gaps

Reported support for each specific functional limitation was examined to create the support gaps measure. To examine support gaps, for each beneficiary, each reported ADL/IADL difficulty was compared to reported support for that specific difficulty and assessed for incongruence. The presence of a support gap was noted where a given ADL or IADL limitation was reported but the sample person/proxy reported that no help was received with the limitation, there were no reported helpers for that ADL or IADL, and no special equipment was reported (for ADLs only) and was documented for each person. A beneficiary received a '1' for the dichotomous variable of *any support gaps* if any of their reported ADLs/IADLs met the aforementioned criteria for a support gap.

The outcome variable "any ADL/IADL support gaps" draws from the literature on treatment gaps and unmet needs for functional limitations. In the literature, treatment gaps represent the absolute difference between the true prevalence of a disorder and the treated proportion of individuals affected by the disorder (Kohn, Saxena, Levav, & Saraceno, 2004). The treatment gap may alternatively be expressed as the percentage of individuals who require care but do not receive treatment (Kohn et al., 2004). Similarly, this study proposes that a support gap may be expressed as the percentage of individuals in the sample of persons who report either ADL or IADL difficulties in this case but who reportedly do not report receiving any help, either from individuals or special equipment (ADLs only) for any of those identified difficulties. Each ADL/IADL and associated reporting of support was assessed separately to identify ADL/IADL-specific gaps. Then an indicator variable denoting whether any such gaps were present was created.

Many older adults with reported ADL/IADL difficulties and an expressed need for assistance with those difficulties but with no reported support for those difficulties are considered to have *unmet functional needs*. Unmet functional needs are associated with negative consequences such as being unable to eat when hungry and experiencing discomfort due to no help with getting to the bathroom (Desai, Lentzner, & Weeks, 2001; LaPlante, Kaye, Kang, & Harrington, 2004). Lack of support for functional limitations, without expressed need for such help, has also been referred to as unmet needs in the literature using the MCBS (Arbaje et al., 2008). The MCBS does not include questions on a beneficiary's expressed level of need in terms of the ADL/IADL difficulties assessed. However, the assessment questions for these limitations included the term "due to a health problem,"

suggesting that respondents attribute these difficulties to a health deficit (e.g., disease, condition, disability).

Despite the inclusion of this term in the assessment questions, it cannot be assumed that the specified limitations are solely due to complications from dementia. There may be other unmeasured health conditions or circumstances to which these limitations may be attributed. Further, the presence of limitations in the ability to perform everyday activities among older persons does not necessarily imply that these limitations are a direct consequence of psychiatric disorders, especially age-related psychiatric disorders such as dementia (Wilms, Kanowski, & Baltes, 2000). Such limitations may be due to age-related effects such as a decline in physical health or mobility or are a consequence of the aging process (Wilms, Kanowski, & Baltes, 2000). Correspondingly, in that functional impairments may not necessarily be due to dementia, not all beneficiaries with dementia who report ADL/IADL functional limitations may necessarily *need* help with those difficulties. Although expressed need for assistance is not explicitly available in this study based on the assessment questions, the reporting of experiencing difficulty with or not being able to perform a daily task because of a health problem, particularly among older persons who may have more advanced cognitive impairment (functional impairment is consistently used as a measure of dementia severity (Moore, Zhu, & Clipp, 2001)), signifies a functional deficit that could have a significant impact on quality of life. Furthermore, in a recent report published by the MCBS examining functional difficulties and helpers among Medicare beneficiaries, the lack of reported help for ADLs/IADLs is referred to as a potential unmet need (CMS, 2014). Correspondingly, in this study, lacking (i.e., not reporting) direct assistance for

functional deficits could represent unmet support needs. However, this cannot be confirmed in this study.

Proportions and Bivariate Tests

Similar to Aim 1a, the prevalence of support gaps across rural and urban residence is described. Additionally, bivariate tests using Chi-square or Fisher's exact tests, as appropriate, were conducted to examine baseline rural vs. urban group differences in the prevalence of ADL/IADL support gaps.

Multivariable Regression Models

Because disparities refer to the aspects of observed group differences that are unfair, meaning that not all differences necessarily denote disparities (Le Cook, McGuire, & Zuvekas, 2009), it is important for researchers to account for this distinction by going beyond simple unadjusted difference measures of disparity and applying statistical modeling techniques such as multiple regression analyses that control for influential demographic and socioeconomic status measures such as age, sex, income, and education (Le Cook, McGuire, & Zuvekas, 2009).

As such, for the dichotomous outcome variable of *any IADL/ADL support gaps*, multivariable GLMs using a GEE approach (accounts for correlation across observations) with a binomial distribution, logit link function, exchangeable correlation structure, and robust standard errors were applied for each dichotomous support gap outcome (i.e., *any ADL/IADL support gaps, any ADL gaps,* and *any IADL gaps*). Results from this marginal model were interpreted as population-averaged. The statistical model estimated is depicted in Equation 3.

Equation 3: $E(Y_{it}=1)=f[X_{it}\beta]$, where

Y_{it} represents the binary outcomes of *any ADL/IADL support gaps, any ADL*

gaps, and *any IADL gaps*, as separate models were run for each outcome;

i=individual;

t=time;

X_{it} represents a vector of predictors, including rural vs. urban residence and

other demographic, socioeconomic, and health status variables;

and β is a vector of coefficients for the predictors in X_{it}.

These other predictors include: 1) demographic variables (i.e., age, sex, race,

ethnicity, marital status, and living situation); 2) socioeconomic variables (i.e., income,

education, Medicaid participation); and 3) health status variables (i.e., general health status

rating and number of co-morbidities). Study year and a MCBS panel indicator (i.e., year of

entry into the MCBS) were also included as predictors to assess temporal and study panel

variation.

Multiple Imputation

Multiple imputation was applied to replace missing values for four variables included

in the regression models: rural vs. urban residence (7 missing), income (15 missing),

education (34 missing), and general health status rating (8 missing). The percent missing for

each of these variables is 0.46%, 0.99%, 2.25%, and 0.53%, respectively (out of 1509

observations). Multiple imputation assumes that the data are missing at random and ignorable

after controlling for relevant auxiliary variables measured in the survey (Brick & Kalton,

1996). Under this assumption, the purpose of multiple imputation is to produce more

efficient and less biased parameter estimates than would be produced using complete case

analysis (Royston & White, 2011). The multiple imputation procedure imputes missing values based on other non-missing characteristics in the data. Several replications are created so that better variance estimates can be obtained. Based on results from Monte Carlo simulations testing different multiple imputation models, Graham, Olchowski, and Gilreath (2007) suggest that the number of imputations selected should be based on the fraction of missing information and tolerance for reduction in power. For 10% missing information and a one-percent reduction in power compared to using 100 imputations, 20 replications or imputations should be applied (Graham, Olchowski, & Gilreath, 2007). Because the fraction of missing information is less than 10% for each of the missing values, 20 replications or imputations were implemented in this analysis.

Missing values for these categorical variables were imputed using the multiple imputation using chained equations (i.e., MICE) or sequential regression imputation technique (Royston & White, 2011; StataCorp., 2013c). MICE imputes multiple variables iteratively using a sequence of univariate imputation models; there is a separate model for each imputation variable (Royston & White, 2011; StataCorp., 2013c). This method allows variable-by-variable specification for the imputation of variables of different types by selecting the appropriate imputation method for each variable and accommodates monotone or arbitrary missing data patterns. As such, missing values for the categorical variables rural vs. urban residence and general health status rating and the dichotomous income and education variables were imputed using the chained equations method via multinomial logistic regression and logistic regression, respectively. Standard errors were obtained using sampling with replacement via the bootstrap method. Estimates for both the non-imputed and

imputed GEE estimation models are provided. Results were largely consistent between the non-imputed and imputed GEE models.

Variable Addition Tests for Attrition Bias

As previously mentioned, this sample has attrition, which could introduce bias. Panel studies typically suffer from attrition, which reduces sample size and can result in biased inferences (Verbeek & Nijman, 1992). Simple variable addition tests for unbalanced panel data models with exogenous explanatory variables were applied to test for the presence of selective nonresponse attrition (Verbeek & Nijman, 1992). As prescribed by Verbeek and Nijman (1992), three variables were included in the regression models for each of the assessed outcomes and tested for significance. The three included variables were: 1) a variable indicating the number of years the beneficiary remained in the study, 2) a binary variable indicating whether the beneficiary was observed during the entire study period, and 3) a binary variable indicating whether the beneficiary was observed in the previous study year. Estimates for both the non-imputed and imputed GEE estimation models are provided.

Results

Aim 1a Results

Table 9 includes the number of beneficiaries residing in the community and reporting at least one ADL/IADL functional limitation across rural and urban residence categories. Similar to the full MCBS sample, the majority of beneficiaries in this sample are U residents. Across all study years, among rural residents, more beneficiaries resided in R,A than R,N.

Rural and Urban Differences in ADL/IADL Limitations and Helper Support

Number of ADL and IADL Functional Limitations

Means and standard deviations for the number of reported ADL and IADL difficulties at baseline across rural and urban locales are presented in Table 10. Beneficiaries living in R,N reported significantly lower total number of ADL/IADL difficulties (lower than R,A and U), ADL difficulties alone (lower than R,A), and IADL difficulties alone (lower than R,A and U). A similar pattern is observed for the pooled means (Table 11). Across outcomes, functional limitations were significantly higher among R,A-dwellers compared to beneficiaries living in R,N; however, the R,A group was not significantly different from U-dwellers.

Number of Helpers

This study was limited to beneficiaries with at least one ADL/IADL limitation. At baseline, the number of helpers ranged from one to five (Mean=1.6; *SD*=0.8). The majority of sample beneficiaries reported having one helper (54.6%). However, a substantial portion reported multiple helpers (i.e., 30.9% reported two helpers; 11.5% reported three helpers; 2.3% reported four helpers; and 0.7% reported having five helpers). Living arrangement and marital status differed significantly among those who reported a single vs. multiple ADL/IADL helpers. Fifty-three percent of beneficiaries who lived alone reported having more than one helper compared to 43% of those who did not live alone (*p*=0.03). In addition, 56% of widowed beneficiaries reported having more than one helper compared to 35% of married beneficiaries and 44% of beneficiaries who were divorced, separated, or never married (*p*<0.001). Across rural and urban groups, the mean number of reported ADL/IADL

helpers is approximately two (Tables 12 & 13). There were no statistically significant geographic differences in reported helpers at baseline.

Prevalence of ADL/IADL Difficulties and Associated Support

The proportion of beneficiaries who report each specific ADL difficulty along with the proportion of those with reported support for the ADL difficulty (i.e., among those reporting the difficulty) at baseline and pooled across study years are presented in Tables 14 and 15, respectively. At baseline, the highest reported ADL limitations among the sample were *walking* (64.2%) and *bathing or showering* (58.4%). These difficulties were also most prominent within geographic groups: R,N (*bathing or showering* (54.7%); *walking* (50.0%)); R,A (*walking* (63.3%); *bathing or showering* (62.4%)); and U (*walking* (66.0%); *bathing or showering* (58.0%)). The reporting of difficulty with *dressing* was significantly lower among R,N residents compared to R,A and U residents. A significantly higher proportion of R,A residents reported this difficulty compared to beneficiaries living in R,N and U. Difficulty with *walking* was significantly lower among R,N residents than U residents. Across ADL difficulties, the vast majority of those reporting each difficulty also reported the presence of support for the difficulty. Among the sample at baseline, the presence of support was lowest for the ADL *eating* (83.2%) (R,N: 71.6%; R,A: 87.0%; and U: 83.2%). Walking and bathing were also the most prominent ADL difficulties in the pooled results.

The highest reported IADL difficulty among the sample at baseline was *doing heavy housework* (79.9%) and *shopping for personal items* (70.3%) (Table 16). Within residence groups, the most reported IADL difficulties were: R,N—*doing heavy housework* (68.8%), *managing money/paying bills* (62.5%); R,A—*doing heavy housework* (87.2%), *shopping for personal items* (76.9%)); and U—*doing heavy housework* (79.7%), *shopping for personal*

items (70.2%)). Several significant geographic differences in the reporting of IADL difficulties were present. Difficulty with *doing light housework, doing heavy housework, preparing meals,* and *shopping for personal items* was significantly lower among R,N-dwellers compared to R,A-dwellers; difficulty with *doing light housework* was also significantly lower for R,N residents compared to U residents. The reported presence of support for each IADL difficulty was relatively high (i.e., above 90%) for all IADL difficulties except *using the telephone* (71.6% with reported support). Within residence groups, the reported presence of support for *using the telephone* was lower than for the other IADL difficulties: R,N (68.6%); R,A (80.0%); and U (69.9%). A similar pattern is observed for the pooled means, where the highest reported IADL difficulties were *doing heavy housework* and *shopping for personal items*, with reported support lowest for the IADL *using the telephone* (Table 17).

Sources of Support/Helper Relationships

The majority of beneficiaries with dementia and functional limitations in this study were receiving help or support from either spouses only or adult children only (47.3%), followed by spouses only (24.6%) and adult children only (22.7%) at baseline (Tables 18 & 19). At baseline, reliance on non-kin only as helpers was highest among beneficiaries residing in R,N compared to those living in both R,A and U (14.3% vs. 4.5% and 5.3%, respectively). Non-kin helper support was significantly different between R,N and U residents. Of note, 29% of beneficiaries reported having had at least one paid home healthcare visit at baseline (R,N (23.4%); R,A (25.6%); and U (29.7%)).

Transitions in the Presence and Sources of ADL/IADL Helper Support

Transition frequencies for the reported presence of support for specific ADLs/IADLs and sources of support (i.e., helpers) for ADL/IADL difficulties in the next study period among those who ever reported receiving such support are shown in Table 20. Across rural and urban categories, the reported presence of support for specific ADLs/IADLs remained fairly stable from one year to the next among those ever reporting each type of support. The lowest percentages for continued support in the next study year among those ever reporting support for the limitation applied to the IADL of *using the telephone* in the rural categories. Twenty-four percent of persons living in R,N who ever reported having support for using the telephone reported not having support for that IADL in the next study year. Twenty-three percent of those residing in R,A lost support for this IADL in the next study year. In comparison, 18% of urban residents lost support for this IADL in the next study year.

Shifts in sources of support from one period to the next among those ever reporting that specific source of support were more pronounced. Continued support from spouses only among those ever reporting spousal help was highest among R,N residents (82.6%). However, fewer R,N residents reported continued support from adult children only in the next study period among those ever reporting such support compared to the other residence groups (R,N (58.3%) vs. R,A (75.0%) and U (74.6%)). The percentage of those still supported by other kin only was highest among those living in R,N (80.0%) and lowest among those living in R,A (42.9%). Continued support from non-kin helpers only in the next study year was lowest among R,A residents (66.7%). Although not directly tied to ADL/IADL helper questions, transitions in paid home health care were also assessed. The percentage of respondents who ever reported receiving paid home health care who also

reported receiving such care in the next study year by residence area were: R,N

(10/15=66.7%); R,A (13/25=52.0%); and U (67/132=50.8%). Overall, these transition

frequencies suggest that the composition of ADL/IADL helper networks, as well as the

receipt of formal care in community residences, among beneficiaries with dementia and

functional limitations are dynamic.

Temporal Trends in ADL/IADL Limitations and Helper Support

Table 21 includes average marginal effects from the multivariable GLMs using a

GEE approach comparing the rural groups to urban residence for the continuous functional

limitation and helper support measures over time; these models only included rural vs. urban

residence and study year variables. Across all outcomes, there was a statistically significant

positive time trend. On average, the number of functional limitations (i.e., total limitations,

ADLs alone, and IADLs alone) and helpers increased significantly over time among the

sample. Further, on average, the number of IADLs was significantly lower among those

living in R,N compared to U communities. Residential area was not significantly associated

with a change in the number of ADL/IADL helpers over time, on average.

Means for each outcome and residence group were plotted over time and are depicted

in Figures 2–5. As illustrated in Figure 2, the mean total number of ADL/IADL limitations is

increasing over time across all residence groups and is highest among R,A residents across

all study years. The mean total number of ADL/IADL limitations is significantly lower

among R,N residents at baseline compared to the other two residence groups. As indicated by

overlap of the confidence intervals, there is no significant difference between the groups in

the other time periods. In Figure 3, it is evident that the mean number of ADLs is increasing

over time across all three residence groups. The mean number of ADLs is significantly lower

among R,N residents at baseline. No significant group differences are present in subsequent study years. The mean number of ADLs is also increasing faster among these residents than for the other two groups, as indicated by the sharp positive slope. Similarly, in Figure 4, the mean number of IADLs is increasing over time across all residence groups. At baseline, the mean number of IADLs among R,N-dwellers is significantly lower compared to R,A and U beneficiaries; this difference does not persist over time. Across all study years, the mean number of reported ADL/IADL helpers is not significantly different between the three residence groups at baseline (Figure 5). However, the rate of increase in the mean number of helpers is significantly higher among U residents than for rural-dwellers in the community with dementia and functional limitations.

Table 9. Community-Dwelling Beneficiaries with At Least One ADL/IADL Limitation across Study Years and Rural vs. Urban Residence, N (%)

	Study Year 1	Study Year 2	Study Year 3	Study Year 4	*Total*
Rural, Not adjacent to a metro or micro area (R,N)	64 (8.9)	37 (9.7)	24 (10.0)	19 (11.6)	144 (9.6)
Rural, adjacent to a metro or micro area (R,A)	117 (16.3)	60 (15.8)	38 (15.8)	27 (16.5)	242 (16.1)
Urban (U)	536 (74.8)	284 (74.5)	178 (74.2)	118 (72.0)	1,116 (74.3)
Total	717	381	240	164	1,502

Table 10. Reported Number of ADL/IADL Limitations at Baseline, Mean (*SD*)

(N=717)	Total Number of ADL/IADL Limitations	Total Number of ADL Limitations	Total Number of IADL Limitations
Rural, Not adjacent to a metro or micro area (R,N) n=64	5.2 (3.3)	3.4 (2.1)	1.9 (1.7)
Rural, adjacent to a metro or micro area (R,A) n=117	7.0 (3.6)	4.3 (1.8)	2.7 (2.1)
Urban (U) n=536	6.5 (3.5)	3.9 (2.0)	2.6 (2.0)
Total	6.5 (3.5)	3.9 (2.0)	1.9 (1.7)
p-value	**Test of association:** 0.004**	**Test of association:** 0.010**	**Test of association:** 0.015*
	Test of direction of association: R,N vs. R,A 0.003**	**Test of direction of association:** R,N vs. R,A 0.008**	**Test of direction of association:** R,N vs. R,A 0.018*
	R,N vs. U 0.023*		R,N vs. U 0.023*

Notes. *p* values correspond to one-way analysis of variance (ANOVA) tests with Bonferroni correction for rural vs. urban between group differences in means. Reported number of difficulties out of a possible 12 total ADL (6) and IADL (6) difficulties.
*p <0.05
**p<0.01
***p<0.001

Table 11. Reported Number of ADL/IADL Limitations: Pooled, Mean (*SD*)

N=1502	Total Number of ADL/IADL Limitations	Total Number of ADL Limitations	Total Number of IADL Limitations
Rural, Not adjacent to a metro or micro area (R,N) n=144	6.0 (3.7)	3.8 (2.1)	2.2 (2.1)
Rural, adjacent to a metro or micro area (R,A) n=242	6.8 (3.6)	4.2 (1.8)	2.7 (2.1)
Urban (U) n=1116	6.6 (3.6)	4.0 (2.0)	2.7 (2.1)
Total	6.6 (3.6)	4.0 (2.0)	2.6 (2.1)

Note. Reported number of difficulties out of a possible 12 total ADL (6) and IADL (6) difficulties.

Table 12. Reported Number of ADL/IADL Helpers at Baseline, Mean (*SD*)

	Study Year 1 N=686	*p*-value
Rural, Not adjacent to a metro or micro area (R,N) **n=63**	1.6 (0.7)	Test of association: 0.669
Rural, adjacent to a metro or micro area (R,A) **n=112**	1.7 (0.9)	
Urban (U) **n=511**	1.6 (0.8)	
Total	1.6 (0.8)	

Notes. Column *P* values correspond to one-way analysis of variance (ANOVA) test.
*p <0.05
**p<0.01
***p<0.001

Table 13. Reported Number of ADL/IADL Helpers: Pooled, Mean (*SD*)

	All Years N=1442
Rural, Not adjacent to a metro or micro area (R,N) **n=142**	1.6 (0.8)
Rural, adjacent to a metro or micro area (R,A) **n=229**	1.7 (0.9)
Urban (U) **n=1071**	1.7 (0.9)
Total	1.7 (0.9)

Table 14. Reported ADL Difficulties and Reported Support at Baseline, N (%)

ADLs		Study Year 1 N=717				
		R,N n=64	R,A n=117	U n=536	Total	*p*-value
Bathing or showering	**Reported Difficulty**	35 (54.7)	73 (62.4)	311 (58.0)	419 (58.4)	0.559
	Reported Support	35 (100.0)	71 (97.3)	295 (94.9)	401 (95.7)	0.455[a]
Dressing	**Reported Difficulty**	16 (25.0)	65 (55.6)	227 (42.4)	308 (43.0)	**Test of association:** <0.001*** **Test of direction of association:** R,N vs. U: 0.021* R, A vs. U: 0.03* R,N vs. R,A: <0.001***
	Reported Support	15 (93.8)	62 (95.4)	215 (94.7)	292 (94.8)	0.900[a]
Eating	**Reported Difficulty**	7 (10.9)	23 (19.7)	101 (18.8)	131 (18.3)	0.276
	Reported Support	5 (71.6)	20 (87.0)	84 (83.2)	109 (83.2)	0.681[a]
Getting in or out of bed or chairs	**Reported Difficulty**	18 (28.1)	53 (45.3)	233 (43.5)	304 (42.4)	0.050
	Reported Support	13 (72.2)	48 (90.6)	203 (87.1)	264 (86.8)	0.146[a]
Walking	**Reported Difficulty**	32 (50.0)	74 (63.3)	354 (66.0)	460 (64.2)	**Test of association:** 0.040*

ADLs		R,N n=64	R,A n=117	U n=536	Total	*p*-value
						Study Year 1 N=717
						Test of direction of association:
						R,N vs. U: 0.033*
	Reported Support	25 (78.1)	68 (92.0)	306 (86.4)	399 (86.7)	0.146[a]
Using the toilet	**Reported Difficulty**	12 (18.8)	33 (28.2)	164 (30.6)	209 (29.2)	0.139
	Reported Support	11 (91.7)	32 (97.0)	145 (88.4)	188 (90.0)	0.321[a]

Notes. Rural/urban proportions are among the total in the respective rural/urban category. Among those reporting the difficulty, the number and percentage of those reporting support for that difficulty are provided. Column *p* values correspond to Chi-square or Fisher's Exact Tests for rural vs. urban between group differences in proportions (overall test of association) with Bonferroni-corrected *p* values for pairwise comparisons.
[a]Fisher's exact test
 *p <0.05
** p<0.01
*** p<0.001

Table 15. Reported ADL Difficulties and Reported Support: Pooled, N (%)

ADLs		All Years N=1502			
		R,N n=144	R,A n=242	U n=1116	Total
Bathing or showering	**Reported Difficulty**	82 (56.9)	142 (58.7)	644 (57.7)	868 (57.8)
	Reported Support	79 (96.3)	138 (97.2)	621 (96.4)	838 (96.5)
Dressing	**Reported Difficulty**	47 (32.6)	128 (52.9)	503 (45.1)	678 (45.1)
	Reported Support	45 (95.7)	120 (93.8)	480 (95.4)	645 (95.1)
Eating	**Reported Difficulty**	24 (16.7)	48 (19.8)	225 (20.2)	297 (19.8)
	Reported Support	20 (83.3)	42 (87.5)	197 (87.6)	259 (87.2)
Getting in or out of bed or chairs	**Reported Difficulty**	47 (37.6)	106 (43.8)	512 (45.9)	665 (44.3)
	Reported Support	39 (83.0)	94 (88.7)	440 (85.9)	573 (86.2)
Walking	**Reported**	75 (52.1)	153	734	962

ADLs		R,N n=144	R,A n=242	U n=1116	Total
	Difficulty		(63.2)	(65.8)	(64.1)
	Reported Support	60 (80.0)	138 (90.2)	635 (86.5)	833 (86.6)
Using the toilet	**Reported Difficulty**	38 (26.4)	66 (27.3)	343 (30.7)	447 (29.8)
	Reported Support	37 (97.4)	57 (86.4)	306 (89.2)	400 (89.5)

Notes: Rural/urban proportions are among the total in the respective rural/urban category. Among those reporting the difficulty, the number and percentage of those reporting support for that difficulty are provided.

Table 16. Reported IADL Difficulties and Reported Support at Baseline, N (%)

IADLs		R,N n=64	R,A n=117	U n=536	Total	p-value
			Study Year 1 N=717			
Using the telephone	**Reported Difficulty**	35 (54.7)	65 (55.6)	259 (48.3)	359 (50.1)	0.271
	Reported Support	24 (68.6)	52 (80.0)	181 (69.9)	257 (71.6)	0.248
Doing light housework	**Reported Difficulty**	25 (39.1)	72 (61.5)	308 (57.5)	405 (56.5)	**Test of association:** 0.009** **Test of direction of association:** R,N vs. U: 0.015* R,N vs. R,A: 0.012*
	Reported Support	25 (100.0)	64 (88.9)	283 (91.9)	372 (91.9)	0.219[a]
Doing heavy housework	**Reported Difficulty**	44 (68.8)	102 (87.2)	427 (79.7)	573 (79.9)	**Test of association:** 0.012* **Test of direction of association:** R,N vs. R,A: 0.009*
	Reported Support	43 (97.7)	88(86.3)	385 (90.2)	516 (90.1)	0.092[a]
Preparing meals	**Reported Difficulty**	33 (51.6)	84 (71.8)	336 (62.7)	453 (63.2)	**Test of association:** 0.023*

	IADLs	R,N n=64	R,A n=117	U n=536	Total	p-value
						Study Year 1 N=717
						Test of direction of association: R,N vs. R,A: 0.018* 0.049*[a,b]
	Reported Support	33 (100.0)	75 (89.3)	319 (94.9)	427 (94.3)	
Shopping for personal items	**Reported Difficulty**	38 (59.4)	90 (76.9)	376 (70.2)	504 (70.3)	**Test of association:** 0.047*
						Test of direction of association: R,N vs. R,A: 0.039*
	Reported Support	38 (100.0)	82 (91.1)	360 (95.7)	480 (95.2)	0.074[a]
Managing money (paying bills)	**Reported Difficulty**	40 (62.5)	88 (75.2)	372 (69.4)	500 (69.7)	0.194
	Reported Support	40 (100.0)	84 (95.5)	361 (97.0)	485 (97.0)	0.421[a]

Notes. Rural/urban proportions are among the total in the respective rural/urban category. Among those reporting the difficulty, the number and percentage of those reporting support for that difficulty are provided. Column p values correspond to Chi-square or Fisher's Exact Tests for rural vs. urban between group differences in proportions (overall test of association) with Bonferroni-corrected p values for pairwise comparisons.
[a]Fisher's exact test
[b] Pairwise Bonferroni-corrected p values not statistically significant at alpha=0.05.
 *$p < 0.05$
** $p < 0.01$
*** $p < 0.001$

Table 17. Reported IADL Difficulties and Reported Support: Pooled, N (%)

IADLs		All Years N=1502			
		R,N n=144	R,A n=242	U n=1116	Total
Using the telephone	**Reported Difficulty**	83 (57.6)	128 (52.9)	552 (49.5)	763 (50.8)
	Reported Support	61 (73.5)	94 (73.4)	389 (70.5)	544 (71.3)
Doing light housework	**Reported Difficulty**	66 (45.8)	149 (61.6)	679 (60.8)	894 (59.5)
	Reported Support	64 (97.0)	135 (90.6)	628 (92.5)	827 (92.5)
Doing heavy housework	**Reported Difficulty**	113 (78.5)	210 (86.8)	904 (81.0)	1227 (81.7)
	Reported Support	105 (92.9)	186 (88.6)	820 (90.7)	1111 (90.6)
Preparing meals	**Reported Difficulty**	82 (56.9)	166 (68..6)	716 (64.2)	964 (64.2)
	Reported Support	78 (95.1)	152 (91.6)	677 (94.6)	907 (94.1)

IADLs		All Years N=1502			
		R,N n=144	R,A n=242	U n=1116	Total
Shopping for personal items	**Reported Difficulty**	99 (68.8)	188 (77.7)	815 (73.0)	1102 (73.4)
	Reported Support	96 (97.0)	173 (92.0)	781 (95.8)	1050 (95.3)
Managing money (paying bills)	**Reported Difficulty**	103 (71.5)	168 (69.4)	785 (70.3)	1056 (70.3)
	Reported Support	100 (97.1)	162 (96.4)	758 (96.6)	1020 (96.6)

Notes: Rural/urban proportions are among the total in the respective rural/urban category. Among those reporting the difficulty, the number and percentage of those reporting support for that difficulty are provided.

Table 18. Sources of Support for IADL/ADL Limitations at Baseline, N (%)

	Study Year 1 N=688				
	R,N **n=63**	**R,A** **n=112**	**U** **n=513**	**Total**	*p*-value
Spouses only	17 (26.6)	31 (26.5)	123 (23.0)	171 (24.6)	0.656
Adult Children only	9 (14.1)	24 (20.5)	123 (23.0)	156 (22.7)	0.210
Other Kin only	5 (7.8)	5 (4.3)	37 (6.9)	47 (6.8)	0.542[a]
Non-Kin only	9 (14.3)	5 (4.5)	27 (5.3)	41 (6.0)	**Test of association:** 0.026*[a] **Test of direction of association:** R,N vs. U: 0.033*
Multiple sources/helper relationships	23 (35.9)	47 (40.2)	203 (37.9)	273 (39.7)	0.774

Notes. Column *p* values correspond to Chi-square or Fisher's Exact Tests for rural vs. urban between group differences in proportions (overall test of association) with Bonferroni-corrected *p* values for pairwise comparisons.
[a]Fisher's exact test
* *p* <0.05
** *p*<0.01
*** *p*<0.001

Table 19. Sources of Support for IADL/ADL Limitations: Pooled, N (%)

	All Years N=1444			
	R,N n=142	R,A n=229	U n=1073	Total
Spouses only	36 (25.4)	57 (24.9)	257 (24.0)	350 (24.2)
Adult Children only	23 (16.2)	52 (22.7)	254 (23.7)	329 (22.8)
Other Kin only	12 (8.5)	14 (6.1)	71 (6.6)	97 (6.7)
Non-Kin only	17 (12.0)	10 (4.4)	62 (5.8)	89 (6.2)
Multiple sources/helper relationships	54 (38.0)	96 (41.9)	429 (40.0)	579 (40.1)

Table 20. Transition Frequencies for the Presence and Sources of Community-based Support for ADLs/IADLs, N (%)

	Rural, not adjacent to a metro or micro area (R,N)	Rural, adjacent to a metro or micro area (R,A)	Urban (U)
Support for ADLs			
Bathing or Showering	35/36 (97.2)	51/51 (100.0)	242/244 (99.2)
Dressing	20/20 (100.0)	35/37 (94.6)	186/188 (98.9)
Eating	8/8 (100.0)	9/9 (100.0)	50/51 (98.0)
Getting in or out of bed or chairs	15/17 (88.2)	23/27 (85.2)	157/170 (92.4)
Walking	20/21 (95.2)	52/57 (91.2)	241/260 (92.7)
Using the toilet	17/17 (100.0)	13/15 (86.7)	90/98 (91.8)

	Rural, not adjacent to a metro or micro area (R,N)	Rural, adjacent to a metro or micro area (R,A)	Urban (U)
Support for IADLs			
Using the telephone	22/29 (75.9)	24/31 (77.4)	122/149 (81.9)
Doing light housework	23/25 (92.0)	46/48 (95.8)	252/258 (97.7)
Doing heavy housework	42/47 (89.4)	76/79 (96.2)	347/366 (94.8)
Preparing meals	27/29 (93.1)	59/61 (96.7)	267/274 (97.5)
Shopping for personal items	40/43 (93.0)	69/70 (98.6)	343/350 (98.0)
Managing money (paying bills)	49/52 (94.2)	68/69 (98.6)	320/328 (97.6)
Sources of Support for ADL & IADL Limitations: Community-Based Helpers			
Spouses only	19/23 (82.6)	23/30 (76.7)	102/128 (79.7)
Adult Children only	7/12 (58.3)	18/24 (75.0)	97/130 (74.6)
Other Kin only	4/5 (80.0)	3/7 (42.9)	24/31 (77.4)
Non-Kin only	7/9 (77.8)	2/3 (66.7)	19/22 (86.4)
Multiple sources/helper relationships	21/28 (75.0)	31/45 (68.9)	157/214 (73.4)

Notes. Denominators represent those who ever reported receiving support for each difficulty and from each source among those who remained in the study in the next study period. For ADL/ IADL support: Applies to beneficiaries who also reported the difficulty in the subsequent time period.

Table 21. Rural vs. Urban Differences and Temporal Trends in the Number of Functional Limitations and Reported Helpers , Average Marginal Effects (Standard Errors)

	Number of ADL/IADL Difficulties	Number of ADLs	Number of IADLs	Number of ADL/IADL Helpers
R,N	-0.821	-0.256	-0.542[*]	-0.0763
	(0.432)	(0.240)	(0.246)	(0.0971)
R,A	0.446	0.279	0.165	-0.00515
	(0.348)	(0.176)	(0.202)	(0.0820)
Study Year	0.396[***]	0.182[***]	0.189[***]	0.0457[*]
	(0.0703)	(0.0420)	(0.0424)	(0.0192)
Observations	1502	1502	1502	1442

Notes. Referent category is Urban. All models are Gaussian-distributed except the *number of ADL/IADL helpers* outcome model, which is Poisson-distributed.

No additional covariates are included in the models.

[*] $p < 0.05$

[**] $p < 0.01$

[***] $p < 0.001$

Figure 2. Mean total number of ADL/IADL difficulties over time across rural and urban residence.
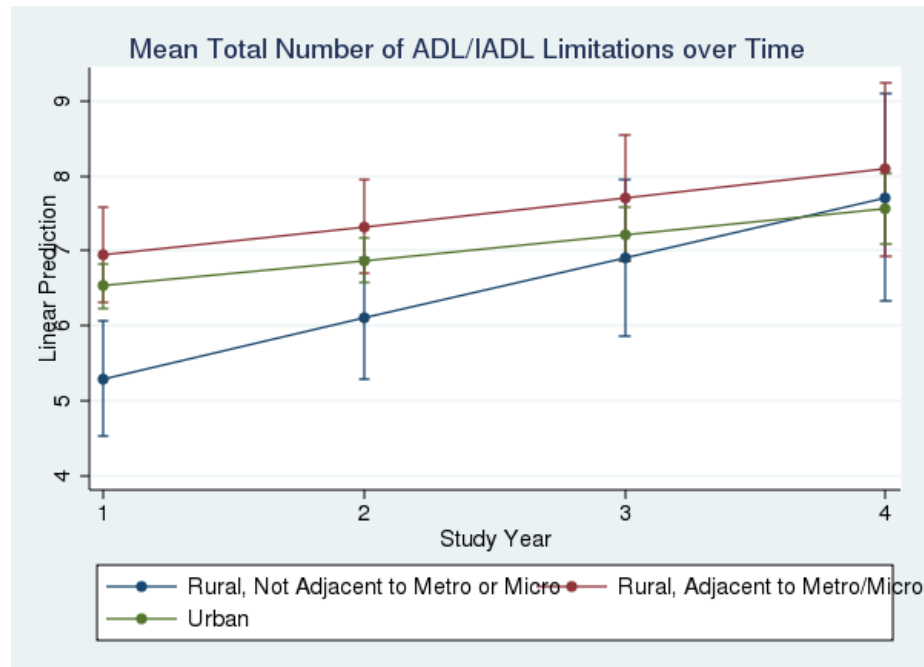
Figure 3. Mean total number of ADL difficulties over time across rural and urban residence.
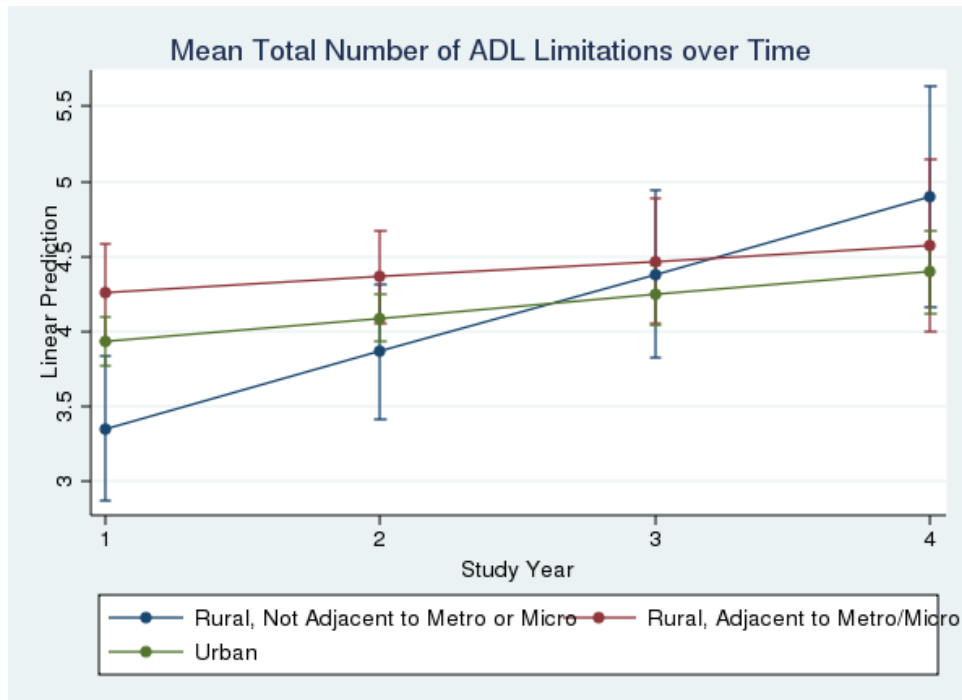
Figure 4. Mean total number of IADL difficulties over time across rural and urban residence.
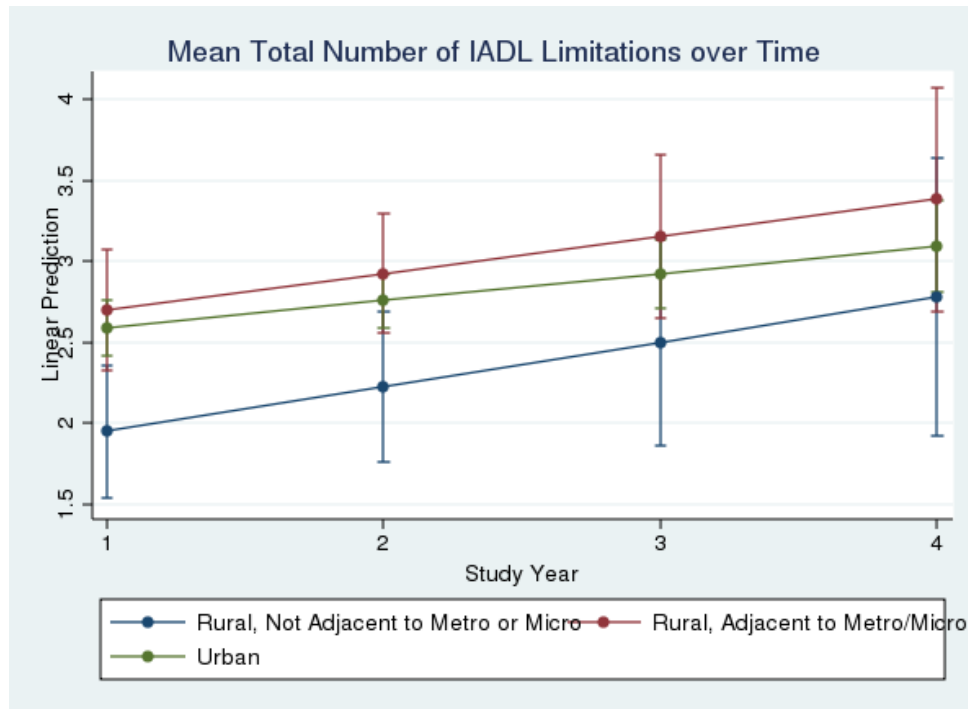
Figure 5. Mean total number of ADL/IADL helpers over time across rural and urban residence.
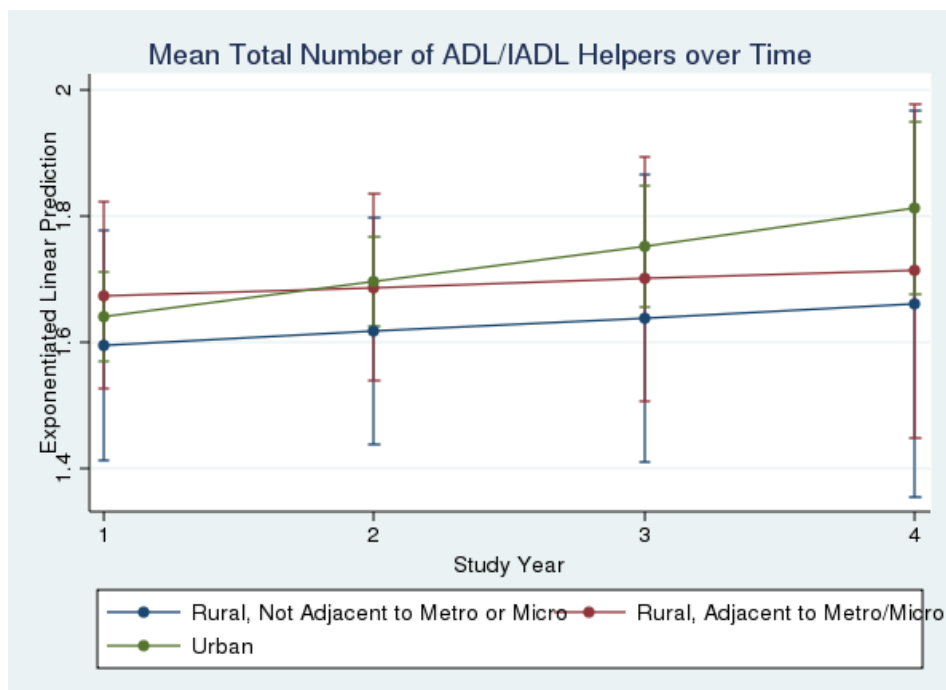
Aim 1b Results

The second part of this aim sought to directly examine the presence of rural vs. urban disparities in support for ADLs/IADLs by assessing support gaps, controlling for key demographic, socioeconomic, and health status factors. These characteristics are described in Table 22. Across study years, the majority of the sample was female; White; widowed, with an annual total household income of $25,000 or less, a high school diploma or greater, no Medicaid participation during the year, did not live alone, and reported *good* general health status rating. On average, beneficiaries were in their early 80s, had close to two comorbidities, and just over six total ADL/IADL functional limitations.

Prevalence of Support Gaps

Thirty-percent of beneficiaries had at least one ADL or IADL support gap at baseline. Overall, no statistically significant differences in the presence of support gaps across rural and urban categories were found. Within residence groups, the prevalence of support gaps was slightly higher, but not statistically different, among R,N residents (32.8%) compared to R,A (27.4%) and U (29.9%) residents (Table 23); pooled results were similar (Table 24). As illustrated in Figure 6, the prevalence of support gaps among the study sample fluctuated across study years for each residence category. Among R,N residents, the prevalence of support gaps notably increased from baseline to year two (33% to 43%, respectively) and decreased from year three to year four (38% to 11%, respectively). This fluctuation is attributed to the reduced sample size in follow-up years, particularly among the rural groups. Among beneficiaries reporting any ADL/IADL support gaps, the highest reported ADL with gaps in support was *walking* (23.5%) and the highest reported IADL with gaps in support was *using the telephone* (44.6%) (Table 25). Additionally, the prevalence of gaps in support

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for the IADL *doing light housework* was significantly higher among R,A residents than R,N residents reporting support gaps. Shopping for personal items was significantly higher in R,A than U.

Similar to the overall sample, within rural and urban residence groups, the highest reported ADL with gaps in support was *walking* (R,N (33.3%); R,A (18.8%); and U (23.1%)) and the highest reported IADL with gaps in support was *using the telephone* (R,N (47.6%); R,A (40.6%); and U (45.0%)). Across each residence category, the next highest reported ADL with gaps in support was *getting in or out of bed or chairs* (R,N (23.8%); R,A (12.5%); and U (13.1%)) and the second highest reported IADL with gaps in support was *doing heavy housework* (R,N (4.8%); R,A (28.1%); and U (17.5%)).

Examining Geographic Disparities in Support

Similar to bivariate analyses, no rural vs. urban disparities in support gaps were identified in any of the non-imputed regression models after controlling for key demographic, socioeconomic, and health status predictors (Table 26). However, several other factors were significantly associated with the presence or absence of functional support gaps among beneficiaries with dementia, holding all other factors constant. Living alone, on average, was associated with an 8.0 percentage point increase in the probability of having any ADL or IADL support gaps, and a 7.9 percentage point increase in the probability of having any IADL support gaps alone. On average, being Hispanic or Latino was associated with a 20.0 percentage point decrease in the probability of having any ADL/IADL support gaps and 21.6 percentage point decrease in the probability of having any IADL gaps alone. On average, entering the MCBS in later years was associated with a 2.1 percentage point decrease in the probability of having any ADL/IADL support gaps and 1.8 percentage point

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decrease in the probability of having any IADL support gaps alone. On average, a one-year increase in age was associated with a 0.4 percentage point increase in the odds of having any IADL support gaps.

Multiple imputation model estimates for the aforementioned outcomes are presented in Table 27. Results for the multiple imputation models were similar to non-imputed models. Living alone remained positively associated with having any total ADL/IADL support gaps and any IADL support gaps alone. Hispanic or Latino ethnicity remained a protective factor for any ADL/IADL support gaps and any IADL support gaps alone. On average, being Hispanic or Latino was associated with a 17.8 and 17.4 percentage point decrease in the probability of having any ADL/IADL support gaps and any IADL support gaps alone, respectively. As in the non-imputed models, MCBS entry in later years remained associated with reduced probability of any ADL/IADL support gaps and any IADL support gaps alone, on average. Additionally, on average, a one-year increase in age was associated with a 0.4 percentage point increase in the probability of having any IADL support gaps.

Attrition Bias

Results for the non-imputed and imputed GEE estimation models assessing rural vs. urban disparities in support with selectivity variable addition tests are reported in Tables 28 and 29, respectively. In both non-imputed and imputed models, only one of the three selectivity bias test variables was statistically significantly associated with a support gap outcome (i.e., the *total number of years in the study* selection variable was associated with the ADL support gaps outcome). On average, a one-year increase in the total number of years in the MCBS was associated with a 3.5 and 3.8 percentage point increase in the probability of having ADL support gaps in the non-imputed and imputed models, respectively. Overall,

results for the non-imputed and imputed models incorporating attrition were largely similar
to the models excluding the attrition variables (i.e., little to no change in the observed
average marginal effects), suggesting a small bias effect.

Table 22. Characteristics of the Sample: Aim 1b. Demographic, Socioeconomic, and Health
Status Predictors, N (%)

		Study Year 1 N=720	Study Year 2 N=383	Study Year 3 N=241	Study Year 4 N=165
Demographic Characteristics					
Rural vs. Urban Residence					
	R, N	64 (8.9)	37 (9.7)	24 (10.0)	19 (11.6)
	R, A	117 (16.3)	60 (15.8)	38 (15.8)	27 (16.5)
	U	536 (74.8)	284 (74.5)	178 (74.2)	118 (72.0)
Lives alone		194 (26.9)	89 (23.2)	53 (22.0)	43 (26.1)
Age (years), Mean (*SD*)		82.1 (7.3)	82.5 (7.3)	83.2 (7.2)	83.6 (7.3)
Female		456 (63.3)	246 (64.2)	150 (62.2)	100 (60.6)
Race					
	White	500 (69.4)	252 (65.8)	152 (63.1)	107 (64.9)
	African American	78 (10.8)	50 (13.1)	30 (12.5)	20 (12.1)
	More than 1 Race	119 (16.5)	65 (17.0)	46 (19.1)	30 (18.2)
	Other Race	23 (3.2)	16 (4.2)	13 (5.4)	8 (4.9)
Ethnicity: Non- Hispanic or Latino		681 (94.6)	358 (93.5)	228 (94.6)	156 (94.6)
Marital Status					
	Married	309 (42.9)	168 (43.9)	109 (45.2)	69 (41.8)
	Widowed	342 (47.5)	185 (48.3)	114 (47.3)	82 (49.7)
	Divorced	42 (5.8)	17 (4.4)	8 (3.3)	7 (4.2)

	Study Year 1 N=720	Study Year 2 N=383	Study Year 3 N=241	Study Year 4 N=165
Separated	7 (1.0)	4 (1.0)	3 (1.2)	0 (0.0)
Never Married	20 (2.8)	9 (2.4)	7 (2.9)	7 (4.2)
Socioeconomic Characteristics				
Income $25K or Less	493 (69.2)	263 (70.8)	170 (70.5)	111 (67.3)
High School Diploma or Greater	393 (55.8)	195 (52.3)	129 (54.4)	95 (59.0)
No Medicaid Participation during the Year	562 (78.1)	287 (74.9)	174 (72.2)	113 (68.5)
Health Status Characteristics				
Number of co-morbidities, Mean (*SD*)	1.4 (1.0)	1.5 (1.0)	1.7 (1.1)	1.8 (1.1)
General Health Status Rating				
Excellent	51 (7.1)	23 (6.0)	15 (6.3)	7 (4.3)
Very Good	103 (14.4)	51 (13.4)	30 (12.6)	22 (13.4)
Good	219 (30.5)	117 (30.6)	71 (29.8)	58 (35.4)
Fair	182 (25.4)	104 (27.2)	68 (28.6)	48 (29.3)
Poor	162 (22.6)	87 (22.8)	54 (22.7)	29 (17.7)

Notes.
Rural/urban totals across study years: 717, 381, 240, 164.
Income totals across study years: 712, 376, 241, 165.
Education totals across study years: 704, 373, 237, 161.
General Health Status Rating totals across study years: 717, 382, 238, 164.

Table 23. Support Gaps for ADL/IADL Limitations at Baseline, N (%)

	Study Year 1				*p*-value
	R,N **n=64**	**R,A** **n=117**	**U** **n=536**	**Total** **N=717**	
Any ADL/IADL Support Gaps	21 (32.8)	32 (27.4)	160 (29.9)	213 (29.7)	0.736
Any ADL Support Gaps	12 (18.8)	14 (12.0)	82 (15.3)	108 (15.1)	0.454
Any IADL Support Gaps	11 (17.2)	23 (19.7)	100 (18.7)	134 (18.7)	0.920

Notes. Column *p* values correspond to Chi-square Tests for rural vs. urban between group differences in proportions (overall test of association).
* *p* <0.05
** *p*<0.01
*** *p*<0.001

Table 24. Support Gaps for ADL/IADL Limitations: Pooled, N (%)

	All Years			
	R,N **n=144**	**R,A** **n=242**	**U** **n=1116**	**Total** **N=1502**
Any ADL/IADL Support Gaps	48 (33.3)	68 (28.1)	334 (29.9)	450 (30.0)
Any ADL Support Gaps	28 (18.1)	49 (12.4)	218 (15.3)	295 (15.1)
Any IADL Support Gaps	26 (19.4)	30 (20.3)	171 (19.5)	227 (19.6)

Figure 6. Prevalence of ADL/IADL support gaps over time across rural and urban residence.
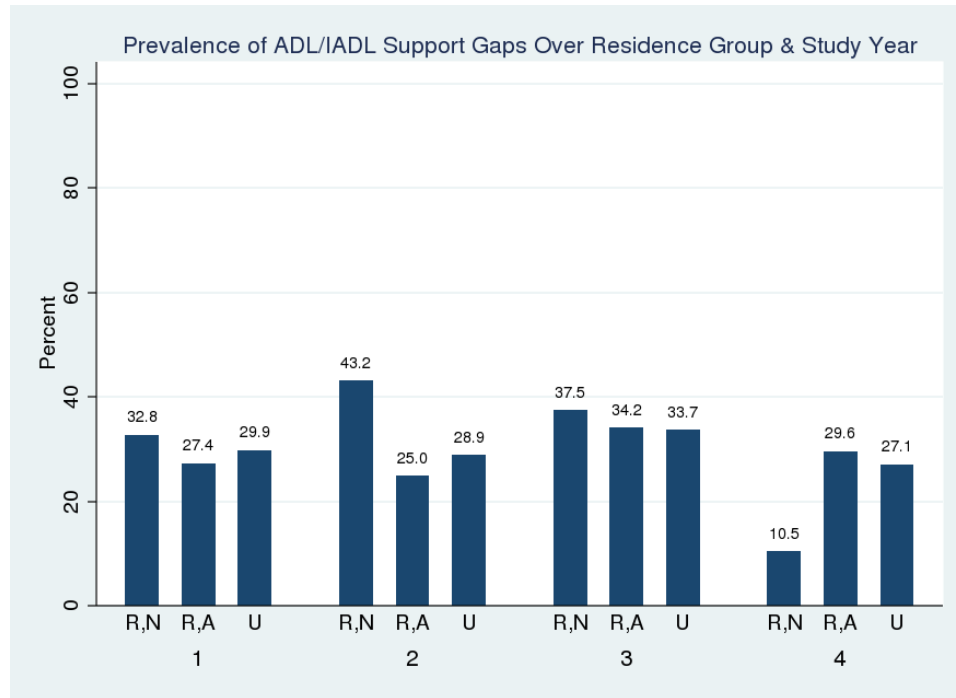
Table 25. ADL/IADL-Specific Support Gaps for ADL/IADL Limitations at Baseline among Beneficiaries with Any Gaps in Reported Support, N (%)

	Study Year 1				
	R,N n=21	R,A n=32	U n=160	Total N=213	*p*-value
	ADL Support Gaps				
Bathing or Showering	0 (0.0)	1 (3.1)	12 (7.5)	13 (6.1)	0.481
Dressing	1 (4.8)	3 (9.4)	9 (5.6)	13 (6.1)	0.783
Eating	2 (9.5)	3 (9.4)	17 (10.6)	22 (10.3)	>0.99
Getting in or out of bed or chairs	5 (23.8)	4 (12.5)	21 (13.1)	30 (14.1)	0.422
Walking	7 (33.3)	6 (18.8)	37 (23.1)	50 (23.5)	0.425

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Using the toilet	1 (4.8)	1 (3.1)	17 (10.6)	19 (8.9)	0.458

<p style="text-align:center">IADL Support Gaps</p>

Using the telephone	10 (47.6)	13 (40.6)	72 (45.0)	95 (44.6)	0.864[a]
Doing light housework	0 (0.0)	8 (25.0)	19 (11.9)	27 (12.7)	**Test of association:** 0.023* **Test of direction of association:** R,N vs. R,A: 0.048*
Doing heavy housework	1 (4.8)	9 (28.1)	28 (17.5)	38 (17.8)	0.104
Preparing meals	0 (0.0)	7 (21.9)	14 (8.8)	21 (9.9)	0.027*[b]
Shopping for personal items	0 (0.0)	7 (21.9)	11 (6.9)	18 (8.5)	**Test of association:** 0.011* **Test of direction of association:** R,A vs. U: 0.045*
Managing money (paying bills)	0 (0.0)	3 (9.4)	10 (6.3)	13 (6.1)	0.421

Notes. Column *p* values correspond to Fisher's Exact or Chi-square Tests for rural vs. urban between group differences in proportions (overall test of association) with Bonferroni-corrected *p* values for pairwise comparisons.
[a] Chi-square test
[b] Pairwise Bonferroni-corrected *p* values not statistically significant at alpha=0.05.
* *p* <0.05
** *p*<0.01
*** *p*<0.001

Table 26. Assessing Disparities in Support for ADL/IADL Limitations: Demographic, Socioeconomic, and Health Status Predictors, Average Marginal Effects (Standard Errors)

	Any ADL/IADL Support Gaps	ADL Support Gaps	IADL Support Gaps
Rural vs. Urban Residence			
R,N	0.0142	0.0403	-0.0225
	(0.0437)	(0.0401)	(0.0344)
R,A	-0.0398	-0.0337	-0.0177
	(0.0339)	(0.0240)	(0.0305)
First year in MCBS	-0.0213*	-0.00900	-0.0182*
	(0.00830)	(0.00648)	(0.00744)
Study Year	-0.005068	-0.00420	0.00360
	(0.0113)	(0.00912)	(0.00972)
Lives alone	0.0797*	0.0248	0.0789**
	(0.0323)	(0.0249)	(0.0270)
Age	0.00264	0.000704	0.00381*
	(0.00203)	(0.00157)	(0.00164)
Male	0.0311	0.0261	0.00463
	(0.0288)	(0.0206)	(0.0264)
Race			
African American	0.0177	0.0526	0.00687
	(0.0444)	(0.0378)	(0.0385)
More than 1 Race	0.0208	0.0109	0.0360
	(0.0472)	(0.0380)	(0.0458)
Other Race	0.0997	0.0556	0.0656
	(0.0758)	(0.0594)	(0.0668)
Hispanic or Latino Ethnicity	-0.200**	-0.0763	-0.216***
	(0.0670)	(0.0486)	(0.0642)
Marital Status			
Married	-0.0319	-0.0292	-0.00654
	(0.0361)	(0.0255)	(0.0315)

Divorced	0.00580	-0.0286	0.0628
	(0.0564)	(0.0460)	(0.0493)
Separated	0.314	0.0966	0.264
	(0.167)	(0.132)	(0.215)
Never Married	-0.0746	-0.0388	-0.0771
	(0.0722)	(0.0603)	(0.0520)
Income $25K or less	-0.0181	-0.0201	0.00304
	(0.0304)	(0.0255)	(0.0272)
High School Diploma or Greater	-0.0296	0.00522	-0.0435
	(0.0279)	(0.0218)	(0.0247)
Medicaid Participation	-0.0110	-0.00707	0.00689
	(0.0339)	(0.0275)	(0.0292)
Number of Co-morbidities	-0.0146	-0.00918	-0.0136
	(0.0128)	(0.0105)	(0.0111)
General Health Status Rating			
Excellent	-0.0599	-0.0300	-0.0300
	(0.0496)	(0.0337)	(0.0429)
Very Good	0.00453	-0.0163	0.00953
	(0.0403)	(0.0280)	(0.0355)
Fair	0.0181	0.0387	-0.0217
	(0.0321)	(0.0257)	(0.0262)
Poor	0.0496	0.0308	0.0535
	(0.0371)	(0.0277)	(0.0333)
Observations	1447	1447	1447

Notes. Referent categories are Urban, White, Widowed, and *Good* General Health Status rating.
$^{*} p < 0.05$ $^{**} p < 0.01$ $^{***} p < 0.001$

Table 27. Assessing Disparities in Support for ADL/IADL Limitations: Demographic, Socioeconomic, and Health Status Predictors (Multiple Imputation Models), Average Marginal Effects (Bootstrapped Standard Errors)

	Any ADL/IADL Support Gaps	ADL Support Gaps	IADL Support Gaps
Rural vs. Urban Residence			
R,N	0.026	0.038	-0.008
	(0.045)	(0.040)	(0.036)
R,A	-0.034	-0.031	-0.007
	(0.034)	(0.024)	(0.032)
First year in MCBS	-0.018*	-0.008	-0.015*
	(0.008)	(0.007)	(0.008)
Study Year	-0.001	-0.001	0.006
	(0.011)	(0.009)	(0.009)
Lives alone	0.088**	0.027	0.080**
	(0.032)	(0.025)	(0.027)
Age	0.003	0.001	0.004**
	(0.002)	(0.002)	(0.002)
Male	0.032	0.030	0.002
	(0.029)	(0.021)	(0.026)
Race			
African American	0.021	0.057	0.022
	(0.044)	(0.038)	(0.039)
More than 1 Race	-0.002	0.006	0.019
	(0.046)	(0.037)	(0.044)
Other Race	0.108	0.055	0.091
	(0.079)	(0.060)	(0.073)

Hispanic or Latino Ethnicity	-0.178** (0.066)	-0.060 (0.046)	-0.174** (0.063)
Marital Status			
Married	-0.019 (0.036)	-0.026 (0.025)	-0.000 (0.031)
Divorced	0.011 (0.056)	-0.034 (0.045)	0.072 (0.050)
Separated	0.086 (0.186)	0.011 (0.100)	0.092 (0.185)
Never Married	-0.068 (0.069)	-0.049 (0.058)	-0.063 (0.051)
Income $25K or less	-0.015 (0.030)	-0.015 (0.026)	-0.003 (0.027)
High School Diploma or Greater	-0.030 (0.028)	0.004 (0.022)	-0.039 (0.025)
Medicaid Participation	0.004 (0.033)	0.008 (0.010)	0.013 (0.011)
Number of Co-morbidities	-0.014 (0.013)	-0.008 (0.010)	-0.013 (0.011)
General Health Status Rating			
Excellent	-0.065 (0.048)	-0.035 (0.033)	-0.036 (0.042)
Very Good	0.008 (0.039)	-0.009 (0.028)	0.013 (0.035)

Fair	0.012	0.037	-0.030
	(0.032)	(0.025)	(0.026)
Poor	0.048	0.036	0.047
	(0.036)	(0.027)	(0.033)
Observations	1509	1509	1509

Notes. Referent categories are Urban, White, Widowed, and *Good* General Health Status rating.
* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Table 28. Assessing Disparities in Support for ADL/IADL Limitations: Demographic, Socioeconomic, and Health Status Predictors (Testing for Selectivity), Average Marginal Effects (Standard Errors)

	Any ADL/IADL Support Gaps	ADL Support Gaps	IADL Support Gaps
Rural vs. Urban Residence			
R,N	0.0111	0.0360	-0.0218
	(0.0437)	(0.0399)	(0.0345)
R,A	-0.0391	-0.0327	-0.0174
	(0.0340)	(0.0244)	(0.0304)
First year in MCBS	-0.0213*	-0.00912	-0.0182*
	(0.00828)	(0.00649)	(0.00745)
Study Year	-0.0184	-0.00802	-0.0102
	(0.0208)	(0.0170)	(0.0175)
Lives alone	0.0794*	0.0238	0.0801**
	(0.0323)	(0.0251)	(0.0269)
Age	0.00304	0.00127	0.00373*
	(0.00206)	(0.00162)	(0.00166)
Male	0.0339	0.0297	0.00441
	(0.0289)	(0.0211)	(0.0264)
Race			
African American	0.0163	0.0513	0.00629

	(0.0443)	(0.0380)	(0.0384)
More than 1 Race	0.0191	0.00931	0.0362
	(0.0468)	(0.0379)	(0.0458)
Other Race	0.0926	0.0473	0.0677
	(0.0755)	(0.0565)	(0.0672)
Hispanic or Latino Ethnicity	-0.200[**]	-0.0771	-0.218[***]
	(0.0675)	(0.0490)	(0.0635)
Marital Status			
Married	-0.0307	-0.0288	-0.00654
	(0.0363)	(0.0260)	(0.0314)
Divorced	0.0100	-0.0251	0.0633
	(0.0572)	(0.0477)	(0.0496)
Separated	0.308	0.0857	0.261
	(0.166)	(0.128)	(0.213)
Never Married	-0.0773	-0.0415	-0.0758
	(0.0704)	(0.0586)	(0.0528)
Income $25K or less	-0.0157	-0.0169	0.00162
	(0.0305)	(0.0256)	(0.0271)
High School Diploma or Greater	-0.0296	0.00521	-0.0432
	(0.0280)	(0.0220)	(0.0246)
Medicaid Participation	-0.0145	-0.0123	0.00818
	(0.0343)	(0.0276)	(0.0294)
Number of Co-morbidities	-0.0147	-0.00957	-0.0138
	(0.0128)	(0.0105)	(0.0111)
General Health Status Rating			
Excellent	-0.0610	-0.0320	-0.0308
	(0.0492)	(0.0328)	(0.0428)
Very Good	0.00242	-0.0189	0.0106
	(0.0401)	(0.0273)	(0.0357)
Fair	0.0203	0.0417	-0.0224
	(0.0322)	(0.0259)	(0.0264)

Poor	0.0557	0.0398	0.0511
	(0.0377)	(0.0285)	(0.0338)
Total Number of Years in the Study	0.0212	0.0351^{*}	-0.00963
	(0.0228)	(0.0174)	(0.0193)
Observed Entire Study Period	-0.00922	-0.0285	0.0134
	(0.0509)	(0.0386)	(0.0435)
Observed in Previous Study Year	0.0139	-0.0149	0.0395
	(0.0425)	(0.0344)	(0.0354)
Observations	1447	1447	1447

Notes. Referent categories are Urban, White, Widowed, and *Good* General Health Status rating.
$^{*} p < 0.05$ $^{**} p < 0.01$ $^{***} p < 0.001$

Table 29. Assessing Disparities in Support for ADL/IADL Limitations: Demographic, Socioeconomic, and Health Status Predictors (Multiple Imputation Models Testing for Selectivity), Average Marginal Effects (Bootstrapped Standard Errors)

	Any ADL/IADL Support Gaps	ADL Support Gaps	IADL Support Gaps
Rural vs. Urban Residence			
R,N	0.022	0.033	-0.009
	(0.045)	(0.039)	(0.036)
R,A	-0.033	-0.030	-0.007
	(0.035)	(0.025)	(0.032)
First year in MCBS	-0.018^{*}	-0.009	-0.015^{*}
	(0.008)	(0.007)	(0.008)

Study Year	-0.014	-0.003	-0.009
	(0.020)	(0.016)	(0.017)
Lives alone	0.088**	0.026	0.082**
	(0.032)	(0.025)	(0.027)
Age	0.004	0.002	0.004**
	(0.002)	(0.002)	(0.002)
Male	0.035	0.033	0.003
	(0.029)	(0.021)	(0.026)

Race
African American	0.020	0.057	0.022
	(0.044)	(0.038)	(0.039)
More than 1 Race	-0.001	0.005	0.019
	(0.045)	(0.037)	(0.044)
Other Race	0.099	0.046	0.091
	(0.078)	(0.057)	(0.073)
Hispanic or Latino Ethnicity	-0.179**	-0.061	-0.176**
	(0.067)	(0.047)	(0.063)

Marital Status
Married	-0.018	-0.026	-0.000
	(0.036)	(0.026)	(0.031)
Divorced	0.016	-0.030	0.073
	(0.056)	(0.047)	(0.050)
Separated	0.081	0.007	0.087
	(0.184)	(0.098)	(0.183)
Never Married	-0.070	-0.051	-0.063

	(0.068)	(0.057)	(0.051)
Income $25K or less	-0.012	-0.012	-0.003
	(0.030)	(0.026)	(0.027)
High School Diploma or Greater	-0.030	0.005	-0.039
	(0.028)	(0.022)	(0.025)
Medicaid Participation	-0.000	0.002	0.017
	(0.034)	(0.027)	(0.029)
Number of Co-morbidities	-0.014	-0.008	-0.013
	(0.013)	(0.010)	(0.011)
General Health Status Rating			
Excellent	-0.067	-0.038	-0.036
	(0.048)	(0.032)	(0.042)
Very Good	0.005	-0.013	0.013
	(0.039)	(0.027)	(0.035)
Fair	0.013	0.040	-0.030
	(0.032)	(0.025)	(0.026)
Poor	0.054	0.040	0.047
	(0.037)	(0.028)	(0.033)
Total Number of Years in the Study	0.031	0.038[*]	-0.005
	(0.022)	(0.017)	(0.019)
Observed Entire Study Period	-0.025	-0.032	0.013
	(0.050)	(0.038)	(0.043)
Observed in Previous	0.010	-0.021	0.038

Study Year	(0.041)	(0.033)	(0.035)
Observations	1509	1509	1509

Notes. Referent categories are Urban, White, Widowed, and *Good* General Health Status rating.
[*]$p < 0.05$
[**]$p < 0.01$
[***]$p < 0.001$

Discussion

The presence and persistence of informal home- and community-based helper support is often critical to the well-being and quality of life of older adults with debilitating illnesses such as dementia and with limitations in their ability to care for themselves. Overall, the level of functional dependence was considerable, yet the number of reported helpers was low. Over half of the sample reported relying on only one helper; in many cases to provide support for multiple functions. Burden of functional difficulty and the composition of community-based helper support differed significantly among rural- and urban-dwelling persons in this study. Living in a rural area that is not adjacent to a metropolitan or micropolitan area versus living in an urban residential area was associated with fewer reported functional difficulties overall and greater reliance on non-kin helpers. Regardless of residential area, the number of functional limitations, as well as the number of helpers increased across study years. Over time, functional needs increased among the sample and correspondingly, on average, the number of community-based helpers also increased.

Despite increases in the number of helpers on average over time, gaps in reported support for specific ADL/IADL limitations were present among the sample in each study year, suggesting potential unmet functional needs. As dementia advances, so does reliance on other persons to assist with daily tasks. Not having support for such activities raises concerns about not only well-being and quality of life but safety and risks for injuries due to falls or

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related events. Among beneficiaries in this study with any reported gaps in support, gaps in support for *walking* and *using the telephone* were most prominent. These are critical daily activities in which lack of adequate support could lead to injury or even fatality in emergency situations. The factors that were associated with the probability of having support gaps, such as age and living alone, may help in the identification of persons who may have unmet daily functioning needs. Ideally, some form of support would have been reported for each identified limitation given the level of functional difficulty among beneficiaries in this sample. The presence of ADL- and IADL-specific gaps suggests that researchers and interventionists should go beyond assessing the presence of any community-based support and examine the presence of support for each functional need, helping secure support for all identified difficulties. Hispanic/Latino ethnicity was a protective factor for persons with dementia and functional limitations having any support gaps. This is consistent with previous research findings that Hispanic/Latino dementia caregivers tend to view family-centered home-based dementia care as a culturally embedded value that predominates among Hispanic/Latino groups (Neary & Mahoney, 2005; Llanque & Enriquez, 2012).

The presence of helper support gaps may relate to caregiver burden and difficulty with managing co-occurring functional limitations for care recipients. Assuming that the presence of just one helper is sufficient to address all functional needs is not an effective approach given the great potential for high caregiver burden. The triple burden of managing personal care, household chores, and medical or nursing tasks is a constant challenge for family and other unpaid caregivers in the community (Reinhard, Levine, & Samis, 2012). Advancing policies and practices that support informal caregivers in their roles, and developing and implementing interventions that assist in identifying and monitoring the

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support systems of older community-dwelling persons with dementia over time are essential to sustaining the informal system of care. The identification of potentially unmet functional needs and heterogeneous helper networks in Aim 1 support the application of person-centered LTSS strategies for patients with dementia and functional difficulties because their support systems may be transitory and/or limited.

Although no residential area differences in support gaps were identified in this part of the study, it remains important when designing person-centered approaches to providing community-based support to consider potential barriers that are unique to rural communities. In rural communities where access to care is often difficult due to distance or other barriers, person-centered measures such as telehealth programs could significantly improve the delivery of dementia-related health care over the disease course by reducing geographic isolation and linking rural older residents with dementia to community resources and supports according to their level of need (Buckwalter, Davis, Wakefield, Kienzle, & Murray, 2002).

There has been growing interest among policy makers to maximize the support of family or other caregivers in the community and increase access to home- and community-based services due to concerns about the exorbitant expenditures associated with increased nursing home use (Levine et al., 2010). Many key policy provisions designed to increase access to home and community-based services such as the *Community First Choice Option* (ACA of 2010 under Section 1915(k)), which offers states a six-percent increase in their federal medical assistance percentage (i.e., Medicaid matching rate) for providing community-based attendant services and supports as an alternative to institutionalization, and the 1915(i) State Plan benefit, which enables states to offer services such as respite or skilled

nursing services in community settings (U.S. Department of Health and Human Services, 2012) are primarily available for Medicaid recipients. Further, many states choose not to participate in these optional programs (Kaiser Family Foundation, 2014).

Low participation in this and other federally sponsored programs suggests that additional and more appealing incentives to states to expand access to home- and community-based services through Medicaid as well as support for the provision of programs to assist older persons who are not eligible for Medicaid but are financially strained are necessary. The majority of sample beneficiaries in this study were not dual-eligible and, thus, may not be eligible for Medicaid-funded LTSS, depending on their state's offerings. These supports are designed to assist in filling in gaps where informal help is insufficient such as those identified in this analysis. Although use of and access to such supports was not measured in this study, the identification of gaps in support for ADL/IADL limitations supports the continued provision of such services for those who need and are eligible to receive them. Fewer than one-third of these beneficiaries received paid assistance in the home (i.e., at least one Medicare-funded home health agency visit during the study year), which could reflect barriers to formal community-based support such as ineligibility.

Despite the aforementioned and other ACA provisions designed to create a more "balanced" system, service offerings are often variable and limited (Reinhard, Kassner, & Houser, 2011). Although the ACA expanded opportunities for unpaid caregiver engagement in clinical processes as well as improved delivery of LTSS in community settings, the ACA did not provide direct financial support for family and other unpaid caregivers (Feinberg & Reamy, 2011). It is important to note that a potential unintended consequence of shifting priorities is increased burden on informal caregivers without sufficient support for their

efforts. There are key advantages to expanding access to community-based support, but such expansions should not come at the expense of the availability and provision of formal care for those who may require or desire such care (Konetzka, 2014). Ultimately, policymakers and other stakeholders should strive to create a system that delivers high-quality care in both community and institutional settings and that facilitates access to care in the setting that best meets patients' needs and preferences.

Several study limitations of this analysis should be considered. First, this study is an unweighted analysis of MCBS data. The MCBS contains longitudinal weights for sample persons with full-year observations in the Access to Care module; these weights are called "backward longitudinal" weights because they apply to only the surviving sample and are used to "look back" to data from previous years (Briesacher et al., 2012). Not all persons in the study cohort remained in the study for all four study years, resulting in a very limited sample for use with the appropriate three-year backward longitudinal weights. This is an important limitation because not accounting for MCBS's weighting, clustering, and stratification design may result in standard errors that are smaller than they should be and estimates that are not generalizable to the U.S. population (Briesacher et al., 2012). As such, inferences from this study's findings are limited to rural and urban community-dwelling Medicare beneficiaries age 65 and older with a dementia diagnosis *and* functional limitations that are willing to participate in the MCBS.

Second, self/proxy-reported data included in this aim's analyses could be subject to measurement error. Reported difficulties may be attributed to other conditions not assessed in the MCBS rather than to dementia. Further, helper and other information could be misreported by beneficiaries and/or their proxies. In linear and nonlinear regression models,

random measurement error could lead to biased estimation of coefficients (i.e., typically attenuation bias) if the error applies to regressors and inflated standard errors if the dependent variable is measured with error and that error is correlated with included factors (Hyslop & Imbens, 2001; Fearn, Hill, & Darby, 2007). In the presence of such error, inferences may be biased. As such, observed differences could be due to a difference in reporting among respondents. Third, variable addition tests for selectivity identified the potential presence of attrition bias with regard to only one of the three model outcomes in Aim 1b. (i.e., ADL support gaps). However, the stability of the estimates in the presence of the attrition variables suggests that such bias is small. Fourth, in follow-up interviews when collecting data on ADL/IADL helpers, the MCBS does not ask whether the reported helper(s) are the same individuals that were reported as providing help in earlier interviews. Due to this, continuity of helper support in terms of whether an individual's support remains exactly the same and is provided by the same individuals is unable to be determined in this study.

Despite these limitations, this study identified the presence of support gaps among a highly vulnerable patient population as well as differences in the types of functional support gaps present across geographic locations. These findings support the application of approaches that acknowledge heterogeneity in needs across different residential communities. Where service offerings do not exist, collective efforts are needed to create them. Community-based care may change over time and render older adults with AD or other debilitating illnesses at increased vulnerability for harm or unnecessary or undesired facility placement. Thus, LTSS approaches should attempt to mitigate any negative effects of these changes by working to assure continuity of care. There is a persistent need for more personalized and contextually specific approaches to care provision, policies, and practices

for older persons affected by dementia. Additional efforts to train and increase the supply of community-based paid workers, to incentivize local and state entities to greater invest in community-based care options, and to establish processes for monitoring, augmenting, and supporting informal support networks in the community among those with dementia and functional limitations are recommended.

CHAPTER 5. RURAL-URBAN RESIDENCE, COMMUNITY-BASED HELPER SUPPORT, AND LIKELIHOOD OF TRANSITION TO A NURSING FACILITY

Introduction

The implications of the projected incidence and prevalence increases in AD or other dementias on the healthcare system are considerable because not only will the number of older persons with dementia increase dramatically but the demand for dementia-related health care will also increase. Older people with dementia have more hospital stays, skilled nursing facility (SNF) stays, and home healthcare visits than older people with other conditions (Medicare Current Beneficiary Survey, 2008. Unpublished tabulations analyzed under contract for the Alzheimer's Association, November 2011; Alzheimer's Association, 2014). Roughly 600,000 Medicare beneficiaries are admitted to a long-term care facility annually (Jacobson, Neuman, & Damico, 2010). In 2006, more than one-third (39%) of transitions to a long-term care facility were from the community, 50% were transfers from a skilled nursing facility, and 11% were transfers from a hospital (Jacobson, Neuman, & Damico, 2010). Factors consistently associated with institutionalization among older persons include age, Caucasian ethnicity/race, living alone, female gender, increased ADL dependence, cognitive impairment, and unavailability of family caregivers or community-based services (Gaugler, Duval, Anderson, & Kane, 2007). Among persons with dementia, severity of disease, Alzheimer's disease diagnosis, ADL dependencies, behavioral symptoms, depression, caregivers reporting greater emotional stress, and personal

preferences for institutionalization are the most consistent predictors of nursing home admission (Gaugler, Yu, Krichbaum, & Wyman, 2009).

Previous research shows that many rural community-dwelling elders with chronic disabilities or impairments lack sufficient support, which may render them vulnerable to nursing home or institutional placement despite preferences to remain at home and/or to use home- and community-based options outside of institutionalization (Coburn & Bolda, 2001; Kane & Kane, 2001; Reinhard, 2010). Examining the effects rural vs. urban residence and helper support in the community, as well as other socio-demographic factors, on residential care transitions out of the community into nursing facilities among older adults with dementia and increased vulnerability due to functional limitations may contribute to more effective strategies to reduce often times avoidable or undesired transitions into nursing facilities among this patient population.

Many care transition pattern studies have tended to focus on rehospitalizations (Sato et al., 2010). Although rehospitalization represents a critical transition for an older person, and particularly an older person with dementia, residential care transitions that involve nursing facilities providing long-term care are also vitally impactful. Transitions into SNFs, which typically refer to nursing facilities providing care for a shorter term, are also important to examine in care transition studies involving Medicare beneficiaries because Medicare incurs a healthy portion of the expenditures for short-term nursing facility services. Similar to rehospitalizations, entry into a SNF also occurs following an index hospitalization and represents an understudied discharge destination. In 2000, SNF expenditures for Medicare were $13 billion for services provided to 1.4 million Medicare patients (U.S. General Accounting Office Report to Congressional Committees, 2002). The U.S. Census Bureau

estimates that in 2010, approximately 1.3 million people age 65 and over were in skilled nursing facilities, representing 3.1% of this population segment (Werner, 2011). Further, Medicare SNF use often precedes longer-term facility placement, so it is important to measure SNF usage in the context of residential transitions into institutions. Movement out of community-living into post-inpatient hospitalization SNFs and long-term nursing facilities is an important aspect of care transition patterns and, as such, this study aim focuses on nursing facility transitions among a highly vulnerable community-dwelling beneficiary group.

Advanced preparation to meet the demands for formal long-term care while concurrently developing supportive interventions to help older persons remain in the community (as medically appropriate and when this is a preferred option) is obligatory given current and impending demands to the healthcare system. To my knowledge, no previous studies have examined the effects of rural vs. urban residence and community-based helper support on the likelihood of residential care transitions out of the community to nursing facilities (i.e., skilled nursing, nursing home, or assisted living facilities) among persons with dementia and identified functional limitations. This chapter seeks to shed new light on the residential trajectories of rural vs. urban community-dwelling elders with this debilitating progressive illness.

Specifically, the objective and associated hypothesis for this aim are:

Aim 2: To examine the effects of rural vs. urban residence and community-based helper support for ADL/IADL functional limitations on the likelihood of any residential care transition out of the community to nursing facilities (i.e., SNFs, nursing homes, or assisted living facilities) during the study period.

H2: Based on evidence that adequate help in the community reduces the risk of permanent nursing home residence (Boaz and Muller, 1994) and that rural elders in the community may have less access to adult children as informal helpers (Glasgow, 2000; Glasgow, 2003), it is hypothesized that rural residence and limited community-based helper support (i.e., single source of community-based support vs. multiple sources) will be associated with an increased likelihood of transition to a residential nursing facility.

Methods

This aim's analyses were limited to beneficiaries who remained in the study for more than one study year from baseline to assess transitions during the follow-up period (N=487). Due to issues with perfect prediction associated with this variable in logistic regression models, 14 cases (2.9%) where a usual source of care was not reported were removed from the sample, resulting in a total sample size of 471 beneficiaries, all reporting a usual source of care. As a result, this variable was not included in the regression models. The mean length of follow-up among beneficiaries included in this aim was 3.3 study years (*SD*=0.9). The MCBS Cost and Use Residence Timeline contains dated summaries on the movement of individuals between community and facility settings (e.g., SNFs, nursing homes, assisted living facilities) throughout the year, allowing for up to twenty occurrences of movement.

The outcome of transitioning to a facility is based on data obtained from this timeline and is not based on the type of interview completed. Although the terms "SNF" and "nursing home" are often used interchangeably, the MCBS distinguishes between the two based on Medicare coverage regulations. A SNF stay is defined as a transitional post-acute stay that is Medicare reimbursable up to 100 days that follows a minimum 3-day hospitalization per

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Medicare regulations (Sato et al., 2010; CMS, 2013b). Therefore, the MCBS distinguishes SNFs from other facility settings as short-term care facilities. As such, this study examines any nursing facility use, whether to short-term or long-term facilities. The two key predictors of interest were rural and urban residence and a single vs. multiple source(s) of community-based support.

The reported number of ADL/IADL helpers among beneficiaries included in this aim's analyses ranged from one to five (Mean=1.6, *SD*=0.8). The dichotomous indicator of support used in this aim and in Aim 3 (the next chapter) was created from the helper relationships variable, where a single source of support includes beneficiaries who rely on spouses only, adult children only, other kin only, or non-kin only for help who also did not report any paid formal home health assistance; multiple sources of support includes beneficiaries who reported multiple types of helpers (i.e., various combinations of helper relationships such as support from adult children and non-kin, or adult children and formal paid home health). In this part of the study, the receipt of any paid home health visits is included in the sources of support measure because this is a global measure of support rather than an assessment of reported support for each ADL/IADL difficulty, as in Aim 1. It was important to account for all assistance received in the community to assess the effect of community-based helper support on transitions to nursing facilities. This support measure aligns with this aim's hypothesis that *limited* community-based support is associated with increased probability of transition.

Because informal community-based support, measured as a single vs. multiple source(s) of help, is a key predictor of interest in this aim's regression models where transitioning to a nursing facility is the outcome, potential endogeneity associated with this

variable must be considered. Endogeneity associated with regression predictors is a common problem in health services research (Terza, Basu, & Rathouz, 2008) and several studies have documented and accounted for endogeneity issues related to informal care and formal healthcare use, such as nursing homes (Lo Sasso & Johnson, 2002; Van Houtven & Norton, 2004; Van Houtven & Norton, 2008; Du, 2012). The concern in studies assessing these relationships is that unobserved characteristics (i.e., omitted variables) may influence both whether someone receives informal care or community-based home health as well as whether they use formal health services such as nursing homes or other nursing facilities (e.g., preferences, attitudes, family values, health status of caregivers, cultural expectations) (Lo Sasso & Johnson, 2002; Van Houtven & Norton, 2008). These unobserved factors violate the assumption of independence of the explanatory variables with the error term and, if ignored, may result in biased and inconsistent estimates (Terza, Basu, & Rathouz, 2008). An additional type of endogeneity may be from the simultaneity associated with informal care and formal care (i.e., informal care may affect formal care and formal care may change informal care), because decisions by helpers or caregivers to provide informal care or use paid home health may be made jointly with decisions regarding nursing facility use (Van Houtven & Norton, 2008).

A commonly implemented method that is designed to deal with endogeneity is the instrumental variables (IV) method (Terza, Bradford, & Dismuke, 2008). Instrumental variables analysis addresses potentially unobservable confounding in observational studies by defining a variable or variables as instruments that affect the explanatory variable whose effects are of interest and that have no direct effect on the outcome measure (Newhouse & McClellan, 1998). This then allows the researcher to estimate how much variation in the

explanatory variable, which is induced by the instrument, affects the outcome measure (Newhouse & McClellan, 1998). The IV approach is often difficult in practice because of the usual difficulty associated with identifying instruments (Himmelberg, Hubbard, & Palia, 1999).

The conventional instrumental variable method of two-stage least squares is useful in linear settings, but inconsistent in non-linear settings (Terza, Bradford & Dismuke, 2008). In non-linear settings, two-stage residual inclusion, rather than two-stage least squares is more consistent (Terza, Bradford & Dismuke, 2008) and was applied here due to the categorical outcome measure.

The regression model is therefore:

Equation 4: $y = M(X_e\beta_e + X_q\beta_q + X_\mu\beta_\mu) + e$, where

y is the binary outcome of a residential care transition to a nursing facility;

$M(\bullet)$ is a known nonlinear function (in this case, logit function) and there are three types of regressors:

X_e is a vector of endogenous regressors (i.e., community-based helper support variables—informal, formal, both, neither);

X_q is a vector of observable exogenous regressors (i.e., environmental, predisposing, enabling, and need factors associated with the study's conceptual model—Table 8);

X_u is a vector of unobservable confounder latent or omitted variables that influence the outcome y and are correlated with the endogenous variables;

β represents coefficients for each vector; and e is the random error (Terza, Basu & Rathouz, 2008).

The correlation between X_e and X_μ is the basis for the problem of endogeneity. The following stages for two-stage residual inclusion analysis were applied:

Stage 1: The endogenous variable was regressed on the instruments and exogenous variables in the model via a reduced form equation and the residuals from this first-stage equation were predicted and saved.

Stage 2: The Stage 1 residuals, in addition to the endogenous variable, were included in the original equation. The endogenous regressor is kept in the model along with the regressors because the residuals remove the endogeneity associated with it, making inclusion unproblematic (Terza, Bradford, & Dismuke, 2008). The standard errors were adjusted using the bootstrap method with 1000 replications to account for the presence of the first-stage residual in the model (Terza, Basu, & Rathouz, 2008). Robust standard errors were applied in the exogenous regression models.

Logistic regression was used in the first stage for the binary single vs. multiple source(s) of community based support variable. The residuals from the first-stage equation, along with the endogenous variable, were included in the second-stage equations (i.e., logistic and multinomial logistic regressions).

Testing and Selection of Instruments

Variables in the literature that have been successfully used as instruments for informal care include family-level variables that affect the informal care decision, such as number of siblings (Van Houtven & Norton, 2004; Charles & Seevak, 2005); number of living daughters, number of sons, and number of children in the family with less than a high school education (Van Houtven & Norton, 2008); and proximity (living nearby) of children to care recipient (Charles & Seevak, 2005). Questions in the MCBS regarding the number of

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living daughters, sons, sisters, and brothers are posed to facility-dwelling participants only in their background questionnaire. Because this study focuses on the community-dwelling population at baseline and those questions were not posed to community-dwelling beneficiaries, these variables were not considered for instrumentation. The family-level variable number of living children was assessed in the MCBS community interviews and was tested as an instrument.

In addition, several individual-level county characteristic variables were tested as instruments: percent of families with female head in 2000, percent of divorced females in 2000, population density per square mile in 2000, unemployment rate in 2000, percent working in state/county of residence in 2000, and females in civilian labor force in 2000. These variables were chosen as instrumental variable options due to their potential association with community-based support. In that helper networks are often expansive and may depend on geographic proximity and availability, demographic variables on population density per square mile and employment may be predictive of the availability and composition of such community-based support. Additionally, caregiving of elderly parents, spouses who are ill, or children is more frequently the primary responsibility of women, who often report a greater caregiving burden than men, (Kramer & Kipnis, 1995; Terrill, Garofalo, Soliday, & Craft, 2012). As such, variables related to the number of women in the work force and competing home demands may affect community-based support for older persons with dementia because much of this help may be provided by women in their lives.

To determine whether instrumental variables analysis was appropriate and feasible, each potential IV was rigorously tested. Specifically, tests of instrument strength using a Wald test for joint significance of all instruments in different combinations (null hypothesis

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is that the coefficients on the identifying instruments are zero) were conducted. A reduced form equation

Equation 5: $y_e = M(X_q\beta_q + X_w\beta_w) + e$, where

y_e represents the endogenous outcome (i.e., single vs. multiple sources of community-based support);

$M(\bullet)$ is a known function (i.e., logit);

X_q is a vector of observable exogenous regressors;

X_w represents a vector of instruments;

β represents coefficients for each vector; and e is the error term.

Logit or probit functions are typically adopted for a dichotomous endogenous variable in the first-stage reduced form 2SRI equation (Bruni, Mammi, & Ugolini, 2014). Several different types of residuals could be applied in the second-stage equation and consensus on the type of residual to use has not been reached. In studies that have tested various residual types, findings across models have been fairly consistent with only modest sensitivity to specification (Garrido, Deb, Burgess, & Penrod, 2012; Bruni, Mammi, & Ugolini, 2014). As such, Pearson residuals were obtained from the first-stage logistic regression model and included in the second-stage logistic and multinomial logistic regression models (Zhang, 2008; Garrido, Deb, Burgess, & Penrod, 2012; Bruni, Mammi, & Ugolini, 2014).

The first-stage logistic regression was initially performed with all seven potential instruments included in the model; the joint F-test was not statistically significant ($\chi2(N=442, 7)=8.5$; $p=0.29$; F=1.21). The associated chi-square statistic was divided by the number of degrees of freedom to obtain the equivalent F-statistic. Subsequently, all potential

instruments were tested individually and in various combinations in first-stage regression models. Population density per square mile was the only significant potential instrument in the first-stage regression models, suggesting the application of an exactly identified first-stage model.

The Wald test from the first-stage regression model testing only population density per square mile as an instrument was statistically significant ($\chi2$ (N=442, 1)=4.7; p=0.03; F=4.7). Based on Staiger & Stock's rule of thumb (1997) that instrumental variables with an F-statistic less than 10 are weak instruments, the identified instrument is not strong. However, given the difficulty associated with identifying instruments, the use of this instrument to test for the presence of endogeneity is a preferred strategy compared to falsely assuming strict exogeneity. The variance inflation factors of the models were tested to determine the degree of collinearity among the included regressors. The mean variance inflation factor (VIF) for this first-stage model was 1.2 (VIF for rural-urban residence (1.08) and population-density per square mile (1.06)), suggesting no major multi-collinearity issues with the model. VIFs for second-stage regression models were also low and unproblematic. The residuals from the first-stage regression model were predicted, saved, and included in the second-stage model. Findings from all models are detailed in the *Results* sections of Chapters 5 and 6 and are interpreted with caution given this limitation.

No further specification tests were applied due to the failure to identify more than one appropriate instrument; the model was exactly identified. A test of over-identification such as a likelihood ratio (LR) test of the second-stage equation including the endogenous variable, the first-stage predicted residuals, and all control variables, estimated with all but one of the theoretically excluded variables (i.e., instruments) (Bollen, Guilkey, & Mroz, 1995; Ivlevs &

King, 2012) was not applied because such tests require that the number of instruments exceed the number of endogenous variables included in the model. In this case, the number of instruments equals the number of exogenous variables—one.

Logistic regression with two-stage residual inclusion was used to examine baseline factors associated with the probability of any subsequent transitions out of the community into nursing facilities for any reason (i.e., short- or long-term stays). Multinomial logistic regression with two-stage residual inclusion was used to examine baseline factors associated with the probability of four transition outcomes: short-term facilities only; both short- and long-term facilities; long-term facilities only; and no transitions. These models were also performed under the assumption of potential exogeneity following results from 2SRI models. Average marginal effects are reported for all models.

Results

Characteristics of the sample included in this aim's analyses are shown in Table 30. Thirty-six percent (i.e., 170 out of 471) of beneficiaries who remained in the study for more than one year transitioned to a nursing facility at least once (i.e., ever transitioned) during the follow-up period (Table 31). The distribution of the transition category variable shows that the majority of the sample did not have any transitions during follow-up (64%), 16% transitioned to a SNF only, 11% transitioned to both a SNF and long-term care facility, and 9% did not have any SNF visits and transitioned directly to a long-term nursing facility. Forty-one percent of R,N residents, 30% of R,A residents, and 36% of U residents ever transitioned to a nursing facility (Table 32). Forty-eight percent of beneficiaries reported a single source of community-based support (N=457). Thirty-eight percent of sample persons with multiple sources and 34% of persons with a single source of community-based support

transitioned to a facility during follow-up (Table 33). There were no statistically significant differences in these transition outcomes based on rural vs. urban residence and sources of support in bivariate analyses. In addition, rural-urban residence was not significantly associated with having a single vs. multiple source(s) of support in bivariate analyses (p=0.93); 50% of R,N, 48% of R,A, and 47% of U residents reported a single source of community-based help (N=454). Regression analyses followed to determine if these relationships remained the same after controlling for other factors and if other factors were independently associated with these outcomes.

Results from the first-stage 2SRI regression are provided Table 34. On average and holding all other factors constant, population density per square mile in 2000 was significantly associated with an increase in the probability of having a single source of community-based support in the baseline MCBS study year. In addition, on average, increasing age, number of functional difficulties, and number of co-morbidities were associated with a decrease in the probability of having a single vs. multiple sources of community-based support. The second-stage 2SRI logistic and multinomial logistic regression models were performed with both the single vs. multiple sources of community-based support variable and the predicted first-stage residuals included, plus all other exogenous variables.

Results from the 2SRI and exogenous second-stage logistic regressions are shown in Table 35. There were no statistically significant findings in the 2SRI logistic regression model. In the non-linear framework, the estimated coefficient on the residual in the second-stage model represents a direct test for the exogeneity of the potentially endogenous variable as a function of the tested instrument (Bollen, Guilkey, & Mroz, 1995; Ivlevs & King, 2012).

If the coefficient is not significantly different from zero, one fails to reject the null hypothesis that the potentially endogenous regressor is exogenous. In this case, the residual was not statistically significant, which suggested that the single vs. multiple sources of community-based ADL/IADL support variable was potentially exogenous and that the model should alternatively be estimated as a logistic regression under the assumption of potential exogeneity. It is important to note that a weak instrument was used in the first-stage regression, which could reduce the power to detect endogeneity via the significance of the residual. In the potentially exogenous logistic regression, only marital status was significantly associated with any nursing facility transitions during the follow-up period. On average and controlling for other factors, being married compared to being widowed was associated with a 14.6 percentage point reduction in the probability of transitioning to a nursing facility among beneficiaries with dementia and reported functioning limitations.

Results from the 2SRI and potentially exogenous multinomial logistic regression models are provided in Tables 36 and 37, respectively. Similar to the logistic regression models, the Pearson residual from the first-stage regression was not statistically significant across categorical transition outcomes, suggesting that the support variable was exogenous. In the 2SRI multinomial logistic regression model, the number of co-morbidities was significantly associated with two transition outcomes, on average and holding all other factors constant: 1) a one-unit increase in the number of co-morbidities was associated with a 5.6 percentage point increase in the probability of transitioning to a SNF only versus not transitioning; and 2) a one-unit increase in the number of co-morbidities was significantly associated with a 6.5 percentage point decrease in the probability of transitioning to both a Medicare SNF and long-term nursing facility versus not transitioning during follow-up.

In the multinomial regression model where potential exogeneity was assumed, several factors were significantly associated with residential transition outcomes. The key predictor of interest, rural-urban residence, was associated with transition outcomes. Specifically, on average, living in R,A compared to living in U was associated with a six percentage point decrease in the probability of going to both a SNF and nursing home or assisted living facility versus having no transitions during follow-up. Although not statistically significant, 2SRI model estimates for the rural vs. urban residence variable were consistent with this model's findings; the standard errors are larger in the 2SRI model. On average, a one year increase in age was associated with a 0.5 percentage point increase in the probability of going to both a short- and long-term nursing facility versus not transitioning. Compared to White, Black or African American race was significantly associated with a 7 percentage point decrease in the probability of going to a long-term nursing facility only, on average, versus having no transitions. Being married compared to being widowed was associated with an 11.2 percentage point decrease in the probability of going to both a short-term and long-term facility versus having no transitions, on average. Number of co-morbidities was also associated with nursing facility transitions. On average, a one-unit increase in the number of co-morbidities was associated with a 3.4 percentage point increase and 4.6 percentage point decrease in the probability of transitioning to a SNF only and both SNF and long-term care, respectively, compared to having no residential transitions at all in follow-up years.

Table 30. Characteristics of the Sample: Aim 2, N (%)

Rural vs. Urban Residence (N=468)		
	R, N	49 (10.5)
	R, A	73 (15.6)
	U	346 (73.9)
Single Source of Community-Based Helper Support (N=457)		218 (47.7)
Lives Alone (N=471)		127 (27.0)
Age (years), Mean (*SD*) (N=471)		81.6 (7.4)
Female (N=471)		304 (64.5)
Race (N=471)		
	White	315 (66.9)
	Black or African American	56 (11.9)
	Other Race (Includes more than 1 race)	100 (21.2)
Ethnicity: Non- Hispanic or Latino (N=471)		28 (5.9)
Marital Status (N=471)		
	Married	205 (43.5)
	Widowed	218 (46.3)
	Divorced, Separated, or Never Married	48 (10.2)
Income $25K or Less (N=468)		319 (68.2)
High School Diploma or Greater (N=463)		255 (55.1)
Number of difficulties, Mean (*SD*) (N=471)		6.0 (3.5)
Number of co-morbidities, Mean (*SD*) (N=471)		1.3 (1.0)
General Health Status Rating (N=470)		
	Excellent or Very Good	112 (23.8)
	Good	141 (30.0)
	Fair or Poor	217 (46.2)

Table 31. Transition Outcomes, N (%)

	Total (N=471)
Ever transitioned to a nursing facility at any point during follow-up	
Yes, transitioned to a nursing facility at least once during follow-up	170 (36.1)
Transition Category	
SNF only	74 (15.7)
Both SNF and Nursing Home or Assisted Living Facility	53 (11.3)
Nursing Home or Assisted Living Facility only	43 (9.1)
No transitions during follow-up	301 (63.9)

Table 32. Transition Outcomes by Rural-Urban Residence, N (%)

	R,N (n=49)	R,A (n=73)	U (n=346)	Total (N=468)	*p*-value
Ever transitioned to a nursing facility at any point during follow-up					
Yes, transitioned to a nursing facility at least once during follow-up	20 (40.8)	22 (30.1)	126 (36.4)	168 (35.9)	0.45
Transition Category					
SNF only	7 (14.3)	13 (17.8)	53 (15.3)	73 (15.6)	0.63[±]
Both SNF and Nursing Home or Assisted Living Facility	7 (14.3)	5 (6.9)	41 (11.9)	53 (11.3)	
Nursing Home or Assisted Living Facility only	6 (12.2)	4 (5.5)	32 (9.3)	42 (9.0)	
No transitions during follow-up	29 (59.2)	51 (69.9)	220 (63.6)	300 (64.1)	

Note: [±]Fisher's exact test p-value. Otherwise, is Chi-square.

Table 33. Transition Outcomes by Single vs. Multiple Source(s) of Support, N (%)

	Multiple Sources (n=239)	Single Source (n=218)	Total (N=457)	p-value
Ever transitioned to a nursing facility at any point during follow-up				
Yes, transitioned to a nursing facility at least once during follow-up	92 (38.5)	75 (34.4)	167 (36.5)	0.36
Transition Category				
SNF only	37 (15.5)	35 (16.1)	72 (15.8)	0.55
Both SNF and Nursing Home or Assisted Living Facility	32 (13.4)	20 (9.2)	52 (11.4)	
Nursing Home or Assisted Living Facility only	23 (9.6)	20 (9.2)	43 (9.4)	
No transitions during follow-up	147 (61.5)	143 (65.6	290 (63.5)	

Note: Chi-square test.

Table 34. 2SRI First-Stage Logistic Regression Model: Endogenous Regressor as Outcome (Single (1) vs. Multiple Sources of Support (0))—Aim 2

	Average Marginal Effects (Standard Errors)
Population density per square mile 2000	0.00000665[*] (0.00000303)
Rural vs. Urban Residence	
R,N	0.0206 (0.0730)
R,A	0.0528 (0.0585)
Lives alone	-0.0747 (0.0600)

	Average Marginal Effects (Standard Errors)
Age	-0.0103[**]
	(0.00342)
Male	0.0562
	(0.0479)
Race	
Black or African American	0.0294
	(0.0726)
Other race (Includes more than 1 race)	0.0577
	(0.0584)
Hispanic or Latino ethnicity	-0.136
	(0.110)
Marital Status	
Married	0.0193
	(0.0605)
Divorced, separated, or never married	-0.0826
	(0.0788)
Income $25K or Less	-0.0219
	(0.0514)
High School Diploma or Greater	-0.0386
	(0.0479)
Number of ADL/IADL difficulties	-0.0410[***]
	(0.00610)
Number of Co-morbidities	-0.0641[**]
	(0.0207)
General Health Status Rating	
Excellent or very good	-0.000698
	(0.0614)
Fair or poor	-0.0426
	(0.0539)
Observations	442

Notes: [*] $p < 0.05$, [**] $p < 0.01$, [***] $p < 0.001$
Referent categories are Urban, White, Widowed, and *Good* general health status rating.

Table 35. Factors Associated with the Probability of Transition to a Nursing Facility during Follow-Up: 2SRI and Exogenous Logistic Regression Second-Stage Model Results

	2SRI Average Marginal Effects (Bootstrapped Standard Errors)	Exogenous Average Marginal Effects (Standard Errors)
Rural vs. Urban Residence		
R,N	0.0194	0.0174
	(0.0879)	(0.0769)
R,A	-0.0659	-0.0739
	(0.0676)	(0.0607)
Single source of community-based support	-0.305	-0.0257
	(0.358)	(0.0492)
Pearson residual	0.128	
	(0.162)	
Lives alone	-0.00793	0.00892
	(0.0714)	(0.0609)
Age	0.00260	0.00563
	(0.00553)	(0.00347)
Male	-0.0493	-0.0660
	(0.0635)	(0.0534)
Race		
Black or African American	-0.103	-0.109
	(0.0817)	(0.0720)
Other Race (Includes more than 1 race)	-0.0635	-0.0795
	(0.0660)	(0.0564)
Hispanic or Latino ethnicity	-0.0659	-0.0382
	(0.114)	(0.0957)

	2SRI Average Marginal Effects (Bootstrapped Standard Errors)	Exogenous Average Marginal Effects (Standard Errors)
Marital Status		
Married	-0.140	-0.146[*]
	(0.0733)	(0.0675)
Divorced, separated, or never married	0.00575	0.0295
	(0.102)	(0.0923)
Income $25K or Less	-0.0881	-0.0809
	(0.0644)	(0.0568)
High School Diploma or Greater	0.0200	0.0322
	(0.0554)	(0.0495)
Number of ADL/IADL difficulties	-0.0145	-0.00273
	(0.0172)	(0.00803)
Number of Co-morbidities	-0.0483	-0.0306
	(0.0324)	(0.0225)
General Health Status Rating		
Excellent or very good	-0.0214	-0.0187
	(0.0668)	(0.0613)
Fair or poor	-0.0348	-0.0226
	(0.0613)	(0.0551)
Observations	442	442

Referent categories are Urban, White, Widowed, and *Good* general health status rating.

Table 36. Factors Associated with the Probability of Nursing Facility Transition Outcomes during Follow-Up: 2SRI Multinomial Logistic Regression Second-Stage Model Results, Average Marginal Effects (Bootstrapped Standard Errors)

Comparison outcome: No Transitions	SNF only	Both SNF and Nursing Home or Assisted Living Facility	Nursing Home or Assisted Living Facility only
Rural vs. Urban Residence			
R,N	-0.0172	0.0341	0.00738
	(0.0716)	(0.0633)	(0.0919)
R,A	0.00573	-0.0526	-0.0186
	(0.0641)	(0.0639)	(0.129)
Single source of community-based support	0.348	-0.350	-0.318
	(0.298)	(0.258)	(0.254)
Pearson residual	-0.160	0.144	0.146
	(0.135)	(0.114)	(0.117)
Lives alone	0.0369	-0.00468	-0.0405
	(0.0586)	(0.0478)	(0.0478)
Age	0.00549	0.00122	-0.00397
	(0.00435)	(0.00378)	(0.00370)
Male	-0.0572	-0.0221	0.0285
	(0.0505)	(0.0440)	(0.0402)
Race			
Black or African American	0.0123	-0.0455	-0.0622
	(0.0791)	(0.0910)	(0.182)
Other Race (Includes more than 1 race)	-0.0317	-0.0107	-0.0165
	(0.0482)	(0.0538)	(0.0561)
Hispanic or Latino ethnicity	0.0628	-0.132	-0.00330
	(0.274)	(0.464)	(0.253)

Comparison outcome: No Transitions	SNF only	Both SNF and Nursing Home or Assisted Living Facility	Nursing Home or Assisted Living Facility only
Marital Status			
Married	-0.0308	0.00213	-0.109
	(0.0584)	(0.0473)	(0.0599)
Divorced, separated, or never married	-0.0654	0.00881	0.0477
	(0.216)	(0.101)	(0.124)
Income $25K or Less	0.0488	0.0107	-0.0529
	(0.0481)	(0.0418)	(0.0457)
High School Diploma or Greater	0.0471	-0.0396	0.00789
	(0.0434)	(0.0372)	(0.0386)
Number of ADL/IADL difficulties	0.00718	-0.00883	-0.0138
	(0.0141)	(0.0127)	(0.0118)
Number of Co-morbidities	0.0557*	-0.0653*	-0.0469
	(0.0265)	(0.0277)	(0.0315)
General Health Status Rating			
Excellent or very good	-0.0510	0.0294	-0.000104
	(0.0505)	(0.0498)	(0.0432)
Fair or poor	-0.0214	-0.0188	0.00861
	(0.0488)	(0.0361)	(0.0418)
Observations	442	442	442

Referent categories are Urban, White, Widowed, and *Good* general health status rating.

Table 37. Factors Associated with the Probability of Nursing Facility Transition Outcomes during Follow-Up: Exogenous Multinomial Logistic Regression Second-Stage Model Results, Average Marginal Effects (Standard Errors)

Comparison outcome: No Transitions	SNF only	Both SNF and Nursing Home or Assisted Living Facility	Nursing Home or Assisted Living Facility only
Rural vs. Urban Residence			
R,N	-0.0159	0.0318	0.00288
	(0.0578)	(0.0558)	(0.0480)
R,A	0.0163	-0.0600*	-0.0277
	(0.0522)	(0.0305)	(0.0366)
Single source of community-based support	0.000168	-0.0350	0.00133
	(0.0383)	(0.0326)	(0.0320)
Lives alone	0.0155	0.0159	-0.0208
	(0.0494)	(0.0391)	(0.0357)
Age	0.00181	0.00458*	-0.000365
	(0.00284)	(0.00228)	(0.00195)
Male	-0.0362	-0.0391	0.00741
	(0.0436)	(0.0351)	(0.0303)
Race			
Black or African American	0.0191	-0.0513	-0.0695*
	(0.0644)	(0.0417)	(0.0303)
Other Race (Includes more than 1 race)	-0.0138	-0.0270	-0.0349
	(0.0426)	(0.0402)	(0.0333)
Hispanic or Latino ethnicity	0.0309	-0.106	0.0333
	(0.0762)	(0.0773)	(0.0578)
Marital Status			
Married	-0.0230	-0.00683	-0.112**
	(0.0557)	(0.0425)	(0.0394)

Comparison outcome: No Transitions	SNF only	Both SNF and Nursing Home or Assisted Living Facility	Nursing Home or Assisted Living Facility only
Divorced, separated, or never married	-0.0875	0.0283	0.101
	(0.0576)	(0.0589)	(0.0821)
Income $25K or Less	-0.0574	0.0195	-0.0431
	(0.0421)	(0.0365)	(0.0358)
High School Diploma or Greater	0.0326	-0.0269	0.0234
	(0.0386)	(0.0325)	(0.0330)
Number of ADL/IADL difficulties	-0.00745	0.00453	-0.000121
	(0.00573)	(0.00564)	(0.00510)
Number of Co-morbidities	0.0339*	-0.0455**	-0.0253
	(0.0163)	(0.0145)	(0.0170)
General Health Status Rating			
Excellent or very good	-0.0563	0.0307	0.00391
	(0.0460)	(0.0425)	(0.0350)
Fair or poor	-0.0371	-0.00754	0.0242
	(0.0442)	(0.0342)	(0.0345)
Observations	442	442	442

Referent categories are Urban, White, Widowed, and *Good* general health status rating.

Discussion

The purpose of this aim was to determine if rural-urban residence and/or level of

community-based support were associated with transitioning out of community residences

into nursing facilities. Despite the expectation that living in any rural area would be associated with increased likelihood of transition compared to living in an urban area, residing in a rural area that is adjacent to a metropolitan or micropolitan area was associated with reduced probability of transition to both a SNF and long-term care facility versus not transitioning at all during the follow-up period, controlling for community-based help and other factors. This finding could relate to heterogeneity in the distribution of facilities, the ability to access them, and other underlying factors affecting usage within rural communities. Living in an urban area may present greater opportunities for facility use due to increased access to facilities with SNF and/or long-term care beds. In addition, due to their proximity to urban areas, persons living in R,A versus R,N may have better access to specialists or other treatments or other home- and community-based services not measured in this study that help support continued community living.

The community-based support variable was not significantly associated with transition outcomes. Because everyone included in the analysis reported at least one helper, this study compared having a single to having multiple sources of community-based support. This measure of level of support differs from a measure that compares the presence and non-presence of support. Lacking support completely may have more of an impact on transitions to facilities than more or less support. Marital status emerged as an essential factor associated with continued community residence; being married compared to being widowed was associated with reduced probability of any transitions to nursing facilities as well as transitioning to a long-term care facility vs. not transitioning at all. It is well established in the literature that spousal caregivers are primary providers of long-term care and are typically the first to step in when such care is needed. In addition, Black or African American race, as

compared to White race, was associated with reduced probability of transitioning from the community to a long-term care facility (i.e., nursing home or assisted living) versus not transitioning at all among persons with dementia and functional limitations included in this study. African Americans consistently experience disparities in access to formal healthcare services. Although nursing home use has steadily increased among minorities over time, African Americans remain less likely to be placed in a nursing home than Whites (Akamigbo & Wolinsky, 2007). Regardless of level of need, many minority families refrain from institutionalizing their disabled elderly. Minority elders with greater care needs, such as persons with dementia, are more likely than Whites to be cared for by children or others in the community versus in a nursing facility (Yarry, Stevens, & McCallum, 2007). Familial and communal expectations regarding the provision of caregiver support for older African Americans, as well as extended support networks, are often key determinants of community vs. facility residence. The findings that the number of co-morbidities was associated with an increase in the probability of transitioning to a SNF only and was associated with a reduction in the probability of transitioning to both a SNF and long-term care facility versus not transitioning at all suggests that persons in this sample with more co-morbidities may be more likely to have acute episodes where shorter-term rehabilitative care in SNFs is needed but that they may transition back to the community versus to a long-term nursing facility following a SNF stay.

Healthcare policymakers and other stakeholders are committed to identifying measures to not only reduce costs but also to creating medical homes for the sickest and most vulnerable patients, improving care coordination, and delaying or avoiding costly nursing home or skilled nursing facility placement (Levine et al., 2010). Increased demand for long-

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term care services and supports coinciding with the projected increases in the prevalence of dementia due to rapid population aging will undoubtedly challenge the system's capacity for quality care provision sans adequate planning across the care continuum, of which community-based living is a critical aspect. This aim's finding that R,A residents were less likely than U residents to transition to nursing facilities could relate to enhanced efforts to provide better access to LTSS. However, this relationship was not observed among R,N dwellers, which could mean that R,N dwellers remain more isolated from such services than their R,A counterparts.

Several limitations of this aim's analyses should be considered. Because this is an unweighted analysis of MCBS data, these findings are not generalizable to the entire Medicare population. In addition, this analysis did not assess the total number or various combinations of nursing facility transitions. Because dually eligible beneficiaries were included in the sample, not controlling for access to other supportive home- and community-based services or LTSS that would be largely accessible through Medicaid enrollment such as attendant care, homemaking, transportation assistance, or home-delivered meals, which were not available in the MCBS, is a limitation because the receipt of these services could also have an impact on nursing facility use. The Medicare claims data that accompany the MCBS data modules only include data for beneficiaries included in the respective module and for that particular file year (CMS, 2013b). Medicare claims on historical or future events for past or current participants are not included in the standard release (CMS, 2013b). Therefore, an indicator of previous nursing facility use prior to MCBS study entry was not included in the regression models. Such a variable could have been used as a proxy indicator

of factors that were not measured in the data, such as preferences for facility care or access to nursing facilities.

Additionally, the use of a weak instrument to test for endogeneity associated with the community-based support variable is a key limitation. The non-significance of the residual in the second-stage 2SRI regression models could be associated with a lack of statistical power to detect endogeneity due to the smaller sample size and weak association of the instrument with the potentially endogenous regressor rather than to a truly exogenous relationship between the variables. In the context of weak instruments, 2SRI model results are unreliable because the standard errors associated with IV estimates can be inflated and lead to statistical non-significance (Nichols, 2006). This likely explains the difference between the significant predictors identified in the 2SRI vs. exogenous regression models. However, weak instruments are commonplace in empirical research due to the difficulty associated with identifying strong instruments (Stock, Wright, & Yogo, 2002) and this strategy was preferred over assuming exogeneity in the absence of any instrumental variables testing. Future studies examining the effect of informal or community-based care on transition outcomes should seek to identify stronger instruments to include in instrumental variables regression models for more confident conclusions regarding the presence of endogeneity bias. A larger study and one that includes family-level variables to test as instruments might result in more power to determine whether endogeneity is a valid concern in residential care transition studies among this patient population. Unfortunately, such variables were either not available in the data for these beneficiaries or not significantly associated with the endogenous regressor.

Despite these limitations, this study provides unique information regarding the movement of persons with dementia and functional limitations living in rural and urban

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community settings into nursing facilities, accounting for both informal and formal sources of community-based support. This is often not feasible due to data limitations. However, the MCBS provided a unique opportunity for concurrent examination.

Rebalancing long-term care away from institutions toward home- and community-based services is a policy goal that not only exists at the system -level (i.e., it is largely driven by the need to manage healthcare costs) but is shared by many older adults and their family caregivers (Levine et al., 2010). Although postponing or foregoing the transition to a nursing facility has become the preferred care strategy, nursing homes and other institutions serve a special purpose in elder care. As this aim's findings show, a substantial portion of persons with dementia and functional limitations in the study sample transitioned to nursing facilities. Transitions into facilities for short- or long-term care may be a necessary and/or desired option at some point for many elders with dementia and their families. Therefore, as the older adult population at risk for developing AD grows, so does the need for a larger dementia care workforce, both in institutions and communities, to meet impending demands and service needs. Monitoring the movement of the larger population of older adults with dementia, not just those with access to Medicaid, into facilities is critical because information regarding such usage may contribute to advanced programs and services that promote sustained patient-centered care. The assurance of such care is rooted in the awareness and ability of persons with dementia and limited functioning, and their caregivers to access any care options that are desired.

CHAPTER 6. RURAL-URBAN RESIDENCE, COMMUNITY-BASED HELPER SUPPORT, AND TIME-TO-TRANSITION

Introduction

Older adults with dementia have an increased risk of transitioning to nursing facilities. A previous state-based study examined time-to-nursing home placement among Medicaid enrollees and found that the rate of nursing home placement for persons with dementia was more than twice as high as that for persons without dementia (Sands et al., 2012). In Chapter 5's exogenous multinomial regression model, older age was associated with increased probability of transition to both a skilled nursing facility (SNF) and nursing home or assisted living facility versus not transitioning at all. Examining not only whether older beneficiaries with dementia and functional limitations transition out of the community into nursing facilities but also the timing or rate of such transitions is an important research pursuit. The identification of factors associated with the rate of transition to a nursing facility, including rural vs. urban residence and community-based support, may better inform efforts to improve transitional care across residential settings.

To my knowledge, no previously published studies have examined rural vs. urban differences or the effect of community-based helper support on time-to-transition among Medicare beneficiaries with dementia and functional limitations. Similar to the methods employed by Toloza and colleagues (2004) to examine baseline predictors of vascular events, this study includes a time-to-event analysis as an alternative to the multivariable models examining predictors of nursing facility transitions included in Chapter 5's analysis.

Specifically, this study aim assesses the rate of residential care transitions to nursing facilities among the study sample to determine if predictors associated with transitions are similar in time-to-event analyses. The objective and associated hypothesis for this aim are:

Aim 3: To examine the effects of rural vs. urban residence and community-based helper support for ADL/IADL functional limitations on the length of elapsed study time (i.e., in days) to the first residential care transition to a nursing facility.

H3: On the basis of existing literature demonstrating that informal care provided by adult children delays nursing home entry (Van Houtven & Norton, 2004) as well as evidence of reduced access to adult children as caregivers among rural elders (Glasgow, 2000; Glasgow, 2003), it is hypothesized that rural residence and limited community-based helper support (i.e., single source of community-based support vs. multiple sources) will be associated with fewer elapsed days-to-first transition.

Methods

This aim's analyses included all beneficiaries who remained in the study beyond the baseline year with available duration data for the time-to-event analysis (n=430). The mean length of follow-up among these beneficiaries was 3.3 study years (SD=0.9) and ranged from two to four years. As in Aim 2 (Chapter 5), the number of reported ADL/IADL helpers ranged from one to five (Mean=1.6; *SD*=0.8) and a global measure of community-based support that accounts for both informal helpers and paid home health visits was included in the analysis. The MCBS contains start dates for beneficiaries' transitions between community, long-term facility residence (i.e., any facility other than a Medicare SNF), and Medicare SNF residence settings during the year. As a result, time-to-first nursing facility transition was measured and analyzed among the study sample. A beneficiary's first

community interview date served as the origin of time. The first nursing facility start date as obtained from the MCBS Residence Timeline file served as the endpoint for beneficiaries experiencing a transition. Duration time is measured in number of days. Survival times were right-censored at the last interview date, as available. Because the MCBS Access to Care module only includes persons who were alive during the MCBS study year (i.e., fall-round to fall-round) and death dates provided reflect beneficiaries who died after the fall round interview and prior to the next interview (on or before December 31st of the calendar year), all death dates occur following the last interview. As such, although death could represent a competing risk for transition, in this analysis, no documented deaths occurred prior to the last interview. In other words, no beneficiary died prior to the end of their risk period. Dates that included the month and year but were missing the day, were replaced with the 15th.

Survival analysis methods were used in this aim to examine time-to-first nursing facility residential care transition during the study period. Specifically, a Cox proportional hazards regression model with fixed covariates and robust standard errors was applied. The statistical model for the hazard function estimated is depicted in Equation 6 (Walters, 2009).

Equation 6: $h_i(t) = h_0(t) \exp(\beta_1 x_{i1} + \beta_2 x_{i2} + \ldots + \beta_k x_{ik})$, where

$h_i(t)$ represents the hazard or risk of transition at time t (or the conditional probability of event at time t having survived to that time);

$h_0(t)$ is the baseline or underlying hazard function that corresponds to the probability of reaching the event when all of the explanatory variables are equal to zero;

x represents the explanatory variables included in the model;

β represents the coefficients associated with the included explanatory variables;

i is a subscript for observation;

and k is a constant for the explanatory variable count.

These models operate under the proportional hazards assumption, which assumes a constant relationship between the dependent variable and the explanatory variables. A test of nonzero slope (null hypothesis is that the slope is zero) using a generalized linear regression of the scaled Schoenfeld residuals on time, which is equivalent to testing that the log hazard-ratio function is constant over time, was used to test this assumption (Grambsch & Therneau, 1994).

Plots of the Kaplan-Meier estimates of the survivor functions were also generated; this is a plot of the survival function against time (Bewick, Cheek, & Ball, 2004). Comparisons of survival curves for the rural-urban residence categories and community-based support for ADL/IADL limitations variables were examined via Kaplan-Meier plots and formally tested via log rank tests. Breslow's method for handling ties, or cases that reach the event at the same time, was applied. The median, or the point at which 50% of those in the sample or group experienced a transition, is used for comparisons.

Using the same methods described in Chapter 5, instrumental variables analysis (i.e., 2SRI) was performed to test and control for potential endogeneity associated with the community-based support variable. The same first-stage regression model from Chapter 5 was applied here; the joint F-test was not statistically significant ($\chi2$ (N=402, 7)=8.76; p=0.27; F=1.25). Similar to Aim 2, population density per square mile in 2000 was the only identified instrument for the community-based helper support variable ($\chi2$ (N=402, 1)=4.93;

p=0.03; F=4.9). All persons with available data for this aim's analysis reported a usual source of care, so this variable was not included in the regression models.

Results

Characteristics of the sample included in this aim's analysis are provided in Table 38. Duration data were available for 159 of the 170 beneficiaries who experienced a nursing facility transition. The total analysis time at risk for the sample was 306,000 days. The last observed exit time was 1,241 days.

Transition times are summarized in Table 39. Among those who transitioned to a nursing facility, the mean time to transition was 454 (*SD*=304) days, with a median transition time of 383 days. The median transition time was shortest among U residents. Those living in R,N had a longer median duration than the other residence groups. However, a log rank test for the equality of survival functions across rural vs. urban residence was not statistically significant (*p*=0.47). Durations were also examined by single vs. multiple source(s) of community-based support. The median transition time was shortest among those reporting reliance on multiple sources of support (372 days) vs. 406 days for those with a single source of support. However, a log rank test for the equality of survivor functions was not statistically significant (*p*=0.18). Kaplan-Meier plots of the estimated survival functions against time for the entire sample, and across residence and support groups, are illustrated in Figures 7–9.

Results from the first-stage 2SRI regression in this aim's analysis are provided Table 40. As in Aim 2, on average and holding all other factors constant, population density per square mile in 2000 was significantly associated with an increase in the probability of having a single source of community-based support. Per protocol, the second-stage 2SRI Cox

proportional hazards regression model was performed with both the single vs. multiple sources of community-based support variable and the predicted first-stage residuals included, plus all other exogenous variables.

Results from the second-stage 2SRI and Cox proportional hazards regression models where potential endogeneity was assumed are depicted in Table 41. In the 2SRI model, number of co-morbidities was negatively associated with the hazard rate for transition. A one-unit increase in the number of co-morbidities was associated with a 23% reduction in the hazard rate for transition. The non-significance of the residual in the second-stage model suggested a potentially exogenous relationship between community-based helper support and transition outcomes. As such, the model was performed under the assumption of potential exogeneity. However, a weak instrument was applied and the presence of endogeneity cannot be definitely ruled out.

In the model assuming potential exogeneity, age was significantly associated with a 3.1% increase and number of co-morbidities was associated with a 17% decrease in the hazard rate for transition. The test of the proportional hazards assumption from the regression of the scaled Schoenfeld residuals on time was not statistically significant (global $p=0.84$), indicating that the model did not violate the proportional hazards assumption (this test was also not statistically significant for the 2SRI second-stage model (global $p=0.75$)).

Table 38. Characteristics of the Sample: Aim 3, N (%)

Rural vs. Urban Residence (N=427)		
	R, N	47 (11.0)
	R, A	64 (15.0)
	U	316 (74.0)
Single Source of Community-Based Helper Support (N=417)		200 (48.0)
Lives Alone (N=430)		117 (27.2)
Age (years), Mean (*SD*) (N=430)		81.5 (7.4)
Female (N=430)		280 (65.1)
Race (N=430)		
	White	290 (67.4)
	Black or African American	52 (12.1)
	Other Race (Includes more than 1 race)	88 (20.5)
Ethnicity: Non- Hispanic or Latino (N=430)		26 (6.1)
Marital Status (N=430)		
	Married	185 (43.0)
	Widowed	199 (46.3)
	Divorced, Separated, or Never Married	46 (10.7)
Income $25K or Less (N=427)		291 (68.2)
High School Diploma or Greater (N=422)		227 (53.8)
Number of difficulties, Mean (*SD*) (N=430)		6.0 (3.4)
Number of co-morbidities, Mean (*SD*) (N=430)		1.4 (1.0)
General Health Status Rating (N=429)		
	Excellent or Very Good	104 (24.2)
	Good	134 (31.2)
	Fair or Poor	191 (44.5)

Table 39. Mean and Median Nursing Facility Transition Times (days)

	n	Mean(*SD*)	Median
Overall			
Transitioned to a nursing facility	159	454 (304)	383
Rural -Urban Residence			
R,N	20	489 (286)	442
R,A	19	469 (321)	412
U	118	450 (308)	380
Sources of Community-based Support for ADLs/IADLs			
Single Source	69	464 (308)	406
Multiple Sources	87	449 (305)	372

Table 40. 2SRI First-Stage Logistic Regression Model: Endogenous Regressor as Outcome (Single (1) vs. Multiple Sources of Support (0))—Aim 3

	Average Marginal Effects (Standard Errors)
Population density per square mile 2000	0.00000688[*] (0.00000310)
Rural vs. Urban Residence	
R,N	0.0296 (0.0739)
R,A	0.0368 (0.0641)
Lives alone	-0.0789 (0.0628)
Age	-0.00888[*] (0.00359)
Male	0.0662 (0.0506)

	Average Marginal Effects (Standard Errors)
Race	
Black or African American	0.0592
	(0.0750)
Other race (Includes more than 1 race)	0.0397
	(0.0635)
Hispanic or Latino ethnicity	-0.113
	(0.115)
Marital Status	
Married	0.0179
	(0.0633)
Divorced, separated, or never married	-0.0497
	(0.0820)
Income $25K or Less	-0.0446
	(0.0542)
High School Diploma or Greater	-0.0324
	(0.0498)
Number of ADL/IADL difficulties	-0.0410***
	(0.00659)
Number of Co-morbidities	-0.0620**
	(0.0218)
General Health Status Rating	
Excellent or very good	-0.0234
	(0.0630)
Fair or poor	-0.0564
	(0.0566)
Observations	402

Notes: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Referent categories are Urban, White, Widowed, and *Good* general health status rating.

Table 41. Factors Associated with the Hazard Rate for Transition to a Nursing Facility during Follow-Up: 2SRI and Exogenous Cox-Proportional Hazards Second-Stage Model Results

	2SRI Hazard Ratios (Bootstrapped Standard Errors)	Exogenous Hazard Ratios (Standard Errors)
R,N	1.178 (0.342)	1.146 (0.299)
R,A	0.681 (0.211)	0.667 (0.185)
Single source of community-based support	0.251 (0.305)	0.954 (0.172)
Pearson residual	1.842 (0.989)	N/A
Lives alone	0.956 (0.259)	1.051 (0.240)
Age	1.018 (0.0198)	1.031[*] (0.0140)
Male	1.030 (0.272)	0.932 (0.209)
Black or African American	0.785 (0.268)	0.725 (0.223)
Other Race (Includes more than 1 race)	0.793 (0.192)	0.757 (0.173)
Hispanic or Latino ethnicity	0.749 (0.324)	0.829 (0.296)
Married	0.633 (0.184)	0.617 (0.166)

	2SRI Hazard Ratios (Bootstrapped Standard Errors)	Exogenous Hazard Ratios (Standard Errors)
Divorced, separated, or never married	1.173	1.237
	(0.433)	(0.389)
Income $25K or Less	0.756	0.805
	(0.182)	(0.172)
High School Diploma or Greater	1.060	1.109
	(0.224)	(0.216)
Number of ADL/IADL difficulties	0.986	1.043
	(0.0598)	(0.0306)
Number of Co-morbidities	0.767[*]	0.832[*]
	(0.0882)	(0.0721)
General Health Status		
Excellent or very good	0.864	0.903
	(0.218)	(0.200)
Fair or poor	0.859	0.917
	(0.208)	(0.192)
Observations	402	402

Referent categories are Urban, White, Widowed, and *Good* general health status rating.

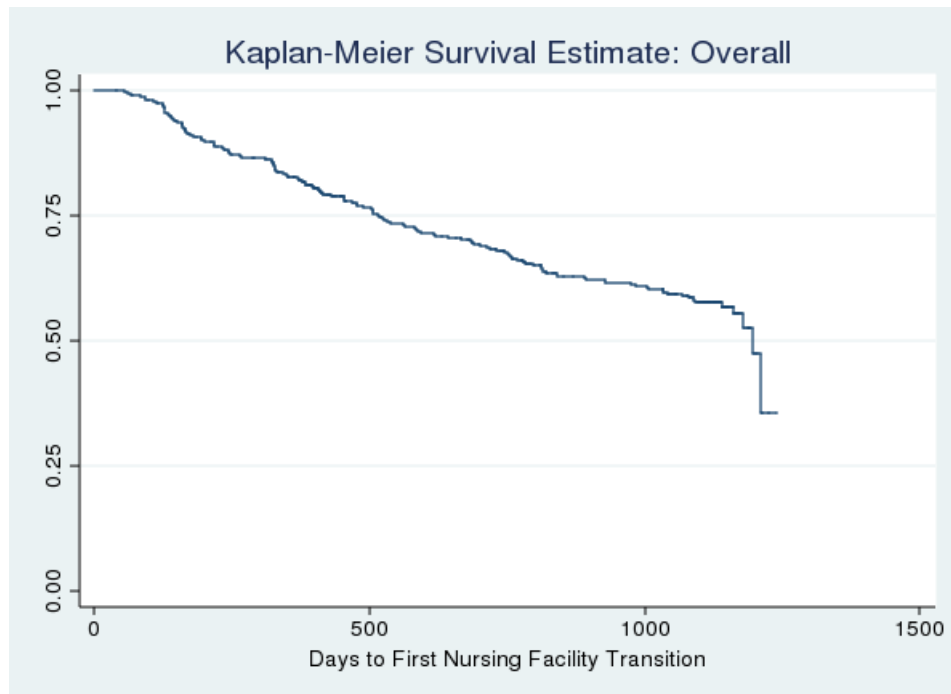Figure 7: Kaplan-Meier survival plot for transition: Overall.

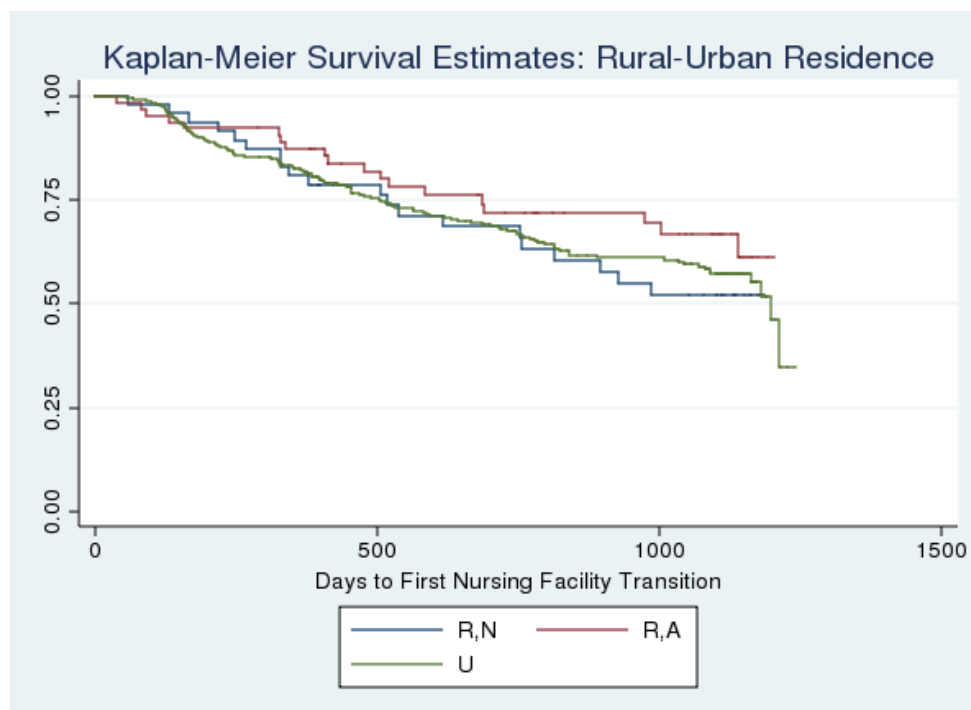Figure 8. Kaplan-Meier survival plot for transition: Rural vs. urban residence.

Figure 9. Kaplan-Meier survival plot for transition: Single vs. multiple source(s) of community-based help.
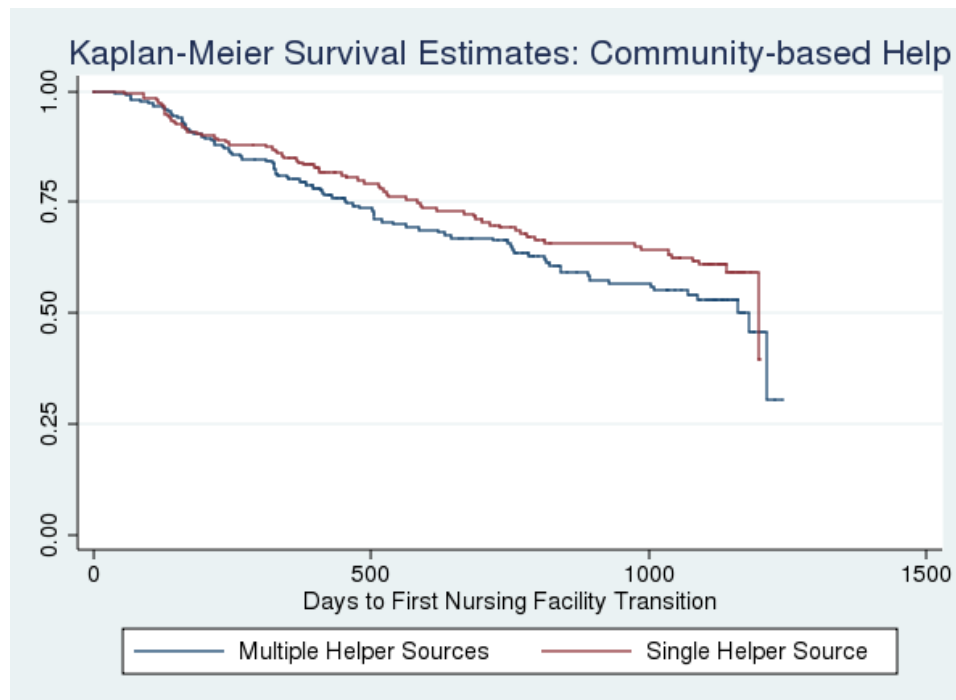
Discussion

The purpose of this study aim was to examine the effect of rural vs. urban residence and community-based helper support on the timing of transitions to nursing facilities among the study sample. Overall, this aim's hypothesis was not supported, given that rural residence and level of community-based support for ADLs/IADLs were not significantly associated with time-to-first nursing facility transition. Aim 2 and Aim 3 models commonly identified two significant predictors: age and number of co-morbidities.

As expected, the rate of transition to a nursing facility increased with age among beneficiaries with dementia and functional limitations. The detrimental effects of dementia advance with age and older age is a critical risk factor for institutionalization in general. Although one would expect that persons with a greater number of co-morbidities would transition to a nursing facility sooner than those with fewer co-morbidities, beneficiaries in

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this study with more co-morbidities had a reduced rate of transition. In Aim 2, persons with greater co-morbidities were more likely to transition to a SNF only and less likely to transition to both a SNF and long-term care facility. This suggests that these beneficiaries may have experienced acute complications requiring SNF care and they may transition to a SNF later due to requiring a longer period of acute hospital-based care. Although hospitalizations were not directly examined in this study, this is a plausible explanation. It is also possible that persons in the study with fewer co-morbidities had greater dementia severity, which facilitated their transition to both a SNF and long-term care facility. However, dementia severity was not measurable in this study.

Although not statistically significant, descriptively, median transition time to a nursing facility was shortest among those living in U and persons with multiple helper sources. Urban dwellers may have a shortened transition time due to increased availability of and access to nursing facilities. Although the ratio of certified nursing home beds and Medicare-certified nursing home beds per resident age 65 or older tends to be higher in rural than urban counties, the supply of nursing home beds varies greatly across states and the majority of nursing facilities remain located in urban or metropolitan areas (Dalton, Howard, Slifkin, Van Houtven, & Poley, 2002). In Aim 2, persons with dementia living in U were more likely to transition to both a Medicare SNF and long-term care facility than R,A dwellers. Increased access to such facilities in general could explain the increased probability of transition and descriptively fewer elapsed days to transition among U residents. In addition, persons who rely on multiple sources of support may have less stable support networks due to challenges associated with coordination of care in the community among these helpers, and thus transitioning to a facility may be a necessary step. Although not

statistically different, these descriptive findings suggest the potential for underlying differences that should be explored in future studies.

Limitations of this analysis should be considered. First, generalizability of these findings is limited. In addition, as discussed in Chapter 5, the use of a weak instrument to test for the presence of endogeneity associated with the community-based support measure is a key limitation. Although the applied methods suggested that no endogeneity was present, this finding could be due to insufficient power to detect such relationships that may be attributed to the weak instrument applied and limited sample size. However, this method was preferred over assuming strict exogeneity with no testing. Last, missing dates for the time-to-event analysis could lead to biased results. As such, the difference in significant predictors identified in Aims 2 and 3 could be attributed to missing data.

Despite these limitations, this study offers unique insight into the timing of transitions into nursing facilities, primarily Medicare SNFs, from community settings among patients with dementia and functional limitations. Given the economic challenges associated with nursing facility care for Medicare beneficiaries with serious chronic illnesses such as dementia, the sustainability of such care for these individuals is threatened. Although transition rates across rural-urban residence were not statistically different in this analysis, continued examination of potential differences in community vs. facility care among rural and urban beneficiaries with dementia and functional limitations may be worth further monitoring.

CHAPTER 7. CONCLUSION

The key contributions of this work are: 1) the longitudinal description of community-based helper support for older persons with dementia and ADL/IADL limitations; 2) the novel examination of rural vs. urban disparities in community-based helper support, more specifically gaps in such support, for older Medicare beneficiaries with dementia and functional difficulties living in the community; 3) the consideration and inclusion of critical contextual factors, particularly those in which significant differences have been documented for rural- vs. urban-dwelling elders; and 4) the use of a longitudinal data set and unique analytical approaches to examine the effects of rural vs. urban residence and community-based helper support on the likelihood and timing of residential transitions to formal care nursing facilities over time. Geographic differences and disparities in community-based helper support and nursing facility transitions among older persons living with dementia remains understudied. Therefore, this study expands the caregiving and transitional care literature bases by providing additional evidence on the experiences of older persons limited by dementia who are living in the community, the level and type of help that they receive or to which they have access, and how transitions to nursing facilities are influenced by where they live, the support they have, and other critical contextual factors.

Summary of Findings

In summary, this study found:

- ***Description of Community-Based Support for ADL/IADL Limitations:***
  Trends
  - On average, means for reported functional limitations and number of

    ADL/IADL helpers increased over time among this sample of Medicare

    beneficiaries with dementia. Additionally, on average, the total number of

    ADL/IADL difficulties and total number of ADLs alone were significantly

    lower among R,N residents compared to U residents over time. There were no

    statistically significant rural vs. urban differences in the reported number of

    ADL/IADL helpers over time. Living in R,N was significantly associated with

    receiving support from non-kin helpers only versus other sources of support.

- ***Transitions in Support (Descriptive Only)***

  - Descriptively, the percent of beneficiaries who ever reported receiving support

    from adult children who also reported receiving help from adult children in

    the next study period was lowest among beneficiaries living in R,N areas.

- ***ADL/IADL Support Gaps***

  - Thirty-percent of beneficiaries had at least one ADL or IADL support gap at

    baseline. There were no statistically significant differences between rural and

    urban beneficiaries in the presence of support gaps over time. Factors

    significantly associated with the presence or absence of any ADL/IADL

    support gaps over time included Hispanic or Latino ethnicity, living alone,

    and total number of difficulties.

- *Likelihood of Transition to a Nursing Facility*
    - Compared to persons living in an urban area, beneficiaries with dementia and functional limitations who lived in a rural area adjacent to a metropolitan or micropolitan area were less likely to transition to both short- and long-term care facilities versus not transitioning at all. Level of community-based support was not significantly associated with nursing facility transitions.

- *Time-to-First Transition to a Nursing Facility*
    - Rural-urban residence and single vs. multiple source(s) of community-based support were not associated with time-to-first nursing facility transition. Increasing age and number of co-morbidities were significantly associated with increased and reduced time-to-first nursing facility transition, respectively.

Study Limitations

Although this study provides a significant contribution to the dementia care literature, these study findings should be considered in the context of several limitations associated with using existing MCBS data. Generally, questions regarding helper support are only asked once per year. This is meant to provide a view of what happened during the year. As such, changes that occur outside of these data points are not accounted for. Additionally, although beneficiaries or proxy respondents may report helpers for ADLs and IADLs, there is no particular order of importance associated with the list of reported helpers. It cannot be assumed that the first reported helper is the primary helper because MCBS does not ask that helpers be listed in order of importance of assistance (Dudgeon et al., 2008). Helper information is also self- or proxy-reported, which is subject to recall bias.

Another limitation is that in follow-up interviews when collecting data on ADL/IADL helpers the MCBS does not ask whether the reported helper(s) are the same individuals that were reported as providing help in earlier interviews. Due to this, continuity of helper support in terms of whether an individual's support remains exactly the same and is provided by the same individuals is unable to be determined in this study. Additionally, other important factors that may influence the relationships in this study such as duration of support provided and patient and family preferences for care were not measured in the MCBS.

To reiterate, this study includes community-dwelling beneficiaries included in newly enrolled panels from 2000–2006 and follow them throughout their potential four years of follow-up interviews. Based on examinations of the online questionnaires, questions regarding prior stays in a facility were only posed to facility-dwelling beneficiaries for whom background questionnaires were completed. This study includes persons who were community-dwelling at baseline who were not asked such questions. Therefore, there is no assessment of whether a beneficiary has transitioned to a nursing home or other nursing facility prior to being integrated back into the community and enrolling in the MCBS. This is a limitation because this study cannot assume that any transitions that occur are the first to have ever occurred for study participants. Transitions to the homes of children or other relatives are not accounted for because this information is unavailable. Nonetheless, the ability to track beneficiaries' movement between settings is a unique and valuable characteristic of the MCBS that greatly contributes to this study's examination of contextual influences on residential transitions, which can inform policy on access to care for individuals living with dementia.

Study eligibility for this research heavily rests on a diagnosis of AD or another form of dementia. Although this study uses both self/proxy-reported diagnoses as well as claims to identify eligible beneficiaries, there is a potential for bias given the self/proxy reporting. The potential for such misreporting should be considered. Further, under-diagnosis of dementia is a serious issue (Solomon & Murphy, 2005). This study may underestimate the prevalence of beneficiaries with any form of dementia in the MCBS. The MCBS also notes that persons in Medicare managed care are not included in claims data, which could also limit study participant identification.

Limitations also arise with regard to the non-application of weights. Each year of MCBS data has several types of sampling weights that can be used to produce estimates from the sample that are generalizable to the Medicare population and that reflect the overall selection probability of each sample person and also include adjustments for survey non-response and post-stratification elements related to sample entry, age, sex, race, region, and metropolitan area status (Briesacher et al., 2012). The MCBS contains longitudinal weights for beneficiaries with full-year observations in the Access to Care module, which are called "backward longitudinal" weights because they apply to only the surviving sample and are used to "look back" to data from previous years (Briesacher et al., 2012). Because this particular MCBS subpopulation suffers from significant attrition across study years, a very limited sample was available for use with the appropriate three-year backward longitudinal weights. This is a critical limitation because not accounting for MCBS's weighting, clustering, and stratification design may result in standard errors that are smaller than they should be or even biased estimates (Briesacher et al., 2012). As a result, this study lacks generalizability to the full Medicare population and inferences are limited to persons with

characteristics of the sample analyzed. Although unweighted studies using the MCBS have previously been published (Mello, Stearns, Norton, & Ricketts, 2003; Briesacher, Stuart, Ren, Doshi, & Wrobel, 2005; Balsa, Cao, & McGuire, 2007; Simoni-Wastila, Zuckerman, Shaffer, Blanchette, & Stuart, 2008; Briesacher, et al., 2012), non-use of the provided MCBS weights is an important study limitation. Limitations associated with this study's design prevent conclusions about causality and the implications of these findings are not definitive.

Despite these limitations, the MCBS provides a unique opportunity to examine the specified relationships concurrently. The concurrent examination of the role of informal community-based care in nursing facility transitions using national level data is a key study strength. This study expands knowledge regarding a critical issue facing older Americans today that has not previously been pursued. Future work should examine strategies for examining geographic disparities in community-based support and associated care transitions in larger, representative samples. Potential avenues for future research along these lines in the MCBS include increasing the sample size of beneficiaries with dementia in one's analysis by including additional panels from new and forthcoming data releases and expanding the study to compare beneficiaries with dementia to other groups of Medicare beneficiaries.

Policy Implications and Future Research

Although this study has limited generalizability, this research has immediate significance and important policy and practice implications for key Medicare stakeholders (i.e., patients, providers, and policy makers) and can inform future work in this area. With millions of aging Americans at risk for developing dementia, there is considerable public policy and clinical interest in effective and efficient ways to assist people with dementia to continue to live in community settings as independently as possible (Levine et al., 2010).

Family or other informal caregivers are essential to maintaining persons with dementia in the community. Because most home care occurs over time, the persistence of the support network is especially relevant (Porter & Ganong, 2005).

Findings from this study suggest that the support networks of older persons in the community with dementia differ across rural and urban communities and that they may change over time. Persons with dementia should have equitable access to alternative care options, including community-based supports when nursing home placement is either inaccessible or undesired. The success of improved transitional care rests squarely on the sustained involvement, training, and support of family caregivers (Levine et al., 2010).

This study's finding that gaps in community-based support are present among Medicare beneficiaries with dementia and functional limitations, a population that typically requires sufficient and sustained support to complete basic activities of daily living, highlights the need to continue to develop and implement legislative provisions that seek to equalize access to community-based care options that supplement unpaid community-based care. The 1999 Supreme Court ruling in *Olmstead v. L.C.* ((98-536) 527 U.S. 581 (1999)) has played a prominent role in helping older adults with disabilities remain in or return to their communities—since this ruling there has been steady growth in home and community-based long-term care service options (Kasper, 2005). Following the Olmstead ruling, people with disabilities, including elderly persons, gained greater access to community-based services that would support community living. Such policies demonstrate a growing commitment on the government's part to assist patients, families, and providers in meeting the challenges of dementia and long-term care and reduce gaps in access to alternative residential elder care options.

Improved care for older adults with dementia should involve well-supported options for patients and families and include collaborative and sustained partnerships between healthcare stakeholders. The knowledge gained from this study highlights areas of need in terms of community-based support (i.e., gaps in reported support for reported functional difficulties) among elders with this illness. This information may be incorporated into daily healthcare practice operations by assessing and placing greater attention on the availability of and changes in helper support over time for older persons with dementia being served and cared for. Although the literature includes information on intervention programs designed to help caregivers of persons with dementia such as continuing care models, case management models, respite and day care programs, and various caregiver support groups (Toseland et al., 2002), more tailored interventions and strategies may be necessary to account for community-specific functional support needs.

Given the persistent impact of dementia on the rapidly aging population, it is imperative that our healthcare system's infrastructure, policies, and practices adequately address the growing and impending needs of America's elders, particularly those living in medically underserved communities. Transitional care is a complex issue and this study merely scratches the surface when it comes to understanding the complexities associated with these outcomes. However, this study does offer key insights into the residential transitions of older community-dwelling adults impacted by AD, which is one of the primary diseases affecting functioning and quality of life among older Americans today. The policy agenda should be expanded to place additional focus on transitions beyond hospitalizations, particularly among people with dementia, because transitions to short- and long-term nursing facilities are equally impactful for patients, their families, and the healthcare system. Care

needs increase substantially with progressing dementia and formal health services, such as nursing home or skilled nursing facility care, may be necessary or preferred option (Toseland et al., 2002). However, equitable access to well-supported community living for older adults affected by dementia or their family members who desire to receive care in community residences rather than institutions, regardless of geographic location, should remain a policy goal.

APPENDIX. STUDY INCLUSION AND EXCLUSION CRITERIA (BASELINE)

Inclusion	Exclusion
• Medicare beneficiaries with enrollment years into the MCBS from 2000-2006	• Person who receives Medicare benefits who either was not enrolled in the MCBS at all, enrolled prior to 2000, or enrolled after 2006.
• Enrolled in fee-for-service Medicare	• Enrolled in Medicare advantage/group health plan
• Age 65 and above	• Less than 65 years old
• Non-Puerto Rico residents	• Puerto Rico residents
• Community-dwelling (i.e., completed MCBS Community interview at baseline)	• Institutional or facility-dwelling persons (Completed MCBS Facility interview at baseline)
• Self/Proxy report at least one ADL or IADL difficulty	• Persons who do not self/proxy report at least one ADL or IADL difficulty
• Have either a self-reported or claims identified diagnosis of any form of dementia (i.e., per diagnosis codes)	• Persons who do not self/proxy-report dementia and lack evidence of a dementia diagnosis in linked claims files
• Medicare-eligible due to age or disability, No ESRD	• Medicare-eligible due to End-Stage Renal disease

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