

©Copyright 2017

Michelle Pui-Yan Yip

Home Care Provision and Quality of Life among Older Adults

Michelle Pui-Yan Yip

A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2017

Reading Committee:

Barbara B. Cochrane, Chair

Pamela Mitchell

Gunnar Almgren

Program Authorized to Offer Degree:

School of Nursing

University of Washington

**Abstract**

Home Care Provision and Quality of Life among Older Adults

by Michelle Pui-Yan Yip

Chair of the Supervisory Committee:

Barbara B. Cochrane, Professor

The de Tornyay Endowed Professor for Healthy Aging

Family and Child Nursing

Home care is a non-institutional type of long-term care service. Provision of home-based long-term care (also known as personal care service) includes a range of activities of daily living (ADL) assistance and instrumental activities of daily living (IADL) assistance provided to individuals with disabilities and chronic conditions, enabling them to stay in their homes and communities and to maintain independence. The growing number of older adults and people with disabilities have increased the demand for long-term care services and driven up costs. To absorb the increasing demand for long-term care and lower the high spending on institutional care, Medicaid-funded home care has expanded to meet the demand. Medicaid-funded home care

programs provide individualized personal care and home-making services to people with functional limitations and help them remaining at their own residence as long as possible in hopes of promoting quality of life of service recipients and delaying their need for institutional care, particularly among older adults.

The purposes of this study were to describe the quality of home care and explore how it might influence quality of life and nursing home placement. The specific aims were to:

- (1) describe quality of home care of Medicaid-funded home care programs and the factors that influenced quality of home care from case managers' perspectives.
- (2) examine the relationships between provision of home care and quality of life outcome measures (i.e., self-rated health status and well-being index) over four years of follow up among Medicare-beneficiaries who were 65 years and older.
- (3) estimate the odds of long-term nursing home placement by the number of activities of daily living tasks needed and received, while accounting for death as a competing risk event, among Medicare-beneficiaries who were 65 years and older.

This dissertation included a qualitative interview study and two secondary analyses of longitudinal survey data derived from the National Health and Aging Trends Study. The qualitative study involved individual interviews with 11 case managers, who were practicing case management in home care programs in Washington State. The two secondary analyses addressed two research questions. One analysis explored the associations of home care service with self-rated health status and well-being. Another analysis examined the effect of home care service on the odds of nursing home placement in a cohort of 6004 home-dwelling older adults.

The study findings demonstrated a five-level ecological influence on quality of home care and suggested a linkage between quality of home care and quality of life of older service

recipients. Home care service was statistically nonsignificant, but positively associated with self-rated health status and well-being. Significant associations were found between the number of activities of daily living assistance needs and self-rated health status and well-being. Finally, the incidence of nursing home placement was lower for individuals with formal activities of daily living assistance than individuals without such assistance, while accounting for death as a competing-risk event. The incidence of nursing home placement was higher for individuals with informal activities of daily living assistance, increasing age, and increasing number of medical conditions. Future research is needed to develop a set of measures for home care quality and service outcomes, as well as to link home care quality to outcomes.

## TABLE OF CONTENTS

	Page
Chapter I: Introduction to the Study .....	1
Purpose & Specific Aims .....	4
Organization of Dissertation Chapters .....	4
References .....	6
Chapter II: Manuscript #1 – “Case Managers’ Perspectives on Quality of Home Care” .....	11
Abstract .....	12
Introduction .....	13
Purpose .....	15
Methods .....	16
Data Analysis .....	17
Results .....	17
Discussion .....	32
References .....	38
Chapter III: Manuscript #2 – “The relationships between Quality of Home Care and Health-Related Quality of Life” .....	46
Abstract .....	47
Introduction .....	48
Purpose .....	52
Methods.....	53
Data Analysis .....	57
Results .....	58
Discussion .....	60
References .....	66
Chapter IV: Manuscript #3 - “Home care and Nursing Home Placement, Accounting for Death as a Completing Risk among Home-dwelling Older Adults” .....	79
Abstract .....	80
Introduction .....	82
Purpose .....	86
Methods.....	86

Data Analysis .....	89
Results .....	89
Discussion .....	91
References .....	95
Chapter V: Conclusion of Study .....	108

## LIST OF FIGURES

Figure Manuscript #	Page
1. Themes and Subthemes of Quality of Home Care .....	45
2. Flow Chart of Study Participants .....	73
3a and 3b. Mean Self-Rated Health Status and Mean Well-being Index by Participants Overall and Strata of Need for Activities of Daily Living Assistance, (n=6,004) .....	78
4. Flow Chart of Study Participants .....	105

## LIST OF TABLES

Table Number	Page
1. Semi-structured Interview Questions on Quality of Home Care Services .....	44
2. Baseline Characteristics of Study Participants .....	74-75
3. Number and Percent of Participants Identified of Having Activities of Daily Living Assistance Need & Participants Received Activities of Daily Living Assistance .....	76-77
4. Generalized Estimating Equation (GEE) of Relationship of Activities of Daily Living Assistance and Instrumental Activities Daily Living Assistance on Self-Rated Health Status among Three Stratified Groups: (1) Participants Reported of No Need for Activities of Daily Living Assistance, (2) Participants Whose Activities of Daily Living Needs Were Met, and (3) Participants Who Had At least One Unmet Need for Activities of Daily Living Assistance .....	79
5. Generalized Estimating Equation (GEE) of Relationship of Activities of Daily Living Assistance and IADL Assistance on Well-being Index among Three Stratified Groups: (1) Participants Reported of No Need for Activities of Daily Living Assistance, (2) Participants Whose Activities of Daily Living Needs Were Met, and (3) Participants Who Had At least One Unmet Need for Activities of Daily Living Assistance .....	80
6. Characteristics of participants by events (nursing home placement, death, and censored) .....	106
7. Model Results of Competing-risks Regression of Nursing Home Placement, Death as the Completing Risk (Participants = 6004) .....	107

## ACKNOWLEDGEMENTS

I would like to express my deepest appreciation:

- to the University of Washington School of Nursing for the excellent doctoral program that has enriched my nursing profession.
- to Professor Barbara B. Cochrane, my Supervisory Committee Chairperson, who shared her breadth and depth of knowledge, experience, and expertise in research on aging. She had provided invaluable guidance, support, and encouragement throughout the entire program. The opportunity to be a student of Dr. Cochrane has been a great honor.
- to my Supervisory Committee members, Dr. Pamela Mitchell, Dr. Gunnar Almgren, Dr. Jerald Herting, and Dr. Christopher Johnson who provided valuable advice and guidance that made this project a success.
- to the de Tornyay Center for Healthy Aging and Hester McLaws Nursing Scholarship Awards, which provided funding for my dissertation.
- to the PHAST (Public Health Activities and Services Tracking) team of University of Washington. I will remember your words of encouragement in my scholarly journey.
- to my parents Siu-Fung Ng and Juen-Kit Yip, as well as my siblings Pui-Yin, Pak-Lik, and Pui-Sze for all your love and support.
- to my extended family, Kin, Timothy, Jimmy, Kathy, and Zoe for being a part of this journey
- and last by no means least, to my husband Patrick and my children Truman and Emerson. You are always standing next to me at every moment in this journey. Without you, this achievement would never have come to pass.

## **DEDICATION**

This is dedicated to my late father, Juen-Kit Yip,  
for having been the person that you were.

## CHAPTER I: INTRODUCTION TO THE STUDY

Home care is a non-institutional type of long-term care service. Provision of home-based long-term care (also known as personal care service) includes a range of activities of daily living (ADL) assistance and instrumental activities of daily living (IADL) assistance provided to individuals with disabilities and chronic conditions, enabling them to stay in their homes and communities and to maintain independence. A growing number of older adults and people with disabilities have increased the demand for long-term care services and have driven up costs (de Meijer, Koopmanschap Koolman, & van Doorslaer, 2009; McAuley & Arling, 1984). The Center for Medicare and Medicaid Services (CMS) has focused primarily on finding a cost-effective way to deliver long-term care services. To absorb the increasing demand for long-term care and lower the high spending on institutional care, the Patient Protection and Affordable Care Act (ACA) legislation of 2010 continues its effort of balancing long-term care by providing states with incentives toward expanding home and community based long-term care services (HCBS) and reducing reliance on nursing home care (Centers for Medicare & Medicaid Services, 2014; Grabowski, Cadigan, Miller, Stevenson, Clark, & Mor, 2010; Kinoshian, Stallard, & Wieland, 2007; Miller, 2012; Wiener & Anderson, 2009). Among all HCBS, home care is the most preferred form of long-term care by older adults (Fried, van Doorn, Tinetti, & Drickamer, 1998; Guo, Konetzka, Magett, & Dale, 2014; Keenan, 2010; Mattimore, Wenger, Desbiens, Teno, hamel, Liu, ... Oye, 1997). Unlike institutional care and other community-based services, formal home care is the provision of a range of personalized services to individuals with needs for activities of daily living (ADL) and instrumental activities of daily living (IADL) assistance in their own residence (Fenstemacher & Winn, 2011; Hankwitz, 1991; Knight & Tjassing, 1994; Levine, Boal, & Boling, 2003).

With the ACA provision to balance long-term care and a strong preference for home care, more people will receive long-term care through Medicaid-funded home care programs operated by individual states (Kemper, 1992; LeBlanc, Tonner, & Harrington, 2001). Each state defines service eligibilities and service coverages differently. As a result, variations on how home care quality is defined and how quality of home care services should be measured exist (Applebaum & Phillips, 1990; Wiener, Anderson, & Gage, 2009). To improve quality of home care services, policy makers are compelled to better understand home care services and the effects of these services on care recipients' quality of life outcomes.

While policy makers presume home care is an alternative to nursing home care, little is known whether provision of home care can improve service recipients' quality of life outcomes and prevent them entry into nursing homes for long-term placement (Greiner, Qualls, Iwata, White, Molony, Sullivan, ... Setoguchi, 2014). Provision of PCS has been guided mainly by the philosophical assumption that high quality PCS improves health-related quality of life of the service recipients (Wilson & Cleary, 1995; Zubritsky et al., 2013). Little research has been done to examine this philosophical assumption. The main challenge for developing research in this area is a lack of benchmark measures reflecting service qualities. In LTSS, consensus on what is good quality of care is missing. Conventional measures following the structure and process of a quality of care framework, used to measure long-term care service in congregational settings, are inapplicable to measure services delivered to individuals at home. Another challenge is the dearth of national data sets linking service to health outcomes.

For policy makers to better allocate long-term care resources, the type and amount of services and length of time that service recipients received the care are important information for estimating the costs of formal home care (Weissert, Wan, Livieratos, & Pellegrino, 1980). While

home care is more desirable (Geron, Smith, Tennstedt, Jette, Chassler, & Kasten, 2000; Khatutsky, Anderson, & Wiener, 2006), existing studies have had inconsistent findings on the association of home care with duration of home stay (Guo, Konetzka, & Manning, 2015; Murkofsky, Phillips, McCarthy, Davis, & Hamel, 2003; Sands, Xu, Thomas, Paul, Craig, Rosenman, ... Weiner, 2012) and the odds of nursing home placement (Boaz & Muller, 1994; Gaugler, Duval, Anderson, & Kane, 2007; Liu, Coughlin, & McBride, 1991; Newman, Struyk, Wright, & Rice, 1990; Temkin-Greener & Meiner, 1995). A major limitation in these studies has been a lack of specification on how home care was defined, for instance home care services have been defined as the number of hours per month of services, as well as the dollars of Medicaid spending on home care. Given that home care involves a range of services including personal care and home-making services, what remains unknown are the associations of level of home care and types of care tasks with the length of time remaining at home and odds of transitioning to nursing homes for long-term placement among Medicaid home care recipients.

### **Purpose and Specific Aims**

This study is designed specifically to examine factors that influence quality of home care; and test the hypotheses that Medicaid-funded personal care assistance and home-making services, as predictors, increase length of stay in service recipients' homes and decrease odds of institutional long-term care. The specific aims of this study are to:

Aim 1: Describe quality of home care of Medicaid-funded home care programs and the factors that influence quality of home care and outcomes of older adult service recipients, from case managers' perspectives.

Aim 2: Examine the relationships between home care provision and quality of life outcome measures (i.e., self-rated health status and well-being index) over 4-years of follow up among Medicare-beneficiaries who were 65 years and older.

Aim 3: estimate the odds of long-term nursing home placement by the number of activities of daily living tasks need and received, while accounting for death as a competing risk event, among Medicare-beneficiaries who were 65 years and older.

### **Organization of Dissertation Chapters**

This dissertation has been organized in a way to convey the results of the study as a compilation of three distinct manuscripts. Chapter I contains an introduction and overview of the complete study. Chapter II is a qualitative study of interviews with case managers regarding their perspectives on quality of home care and how quality of home care may influence the outcomes of older adult service recipients. Chapter III provides details of the results for Aim 2 as a manuscript entitled "The Relationship between Quality of Home Care and Health-Related Quality of Life." Chapter IV provides details of the results for Aim 3 in the form of a manuscript entitled "Home Care and Nursing Home Placement, Accounting for Death as a Competing Risk

among Home-dwelling Older Adults.” Chapter V contains a summary of the findings for the overall study, study limitations, suggestions for future research.

## References

- Applebaum, R. & Philips P. (1990). Assuring the quality of in-home care: the other challenge for long-term care. *Gerontologist*, 30(4), 444-456.
- Boaz, R. F., & Muller, C. F. (1994). Predicting the risk of "permanent" nursing home residence: the role of community help as indicated by family helpers and prior living arrangements. *Health Services Research*, 29(4), 391-414.
- Centers for Disease Control & Prevention. (2009). Prevalence and most common causes of disability among adults--United States, 2005. *MMWR Morbidity and Mortality Weekly Report*, 58(16), 421-426.
- Centers for Medicare & Medicaid Services (CMS). (2014). Balancing Long-Term Services & Supports Retrieved April 28, 2015, from <http://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-long-term-services-and-supports.html>
- de Meijer, C. A., Koopmanschap, M. A., Koolman, X. H., & van Doorslaer, E. K. (2009). The role of disability in explaining long-term care utilization. *Medical Care*, 47(11), 1156-1163. doi: 10.1097/MLR.0b013e3181b69fa8
- Fenstemacher, P. A., & Winn, P. (2011). Home Care. In N. S. Skolnik (Ed.), *Long-Term Care Medicine: A Pocket Guide* (pp. 4): Humana Press.
- Fried, T. R., van Doorn, C., Tinetti, M. E., & Drickamer, M. A. (1998). Older persons' preferences for site of treatment in acute illness. *Journal of General Internal Medicine*, 13(8), 522-527.

- Gaugler, J. E., Duval, S., Anderson, K. A., & Kane, R. L. (2007). Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatrics*, 7, 13. doi: 10.1186/1471-2318-7-13.
- Geron, S. M., Smith, K., Tennstedt, S., Jette, A., Chassler, D., & Kasten, L. (2000). The home care satisfaction measure: a client-centered approach to assessing the satisfaction of frail older adults with home care services. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55(5), S259-270.
- Grabowski, D. C., Cadigan, R. O., Miller, E. A., Stevenson, D. G., Clark, M., & Mor, V. (2010). Supporting home- and community-based care: views of long-term care specialists. [Research Support, Non-U S Gov't]. *Medical Care Research and Review*, 67(4 Suppl), 126S-140S.
- Greiner, M. A., Qualls, L. G., Iwata, I., White, H. K., Molony, S. L., Sullivan, M. T., . . . Setoguchi, S. (2014). Predicting nursing home placement among home- and community-based services program participants. *American Journal of Managed Care*, 20(12), e535-536.
- Guo, J., Konetzka, R. T., & Manning, W. G. (2015). The causal effects of home care use on institutional long-term care utilization and expenditures. *Health Economics*, 1, 4-17.
- Guo, J. R., Konetzka, T., Magett, E., & Dale, W. (2014). Quantifying Long-Term Care Preferences. *Medical Decision Making*, 1-8. Retrieved from doi:10.1177/0272989X14551641
- Hankwitz, P. E. (1991). Quality Assurance in Home Care. *Clinics in Geriatric Medicine*, 7(4), 847-862.

- Harrington, C., Ng, T., LaPlante, M. P., & Kaye, H. S. (2012). Medicaid Home- and Community-Based Services: Impact of the Affordable Care Act. *Journal of Aging and Social Policy, 24*(2), 169-187.
- Keenan, T. A. (2010). Home and Community Preferences of the 45+ Population. Retrieved from <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf>
- Kemper, P. (1992). The use of formal and informal home care by the disabled elderly. *Health Services Research, 27*(4), 421-451.
- Kinosian, B., Stallard, E., & Wieland, D. (2007). Projected use of long-term-care services by enrolled Veterans. *Gerontologist, 47*(3), 356-364.
- Knight, S., & Tjassing, H. (1994). Health Care Moves to the Home. *World Health* (pp. 413-444).
- LeBlanc, A. J., Tonner, C., & Harrington, C. (2001). State Medicaid Programs Offering Personal Care Services. *Health Care Financing Review, 22*(4), 155-173.
- Levine, S. A., Boal, J., & Boling, P. A. (2003). Home care. *JAMA, 290*(9), 1203-1207.
- Liu, K., Coughlin, T., & McBride, T. (1991). Predicting nursing-home admission and length of stay. A duration analysis. *Medical Care, 29*(2), 125-141.
- Mattimore, T. J., Wenger, N. S., Desbiens, N. A., Teno, J. M., Hamel, M. B., Liu, H., . . . Oye, R. K. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatric Society, 45*(7), 818-824.
- McAuley, W. J., & Arling, G. (1984). Use of in-home care by very old people. *Journal of Health and Social Behavior, 25*(1), 54-64.

- Miller, E. A. (2012). The Affordable Care Act and long-term care: comprehensive reform or just tinkering around the edges? *Journal of Aging and Social Policy*, 24(2), 101-117. doi: 10.1080/08959420.2012.659912
- Murkofsky, R. L., Phillips, R. S., McCarthy, E. P., Davis, R. B., & Hamel, M. B. (2003). Length of stay in home care before and after the 1997 Balanced Budget Act. *JAMA*, 289(21), 2841-2848. doi: 10.1001/jama.289.21.2841
- Newman, S. J., Struyk, R., Wright, P., & Rice, M. (1990). Overwhelming odds: caregiving and the risk of institutionalization. *Journal of Gerontology*, 45(5), S173-183.
- Sands, L. P., Xu, H., Thomas, J., 3rd, Paul, S., Craig, B. A., Rosenman, M., . . . Weiner, M. (2012). Volume of home- and community-based services and time to nursing-home placement. *Medicare Medicaid Research Review*, 2(3), E1-E21. doi: 10.5600/mmrr.002.03.a03
- Sands, L. P., Xu, H., Weiner, M., Rosenman, M. B., Craig, B. A., & Thomas, J., 3rd. (2008). Comparison of resource utilization for Medicaid dementia patients using nursing homes versus home and community based waivers for long-term care. *Medical Care*, 46(4), 449-453. doi: 10.1097/MLR.0b013e3181621eae
- Temkin-Greener, H., & Meiners, M. R. (1995). Transitions in long-term care. *Gerontologist*, 35(2), 196-206.
- Weissert, W. G., Wan, T. T., Livieratos, B. B., & Pellegrino, J. (1980). Cost-effectiveness of homemaker services for the chronically ill. *Inquiry*, 17(3), 230-243.
- Wiener, J. M., & Anderson, W. L. (2009). Follow the Money: Financing Home and Community-based Services. University of Pittsburgh: Pennsylvania Medicaid Policy Center.

Wilson, I. B. & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life.

A conceptual model of patient outcomes. *JAMA*, 273(1), 59-65.

Zubritsky, C., Abbott, K. M., Hirschman, K. B., Bowles, K. H., Foust, J. B., & Naylor, M. D.

(2013). Health-related quality of life: expanding a conceptual framework to include older adults who receive long-term care services and supports. *Gerontologist*, 53(2), 205-210.

**CHAPTER II: Manuscript #1****Case Managers' Perspectives on Quality of Home Care**

To be submitted to the *Journal of Gerontological Nursing*

Instructions for authors: <http://www.healio.com/nursing/journals/jgn/submit-an-article#Authors>

Acknowledgements: This work was supported in part by

The de Tornay Center for Healthy Aging (Healthy Aging Doctoral Scholarship Fund)

and the University of Washington School of Nursing

## Abstract

**Background:** Home care is a non-institutional type of community-based long-term service and support and is covered through Medicaid by many states as an alternative to institutionalized care. Despite the fact that home care has grown rapidly over the last 3 decades, the quality of home care has not received proper emphasis.

**Purpose:** The purpose of this study was to understand how quality of care standards of home care programs are defined and assured and how it may influence the health and quality of life of home care recipients.

**Design and Methods:** This qualitative study included semi-structured interviews with 11 case managers, who have provided case management service for home care recipients in Washington State. Analysis was guided by a social ecological framework.

**Findings:** Quality of home care is influenced by five levels of social ecology that include home care recipient, formal and informal caregivers, organizations, community, and long-term care systems and services. Case managers' perspectives were merged to 13 themes among the five stakeholders.

**Implications:** This study can inform state and national agencies as they develop standardized quality measurement of home care. Beyond simply measuring the quality of home care, policy makers and administrators should take action to ensure that good quality of home care is delivered in order to improve the health and quality of life of care recipients.

## Introduction

Home care or in-home care is a non-residential type of community-based long-term service and support, which has recently drawn strong public interest (National Quality Forum, 2016) in response to an increasing demand for community-based long-term care services and redirection of governmental funding from institutional to community-based settings. In the past 2 years, the U.S. Department of Health and Human Services has partnered with the National Quality Forum to address the quality of home and community-based services (HCBS) and develop recommendations for standardized measurement of HCBS quality. Home care is distinct from residential community-based long-term care. It is a personalized service delivered at a recipient's residence. Accordingly, home care recipients have more control of their daily life and care. Because home care is different from residential care, the quality of home care needs to be studied independently.

HCBS has grown rapidly over the last 3 decades. Since the Medicaid HCBS waiver program was established with the passage of Section 1915(c) of the Social Security Act in the early 1980s, Medicaid has been the major payer and provider of HCBS (Agency for Healthcare Research and Quality (AHRQ), 2012; LeBlanc, Tonner, & Harrington, 2001). Nearly all states have offered HCBS as an alternative to institutionalized care. These services are available to Medicaid beneficiaries who meet the categorically needy eligibility threshold and who have certain functional limitations or disabilities (Duckett & Guy, 2000; Henry J. Kaiser Family Foundation, 2013). The number of Medicaid beneficiaries enrolling in HCBS nationwide has increased dramatically, from 0.24 million in 1990 to over 3.2 million in 2012 (Harrington, Carrillo, Wellin, Norwood, & Miller, 2008; Ng, Harrington, Musumeci, & Reaves, 2015). Home care programs across the nation have expanded to meet the increasing demand for service.

Historically, quality of home care has not received proper emphases, in part because of the absence of a consensus definition of home care across states (Applebaum & Phillips, 1990; Wiener, Anderson, & Gage, 2009). Each state designs and operates its home care program. Under the Centers for Medicare and Medicaid Services (CMS) HCBS Medicaid eligibility waiver program, states can identify a target population and elect to cover a broad array of federally-funded services such as case management, personal care, home making services, adult day health care services, and more (Harrington et al., 2008). The CMS provide states with a great degree of flexibility to implement their own home care program. As a result, there is great variation in home care services across states, which also puts up a barrier to standardizing measures of home care quality. With recent trends toward aging in place and the number of people who require long-term care, policy makers are compelled to better understand home care services and the effects of these services on care recipients' quality of life.

Recent research on home care quality has addressed various components and stakeholders. Many studies about home care quality have focused on recipients' care experience (Guo, Konetzka, Magett, & Dale, 2015; Madigan, 2008), client satisfaction (Anderson, Wiener, & Khatutsky, 2006; Foster, Brown, Phillips, Schore, & Carlson, 2003; Khatutshy, Anderson, & Wiener, 2006), and client self-direction of care (Benjamin, Matthias, & Franke, 2000; Doty, Kasper, & Litvak, 1996; Geron et al., 2000; Young & Sikma, 2003). Some studies have addressed aspects of home care provision, such as performance appraisals of home care aides (Axelsson & Elmstahl, 2004; Harris & Schmidt, 1993), supervision and quality assurance (Hankwitz, 1991; Harris & Schmidt, 1993), and recipient-caregiver relationships (Cohen, Miller, & Weinrobe, 2001; Eustis & Fischer, 1991; Galvin, 2004; Snyder & Keefe, 1985). A few studies have used a community health approach to evaluate home care as a health promotion program

(Feldman et al., 2004; Ferrell & Borneman, 2002; Grundberg, Hansson, Religa, & Hilleras, 2016; Mahler et al., 2014). Substantial research has addressed aspects of care delivery, including service systems and policies (Coward & Cutler, 1989; Kenney, 1993; Shinogle & Wiener, 2006), service- and cost-effectiveness (Guo, Konetzka, & Manning, 2015; Ko et al., 2014; Wegman et al., 2015; Xu et al., 2009), and workforce competencies (Bercovitz et al., 2011; Katcher & Buhler-Wilkerson, 1989; Netten, Jones, & Sandhu, 2007; Stone & Wiener, 2001).

Medicaid case management is an integral component of HCBS in many states. Case managers play a significant role in the implementation of a home care program and oversight of its services. Case managers influence the quality of home care through direct services such as developing client-centered care plans, monitoring and coordinating services, and providing ongoing evaluation of recipients' health and care. Thus, the case managers' perspectives are valuable and important for connecting clients' home care experience with service provision and bridging home care quality with home care policy. Since home care is in the spotlight now, this study makes a contribution to the discourse by reflecting the current practice in state Medicaid home care services and by uncovering the gaps in home care quality measures.

A social ecological framework is adopted to depict the complexity of home care. The social ecological framework is originated from the ecological paradigm that emphasizes multiple levels of social and organizational environments influence home care quality that subsequently impact on health outcomes of care recipients. (McLeroy, Bibeau, Steckler, & Glanz, 1988). The purpose of this paper is to describe case managers' perspectives on the quality of home care and their recommendations for its measurement.

## **Methods**

### **Design**

This qualitative interview study involved a short demographic questionnaire and a semi-structured interview with individual participants. The individual interviews were between 30 and 60 minutes and were guided by a set of predetermined open-ended questions and followed by other questions emerging from the dialogue between interviewer and interviewee.

### **Sampling**

The participants represented a convenience sample of 11 social workers and nurses who provided case management in home care programs at the Department of Social and Health Services (DSHS), Area Agencies on Aging (AAA), and home care agencies in King County, Washington State. The case managers were recruited through contacting supervisors of these agencies and snowballing. The inclusion criteria were: case managers or equivalent professionals who served adult-care recipients. Case managers who primarily served children and youth were excluded. Of the participants, ten were females and one was male, with a mean age of 55 years (range of 40 – 63 years). Nine participants worked for the DSHS or AAA, and two participants were from home care agencies. All case managers had a baccalaureate education or above. Ten of them had over 15 years' experience in geriatric care, including over 10 years in home care. The project was reviewed and deemed exempt by the University of Washington Institutional Review Board. Informed consent was obtained from all participants before data collection began.

### **Data Collection**

Qualitative data were collected using semi-structured interviews with individual participants. Each participant completed a brief demographic questionnaire that included questions on participants' age, gender, ethnicity, educational level, specialty qualifications, years

of geriatric care experience, and years of home care experience. All interviews were conducted by a trained researcher (MY) based on a set of open-ended questions (listed in Table 1). During the interviews, the participants expressed their viewpoints freely, and the interviewer directed the discussion to the main themes, if necessary. The interviews were audio-recorded, and the recordings were transcribed verbatim by a professional transcription service.

### **Data Analysis**

Directed content analysis, guided by a social ecological framework, was used to analyze the interview transcripts (Hsieh & Shannon, 2005). Five levels of environmental influences from McLeroy et al. (1988) were used to inform the categorization of themes. Our coding scheme involved several steps. The researchers started with developing operational definitions of the five levels or thematic categories that included home care-recipients, caregivers, organization, community, and long-term care policy. Next, the researchers reviewed the transcripts sentence by sentence, identified all textual content related to home care quality, and coded the text into the thematic categories. Two researchers (MY and BC) performed the coding independently. One researcher (MY) coded all data, and the other researcher (BC) coded a pilot interview. The two researchers discussed the analysis and findings to ensure consistency in coding.

### **Results**

The case manager interviews were summarized into five main themes and 13 subthemes (as shown in Figure 1). The five main themes were home care recipients, caregivers (informal support and home care aide workers), organizations, community, and long-term care services and systems.

## 1. Individuals - Home Care Recipients

**Care recipients' capabilities to self-direct care.** The case managers indicated that a person receiving home care would be the director of his/her own service. Quality of care strongly depended on the capability to manage one's own services and supervise home care aides. To be successful in self-directed care, the care recipient would be able to acknowledge their own care, identify any issues and concerns, access and utilize resources, and solve problems. Thus, *autonomy, independence, decision-making, and problem solving skills* were essential elements in self-direction. An exemplar of self-direction was:

I have an elderly client, [Care recipient] is in her 70s. . . . She is completely able to direct her care. She is a good advocate for herself. She has had problem for years with finding a good caregiver. We have had an agency for quite a while. And the agency kept sending workers to her, either who could not speak English or who smoked. She could tell you everything that she didn't want them to have. It seemed they could not her together with someone. She is sensitive to cigarette smoke. They kept sending people who smoked. . . . The home care aide [HCA] is American and she speaks English. . . . My client contacted her, met her, and interviewed her... The [HCA] has been working for [care recipient] for probably 4 months, and every time I talked to [care recipient], she was delighted about how great it is for her. [Care recipient] could make a list for her. The [HCA] could read the list and knew exactly what she was supposed to do. When the [HCA] is there, she is able to talk to my client and she can still get her work done. . . . [Care recipient] feels very comfortable with her [HCA]. She trusts her. She feels safe with her.” (I2)

**Connection to the individual's needs.** Several participants suggested that quality of home care is related to the care recipient's health, functional limitations, and care needs. To

measure care needs of care recipients who have a wide range of functional limitations and disabilities, outcome measures should be specific to the individual care recipient and relevant to the person's health status and diagnoses. A case manager made the comment:

[Case Manager] can't possibly screen all those people the same way and have the same results. Probably the biggest reason is that the Center for Medicare and Medicaid requires that they have some kinds of quantifying [persons at different ages with all kinds of disabilities and disorders as well as their needs], and everybody can stick to it. . . . The relationship of those [medical diagnoses and functional limitations] to quality of care is not there. There are some disconnects between [those medical diagnoses and functional limitations and quality of care]. Quality of care should be more connected with the real situation of the client in terms of the care being given. (I8)

Many home care recipients are elderly who have chronic diseases and symptoms. A case manager suggested that quality of care can be reflected by how much a care recipient manages chronic diseases and symptoms:

[Clients] having improved symptom control in their conditions can be a measurement [of quality of care]. A lot of [symptom management] may be achieved through medication management. Like some of the heavy-care clients are not having pressure ulcers, though a client can still get them. But there are some cases that I have I know of where [the client] received exceptional care, and a lot of tenderness, and attentiveness from the caregivers.... I have a client who is in vegetative state. She cannot reposition herself without help. She has never had pressure ulcers, ever. So there are some factors for that.... I think [preventing pressure ulcers] can be a measurement, because the caregiver has been repositioning my client, and it takes skills to do that. (I3)

**Influences on quality of life.** Many participants stated that there is a strong need to measure home care quality and demonstrate the effectiveness of home care service. The case managers recommended taking a holistic approach to evaluating the quality of service given to a care recipient. The measures should address all parts of the care recipient's life and be unique to each individual. They indicated that because the Department of Social and Health Services (DSHS) presently lacks a system of measuring home care quality, developing a set of relevant, reliable, and quantifiable measures is necessary to reflect how care recipients could benefit from their home care services. Beside symptom management, a measurement consideration included care recipients' quality of life. A participant stated:

Measuring quality is really going into every single aspect of a care recipient's needs. That is, all the possible ways to support the care recipient staying at home.... Even at the end, [Care Recipient] ended up in the hospital and passed away. At least [she] was able to have a quality of life for the last few years. So to me, I would define that as a good quality of care. (I10)

A few participants suggested that quality of life was a potential outcome measure for home care and quality of life was attributable to sense of well-being and social engagement. One participant characterized quality of life this way:

My client has multiple sclerosis. Her muscles are deteriorating, and she stays home. After her sister and our [home care] program have helped her, she started going to the adult day health program. It is hard for her to get up in the morning. She struggles when she comes home. She told me she felt good. She is not alone at home. She is out. She is meeting people. She is doing exercise. Home care services really help people to have a better quality of life; otherwise they would be so isolated. (I4)

## 2. Interpersonal – Caregivers

Two types of caregivers were addressed within this theme. The caregivers were (a) informal caregivers who provide non-paid care and support for their family members and (b) home care aide workforce.

### (a) Informal Support

**Importance of family and informal support.** Most case managers addressed that the objective of home care was to complement rather than substitute for family and informal support. The key roles of family and informal support in home care included coordination of care, monitoring home care services, and HCA supervision. Many family and informal caregivers were responsible for performing skilled nursing procedures and tasks, which were outside the scope of HCA practice, unless the procedures and tasks were nurse-delegated to the HCA. A case manager described family involvement as a crucial factor of good quality of home care:

Some of the client's families are very involved in monitoring the in-home care services for the client. Sometimes I may receive the client's family saying that [HCA] is not good or [HCA] is not doing anything or just sits there. In this case, I will get the whole picture of how the client gets the in-home care service because of the client's family's involvement. [To achieve high quality] in-home care, the family's involvement is also a crucial factor. (I1)

The following is an exemplar of good quality home care that is supported by family:

I have a young male [client] who had a brain stem aneurysm and is essentially functionally quadriplegic. . . . He is fully aware, . . . but it's that he cannot communicate. Family is providing the care for him, and he needs suctioning and he is on trach care, tube feeding care, and medications administration, and he is on tube-feeding, and a lot of

these are skilled tasks. The family is doing a great job of it. But the family is wanting a break, so the worker before me had asked for additional time and it was granted. . . . This is not an ordinary client. This is a special-needs type of care, a heavy-care client. This should be your priority. . . . Then I had to have the caregiver set up for nurse delegation. . . . The family wanted them to do some of the skilled tasks. (I3)

### **(b) Home Care Aide Workforce**

**Conformity and compliance with the care plan.** Many case managers suggested that high quality of care would be achieved if care recipients and their HCAs respected and complied with the care plan. The care plan was a contractual agreement among the care-recipient, HCA, and State. It reported details of assessment findings and documented the responsibilities, instructions, and time schedule that served as a practice guideline for HCAs. It also identified any assistance and support family members would provide beyond home care coverage. The extent to which the care plan was executed and followed through could affect the quality of home care being provided. As one participant described it:

A care plan is an individualized, client-centered plan. It consists of interventions and unique elements, . . . and has a schedule created that that [HCA] works for the client. I [case manager] came up with the plan that [all parties] agreed to. . . . The problem we see at home is that some clients' conditions are medically complex. If somebody needs extensive help with eating, the caregiver needs to be there at meal times. Some of the tasks can never be scheduled, like mobility. You can't always have HCA there at all the meal times. So I try to make if it is possible for meal time. You can't always, if somebody is at risk of falls, you can't have someone there all the time. So you try to make if it is possible for the time. You try to get a lifeline button or PERS (Personal

Emergency Response System) unit to call it. If you were to fall, because the person can fall in any setting, they will be able to get help.... Sometimes it is driven more by the [HCA] and does not necessarily always fit for the client.... If the quality of in-home care is good, the caregiver will be reliable and dependable. They will be doing the tasks on the care plan. (I2)

**Standardized HCA training and certification requirements.** All participants agreed with the notion that completion of HCA training and certification is a way of equipping HCAs with the knowledge and skills to provide good quality of home care. In Washington State, the DSHS regulates and sponsors HCA training (including fundamental training and annual continuing education) and certification. Additional training and certification are necessary for HCAs who provide nurse-delegated medical procedures. Home care workers must be compliant with the training and certification requirements in order to serve publicly funded home care beneficiaries. However, the training and certification requirements are less restricted for HCAs who provide service to their family members. As one participant said:

The home care training helps equip [HCAs] to become professional caregivers. It is the way to get more medical knowledge and education on how to provide better services to all the clients.... [HCAs require] not just training but also getting a certificate. But still, for the adult children [working as HCAs], they don't need to get a certificate. (I1)

The participants also pointed out that training and certification requirements are inconsistent across HCAs who are family members, HCAs who are non-family members, and HCAs who are hired by home care agencies. Thus, adult children who provide services for their parents or grandparents are required only to complete a short version of training and can be exempted from certification. Reimbursement of legally responsible relatives (e.g., spouses) as formal HCAs for

the care recipient is prohibited (LeBlanc et al., 2001). Moreover, home care agencies have hiring requirements, particularly for their home care workers, in addition to state regulations. A participant from a home care agency stated:

We require our HCAs to be at least a Nursing Assistant-Registered (NAR). It's ok if they were grandfathered in because they were caregivers for a long time and were working before the new law. All other workers are Nursing Assistant-Certified (NAC), or have completed their course and are ready to take their test. We also require people to have 6 months' experience of caregiving. We do not hire people that are entering the workforce unless they have taken classes and have gotten their NAC or their Home Care Aide-Certified. We differ from the state. The state can hire people and allow HCAs 200 days to get their classes and certification. We don't give them 200 days. We can't afford to take chances on people. (I9)

Although most participants agreed to standardize training and certification requirements, a few participants pointed out that the policy disproportionately affected non-English speaking workers. As one case manager stated:

A lot of the care workforce have English as a second language.... Currently the training is conducted in English and five other languages, and the certification examination is offered in English. A lot of training materials are not translated well or not available to [the trainees]. It sometimes excludes some good quality caregivers because of the language barrier. Those potential caregivers should be accommodated. (I3)

**Standardization of home care aide services.** Many participants claimed that variations in quality of home care services provided by HCAs continue to exist, particularly a family member being the HCA of care-recipient. A way to minimize these differences and improve care

quality would be to make the practice more uniform. A participant described standardized home care:

Quality of care is a team of caregivers.... Quality of care is that the client is able to accept more than one [HCA] and expect the same outcome with each [HCA].” (I4)

A case manager suggested that high quality caregivers are required to perform up to a standard or level of care. The case manager stated:

[High] quality caregivers are people who have had enough training to understand what the [client’s health] issues are. Quality caregivers show up when they say they’re going to show up. Quality caregivers listen to what their client wants, needs, requests. Caregivers are patient and kind. They’re flexible. I think the best caregivers are those caregivers who can work with the client, but also the client’s family.... Good caregivers and good home care require that people are aware of what their limitations are.... You don’t just go in and start changing meds in a med box. You don’t provide services that you’re not trained or qualified to provide. You don’t make assumptions about people. (I6)

A proportion of HCAs were the family members of care-recipients. The large number of family members working as HCAs for their own parents or grandparents has increased the complexity of and resistance to service standardization and quality assurance. The participant case managers held mixed opinions regarding the quality of care that could be provided by a family member:

Most of the IPs (individual providers), are family members, relatives, friends or someone that the person knows. That is the kind of relationship where the caregiver has more ownership of the care [and devoted to the care]. Sometimes it’s just a situation where the family caregiver needs to be watched to keep them from getting burned out, and the case

manager will be able to step in, provide support and encourage them to accept other help.

(I3)

A family members being a HCA conflicts professional and personal interests. In the publicly-funded home care program, the home care coverage of a care recipient can become an income source of the family member HCA. A case manager said:

There is a secondary game issue that occurs quite often. You know the family member becomes reliant on the home care as an income.... Whereas in the in-home setting—especially if there is, even with the agency providers too, but especially with family providers—when the person gets better, the pay is lessened or the number of hours they get with the person is lessened. So there is quite a different mentality towards it.

Oftentimes, it seems like care recipients are presenting their situation to be worse than it is. (I3)

The personal relationship between a care recipient and a family member HCA influences a care recipient's perception to quality of care and a care recipient's decision of initiating or terminating a HCA's service. A case manager stated:

When the paid provider is the child of the client, it is very hard for client to just fire the paid provider. That is a complicated relationship, between the paid provider and the client. For me as a case manager, it is very hard to do anything or try to persuade the client to change the paid provider. But the client said, "She is my daughter, I can't [change providers]." In this aspect, the client can't fully benefit from the in-home care program. (I1)

### **3. Institution**

**Quality case management.** Quality of home care is interwoven with case management. The participants stated that good quality of home care was strongly related to how comprehensive and detailed an assessment case managers made of every aspect of each care recipient's quality of care, including health, daily life, informal support, and even personal preference. The Washington State DSHS adopted an electronic assessment tool (CARE, an acronym for Comprehensive Assessment, Reporting, and Evaluation), which "is a standardized, universal assessment tool used to evaluate functional eligibilities and determine eligible service benefits of prospective care recipients." The electronic tool has improved the consistency of assessments conducted by case managers and reduced discrepancies of service among care recipients:

The CARE assessment tool was quite similar to the tool that is used in nursing homes.... The amount of hours or reimbursement to the provider or other non-in-home providers, like AFH and AL, is affiliated with how people are classified accurately. The CARE classification system is actually better [than the nursing home one] .... it is less subjective and more standardized for sure,... and it has less variance. Doing the CARE assessment requires a lot of professional judgment. There are certain things they are looking for. It does take a very skilled, well-trained case manager to complete the tool because of how complex and sensitive it is, the information you go into. (I3)

**Supervision from home care agencies.** Case managers described home care agencies as an *extra layer* of monitoring mechanisms and supervision to ensure the quality of care provided by agency HCAs. State licensed home care agencies are responsible for hiring, training, paying, supervising, and ensuring the quality of care provided by their HCAs. As one home care supervisor said during the interview:

We [the home care agency] require somebody to come in and take a written competence exam before we hire them. Part of our strategy for that is that we're testing their ability to read, understand, answer questions appropriately, and whether they have basic knowledge of what caregiving is. So a part of that is English competency that we're looking at. A part of that is basic understanding of caregiving and use of the supervisor. . . . We recruit qualified people, so we will be getting caregivers in here that have a knowledge base and an experience base in terms of providing care. So we have the caregivers that are following the care plan, understand what the plan of care is, and call the supervisor when the care plan doesn't reflect the care that's needed. It requires confident and willing caregivers to call their supervisor and say, "This is not the right plan of care for this client." It requires caregivers that have the right interpersonal skills for the client. (I9)

#### **4. Community**

**Community perception of aging and home care.** A few participants suggested that community perception of aging and home care can shape home care services and home care quality.

The idea of aging in place is a community effort. Beside the home care services, it is the people in the community. Different parties should give more care and attention to senior citizens. Family members being supportive, children being supportive; and relatives being supportive. They will be caring for the elderly. To improve that part, probably we need to raise awareness in the community, so people realize it is a community effort, like the taxpayers' effort to provide those services. People should have a high regard for the

elderly whether they are their parents or not. People will then be more appreciative about the home care program. (I11)

A case manager explained how community attitude toward home care services may influence quality of home care:

In the past, when older adult clients were appreciative of their care, they were thankful for every small help or assistance, for instance, if a case manager assisted in getting the client a walking aid. A client who was eligible for 90 hours of personal care took only 80 hours as those hours were adequate to meet her needs and since she was satisfied with her current level of care. (I10)

Within communities, especially small and cohesive communities, people know each other and watch out for one another.

If you go to Eastern Washington or some remote areas where there are only a few providers [HCAs] over there, the providers there are known to the people and recognized if they're outside, if they go down to the store or the church. People watch out for each other. (I8)

**Connection to a network of resources to support aging in place.** Many participants described that good quality of home care was more than basic HCA services. One of them analogized it to the African proverb that “it takes a village to raise a child”. In this case, the proverb would be that it takes a village to support an older adult—to live safely and healthily at home. Home care recipients were identified as individuals with a wide range of physical, mental, and social backgrounds. In such a diverse environment, quality of care is dependent on whether a care recipient connects to the right resources and receives timely referrals to various services.

My client felt strongly about living in her own home and being able to retain her independence. She has many physical issues and frequent falls, especially at nighttime. When she fell, she could not get up. She used the Lifeline to get the fire department to come out and help her get up. Her family wanted her to go to a facility because it seemed like she needed 24/7 care. The case manager worked really hard to balance the safety issue with respect for the elderly client's wishes and her strong will to be independent.... In this case, a good quality of care was the manager trying to think up different ways [to solve a problem] and then working with family members, and finally coming up with some private pay to cover someone to stay with her at night time and continue with the in-home care during the day. At the same time the care manager addressed the safety issues, did some environmental modification, and had an occupational therapist teaching the client how to take safety precautions. The therapist taught her how to use her walker safely, kept reminding her slow down, and did a lot of with medication management and teaching the caregiver how to take care of her and use the medical equipment. In this quality care meant really going into every possible way to support the client staying at home. (I10)

## **5. Long-term Care Systems and Services**

**Quality assurance from a top-down approach.** Many case managers commented that assuring quality of care required regular monitoring of home care services and routinely gathering information on all aspects of a care recipient's condition. Thorough, ongoing monitoring would allow case managers to follow through with the care, pick up the latest changes, and uncover any abuses and negligence. A case manager commented:

Some rules and regulations are good, such as the monitoring plan contact rules. About 10 years ago, there was no rule about contacting clients beside once a year for the annual reassessment.... When the Linda David case happened,...David's husband, who was the paid caregiver, abused her and she ended up in the nursing home. Because of that, the state created the whole monitoring plan contact rule, and case managers try to do extra contacts with the client, three times a year.... The law is there. Case managers strive to do that because of that law. (I2)

**Adoption of a health model to focus on wellness.** The case managers described how the principle of home care is to promote health and wellness of care-recipients. Quality of care should be focused on the goals created by each person and built on the person's strengths, capabilities, and commitment to stay well, rather than on infirmity and deficits. On the contrary, the reimbursement-by-the-payment system was based on a medical model that departs from this underlying principle. Several case managers criticized the CARE tool, which is used to determine beneficiaries' level of care, as being insensitive to health and well-being. The algorithm built into the CARE system was created in such a way as to compute a client's service benefits by overly emphasizing medical diagnoses, functional limitations, and adverse events. Thus, beneficiaries with higher degrees of limitation and need for assistance would receive more care. Repeated comments from the participants pointed to the Medicaid reimbursement system for home care services as a penalizing system in which "the better one gets, lesser the service they receive" logic discourages care recipients from getting well.

A case manager helps clients to develop realistic, achievable goals. That makes them feel they can achieve something. They will see that their own ability has not gone down. You can help them to go through some exercise that is very basic. For example, my client set a

goal of standing up for a few seconds every day, because he had not stood up for many years. That was his goal. So the ultimate outcome for this client was that eventually, after 8 weeks, he could walk to his mailbox to get his mail. That was a very big achievement for him. (I4)

A case manager pointed out that the current reimbursement system focused on quantities and not quality of care. The case manager said:

One of the controversies along the same line in the Medicaid program is that it is not a reward system. It is more like a penalty system. When you get better, you get cut in the number of hours of service you receive. This part of home care reimbursement is dependent on the quantity of care, rather than quality of care. (I6)

### **Discussion**

Our study highlighted case managers' viewpoints on quality of home care and their recommendations for home care measurements. Case managers' perspectives were conceptualized through a social ecology lens that addressed home care quality at five levels of influence, including individual care recipient, formal and informal caregivers, organizations, community, and long-term care services and systems. Our findings depicted that each level directly or indirectly impacted service provision and quality of home care.

Consistent with previous studies of home care quality (Wegman et al., 2015; J. M. Wiener et al., 2009), our findings indicated that quality of home care could affect the health and quality of life of the recipients and that monitoring and measuring home care quality was important and needed to be addressed. Almost all the case managers believed that home care functioned to support clients to age in place safely and independently and to prevent or delay

institutional care or nursing home care. Their concern, however, was that quality of home care did not receive adequate emphasis in terms of how quality can be quantified and measured and how it might impact the care recipient's health and quality of life. A wide variation in the quality of home care services among recipients existed, whereas benchmarks for quality standards were unavailable or otherwise ambiguous (Joshua M. Wiener, Tilly, & Alexih, 2002). Taking two home care services (personal care and homemaking services) as examples, the State of Washington has permitted care recipients a great degree of flexibility and freedom of choice in determining their service tasks, service schedule, and caregivers. Our findings indicate that quality of home care has depended greatly upon a recipient's level of understanding and expectations of service quality (Samuelsson & Wister, 2000), as well as upon the relationship between the care-recipient and HCA (Eustis & Fischer, 1991; Eustis, Kane, & Fischer, 1993).

Many states, including Washington, have addressed the standardization of services by developing and implementing a uniform care plan to guide service provision. Most participants in this study affirmed that *conformity and compliance with the care plan* is a key to service standardization and that will lead to high quality home care. Conformity with the care plan requires all parties, including the care-recipient, HCA and/or home care agency, mutually agree to the services written on a care plan in accordance with the long-term care policy. Compliance takes a further step that services are delivered as how they are stated in the care plan. However, service oversight and monitoring strategies were identified as insufficient and ineffective. The extent of compliance with the care plan largely depended on the autonomy and self-regulation of both the care-recipient and HCA. However, this regulatory system has flaw, where the responsibilities of each party remained undefined.

The variation in home environments was a much less-discussed consideration in the interviews. Although not attributable to quality of home care, housing and living arrangement constitute part of a client's immediate physical and social environment that influences the home care experience and health (Gershon et al., 2008). Care recipients' homes are considered the care settings where HCAs deliver personal care and homemaking services. Despite care recipients' homes being a feature that is unique to home care, little research has been done to examine the impact of home environment on quality of home care. Although each state provides environmental modification to a beneficiary residence through HCBS for accessibility purposes, the home care setting is not regulated in the home care program. Furthermore, measuring and assuring the quality of care in the home care setting is technically challenging and labor intensive, given that care recipients are widely dispersed by geographic location.

Consistent with other research, our study findings indicate that a diverse HCA workforce directly affects quality of home care (Anderson et al., 2006; Stone & Wiener, 2001). HCAs are service providers with diverse backgrounds in education, skills, culture, and language. HCAs can be hired directly by a client as individual providers or through a home care agency. In this study, many care recipients chose to hire their family members. When a family member is the HCA, the line between family role and work role can become blurred. Quality of home care can then be impossible to separate from the factors of familial relationship, family dynamics, and financial involvement. The challenge of monitoring and ensuring home care quality is to collect an unbiased appraisal from the clients regarding the services they receive from family members. It is even more difficult to measure quality of HCA services if the client is cognitively impaired or the family caregiver is also the client's proxy or durable power of attorney. The participants in this study had mixed opinions regarding the practice of hiring family members as HCAs, which

has been the norm in home care services. A few participants suggested eliminating family members as HCAs; however, home care has been facing a workforce shortage and high turnover, so this might not be practical at the present time. Recruitment and retention of HCAs in community-based long-term care is a growing concern. Removing family members from the workforce would undoubtedly create more tension for the home care services, which are already experiencing worker shortages.

One of the distinguishing characteristics of home care is client self-direction of care. More states are moving home care services to a model of client self-direction of care. Self-direction of care gives clients more control of their life. Substantial studies on self-direction of home care have supported that client self-directedness improves the care experience and service outcomes (Benjamin et al., 2000; Doty et al., 1996; Young, 2012; Young & Sikma, 2003). Our participants echoed the results of these studies, indicating that quality of home care was related to how capable a client was of self-direction. Under self-direction of care, the quality of home care should be focused on the goals created by each person and should build on the person's strengths. Future research can focus on care recipients (or their proxies and next of kin), methods of empowerment, such as enabling clients' self-direction, and training the client to be more independent in making decisions and personal choices. At service delivery, case management can address coaching clients and facilitating client access to resources.

### **Strengths**

The major strength of this study is the unique approach used to describe the complex phenomenon of home care. The study provided case managers' perspectives on home care quality and used a social ecological framework to guide conceptualization and data analysis. Following this approach, the findings provided new details and depth of knowledge about

recipients' care experiences and how home care may impact on care recipients.

### **Limitations**

Two limitations of this study are the small sample size and homogeneity of the participants. The participant case managers represented a convenience sample recruited from one geographic region within an administrative region of the Washington State DSHS. Given that Medicaid HCBS vary across states, some findings specific to the Washington State home care program may not be generalizable to services and systems at the national level. However, the study participants comprised a range of diverse sociodemographic backgrounds and substantial experiences in home care. The results are consistent with findings from previous studies, which increases the validity of the derived themes.

### **Conclusion**

Quality of home care is a complex and multifaceted construct that is under multiple influences including home care recipients, caregivers, organizations, community, and long-term care policy. Measurement of the quality of home care services and systems is challenging due to variations among quality standards, difficulty in monitoring services and assessing quality, and lack of good quality indicators for home care. Considering the unique characteristics of home care as distinct from other types of community-based services, it is important to develop a set of standardized quality measurements that is relevant and specific to home care.

### **Implications**

The aging American population is changing the landscape of long-term services and supports. More people are anticipated to age in place and need home care. This study informs policy about the importance of developing standardized quality measurement of home care to

elucidate the effects of home care on service outcomes. Beyond measuring home care, policy makers and administrators should take action to ensure that good quality of home care is delivered to improve the health and quality of life of care recipients.

## References

- Agency for Healthcare Research and Quality (AHRQ). (2012). *Availability and use of state Medicaid HCBS*. Retrieved from <http://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/hcbsfindings/hcbsfind3.html>
- Anderson, W. L., Wiener, J. M., & Khatutsky, G. (2006). Workforce issues and consumer satisfaction in Medicaid personal assistance services. *Health Care Financing Review*, 28(1), 87-101.
- Applebaum, R., & Phillips, P. (1990). Assuring the quality of in-home care: the "other" challenge for long-term care. *Gerontologist*, 30(4), 444-450.
- Axelsson, J., & Elmstahl, S. (2004). Home care aides in the administration of medication. *International Journal for Quality in Health Care*, 16(3), 237-243.  
doi:10.1093/intqhc/mzh041
- Benjamin, A. E., Matthias, R., & Franke, T. M. (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research*, 35(1 Pt 2), 351-366.
- Bercovitz, A., Moss, A., Sengupta, M., Park-Lee, E. Y., Jones, A., & Harris-Kojetin, L. D. (2011). An overview of home health aides: United States, 2007. *National Health Statistics Reports*, 19(34), 1-31.
- Cohen, M. A., Miller, J., & Weinrobe, M. (2001). Patterns of informal and formal caregiving among elders with private long-term care insurance. *Gerontologist*, 41(2), 180-187.
- Coward, R. T., & Cutler, S. J. (1989). Informal and formal health care systems for the rural elderly. *Health Services Research*, 23(6), 785-806.

- Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: lessons from Medicaid. *Milbank Quarterly*, 74(3), 377-409.
- Duckett, M. J., & Guy, M. R. (2000). Home and community-based services waivers. *Health Care Financing Review*, 22(1), 123-125.
- Eustis, N. N., & Fischer, L. R. (1991). Relationships between home care clients and their workers: implications for quality of care. *Gerontologist*, 31(4), 447-456.
- Eustis, N. N., Kane, R. A., & Fischer, L. R. (1993). Home care quality and the home care worker: beyond quality assurance as usual. *Gerontologist*, 33(1), 64-73.
- Feldman, P. H., Peng, T. R., Murtaugh, C. M., Kelleher, C., Donelson, S. M., McCann, M. E., & Putnam, M. E. (2004). A randomized intervention to improve heart failure outcomes in community-based home health care. *Home Health Care Services Quarterly*, 23(1), 1-23.  
doi:10.1300/J027v23n01\_01
- Ferrell, B. R., & Borneman, T. (2002). Community implementation of home care palliative care education. *Cancer Practice*, 10(1), 20-27.
- Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B. L. (2003). Improving the quality of Medicaid personal assistance through consumer direction. *Health Affairs (Millwood), Suppl Web Exclusives*, W3-162-175.
- Galvin, R. (2004). Challenging the Need for Gratitude: Comparisons Between Paid and Unpaid Care for Disabled People. *Journal of Sociology*, 40(2), 137-155.  
doi:10.1177/1440783304043453
- Geron, S. M., Smith, K., Tennstedt, S., Jette, A., Chassler, D., & Kasten, L. (2000). The home care satisfaction measure: A client-centered approach to assessing the satisfaction of frail older adults with home care services. *The Journals of Gerontology Series B:*

*Psychological Sciences and Social Sciences*, 55B(5), S259-S270.

doi:10.1093/geronb/55.5.S259

Gershon, R. R. M., Pogorzelska, M., Qureshi, K. A., Stone, P. W., Canton, A. N., Samar, S. M., . . . Sherman, M. (2008). *Home health care patients and safety hazards in the home: preliminary findings*. Retrieved from

[http://www.ahrq.gov/downloads/pub/advances2/vol1/advances-gershon\\_88.pdf](http://www.ahrq.gov/downloads/pub/advances2/vol1/advances-gershon_88.pdf)

Greiner, M. A., Qualls, L. G., Iwata, I., White, H. K., Molony, S. L., Sullivan, M.

T., . . . Setoguchi, S. (2014). Predicting nursing home placement among home- and community-based services program participants. *The American Journal of Managed Care*, 20(12), e535-e536.

Grundberg, A., Hansson, A., Religa, D., & Hilleras, P. (2016). Home care assistants' perspectives on detecting mental health problems and promoting mental health among community-dwelling seniors with multimorbidity. *Journal of Multidisciplinary Healthcare*, 9, 83-95.  
doi:10.2147/jmdh.s99388

Guo, J., Konetzka, R. T., Magett, E., & Dale, W. (2015). Quantifying long-term care preferences. *Medical Decision Making*, 35(1), 106-113. doi:10.1177/0272989x14551641

Guo, J., Konetzka, R. T., & Manning, W. G. (2015). The causal effects of home care use on institutional long-term care utilization and expenditures. *Health Economics*, 24(Supplement S1), 4-17. doi:10.1002/hec.3155

Hankwitz, P. E. (1991). Quality assurance in home care. *Clinics in Geriatric Medicine*, 7(4), 847-863.

- Harrington, C., Carrillo, H., Wellin, V., Norwood, F., & Miller, N. (2008). Access of target groups to 1915(c) Medicaid home and community based waiver service. *Home Health Care Services Quarterly*, 20(2), 61-80. doi:10.1300/j027v20n02\_04
- Harris, M. D., & Schmidt, D. (1993). Supervision of home care aides. *Home Healthcare Nurse*, 11(4), 51-53.
- Henry J. Kaiser Family Foundation. (2013). A short look at long-term care for seniors. *JAMA*, 310(8), 786-787. doi:10.1001/jama.2013.17676
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi:10.1177/1049732305276687
- Katcher, B. L., & Buhler-Wilkerson, K. (1989). Applying the principles of organizational psychology to improve the selection of home health aides and homemakers: Part I. *Home Healthcare Nurse*, 7(1), 37-41.
- Kenney, G. M. (1993). Is access to home health care a problem in rural areas? *American Journal of Public Health*, 83(3), 412-414.
- Khatutshy, G., Anderson, W. L., & Wiener, J. M. (2006). Personal care satisfaction among aged and physically disabled Medicaid beneficiaries. *Health Care Financing Review*, 28(1), 69-86.
- Ko, M., Newcomer, R., Kang, T., Hulett, D., Chu, P., & Bindman, A. (2014). Payment rates for Personal Care Assistants and the use of long-term services and supports among those dually eligible for Medicare and Medicaid. *Health Services Research*, 49(6), 1812-1831. doi:10.1111/1475-6773.12249
- LeBlanc, A. J., Tonner, C., & Harrington, C. (2001). State Medicaid programs offering Personal Care Services. *Health Care Financing Review*, 22(4), 155-173.

- Madigan, E. A. (2008). People with heart failure and home health care resource use and outcomes. *Journal of Clinical Nursing, 17*(7b), 253-259. doi:10.1111/j.1365-2702.2008.02334.x
- Mahler, M., Sarvimaki, A., Clancy, A., Stenbock-Hult, B., Simonsen, N., Liveng, A., . . . Horder, H. (2014). Home as a health promotion setting for older adults. *Scandinavian Journal of Public Health, 42*(15 Suppl), 36-40. doi:10.1177/1403494814556648
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377.
- National Quality Forum. (2016). *Addressing performance measure gaps in home and community-based services to support community living: priorities for measure development - interim report*. Retrieved from [http://www.qualityforum.org/Measuring\\_HCBS\\_Quality.aspx](http://www.qualityforum.org/Measuring_HCBS_Quality.aspx)
- Netten, A., Jones, K., & Sandhu, S. (2007). Provider and care workforce influences on quality of home-care services in England. *Journal of Aging & Social Policy, 19*(3), 81-97. doi:10.1300/J031v19n03\_06
- Ng, T., Harrington, C., Musumeci, M., & Reaves, E. L. (2015). *Medicaid home and community-based services programs: 2012 data update*. Retrieved from <http://kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2012-data-update/>
- Samuelsson, G., & Wister, A. (2000). Client expectations and satisfaction of quality in home care services. A consumer perspective. *Home Care Provider, 5*(6), 223-230.
- Shinogle, J., & Wiener, J. M. (2006). Medication use among Medicaid users of home and community-based services. *Health Care Financing Review, 2006*(28), 1.

- Snyder, B., & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. *Social Work in Health Care, 10*(3), 1-14. doi:10.1300/J010v10n03\_01
- Stone, R. I., & Wiener, J. M. (2001). *Who will care for us? Addressing the long-term care workforce crisis*. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/73111/lcwf.pdf>
- Wegman, M. P., Herndon, J. B., Muller, K. E., Graham, G. N., Vogel, W. B., Case, K. H., . . . Shenkman, E. A. (2015). Quality of care for chronic conditions among disabled Medicaid enrollees: An evaluation of a 1915 (b) and (c) waiver program. *Medical Care, 53*(7), 599-606. doi:10.1097/mlr.0000000000000371
- Wiener, J. M., Anderson, W. L., & Gage, B. (2009). Making the system work for home care quality. *Journal for Healthcare Quality, 31*(2), 18-23.
- Wiener, J. M., Tilly, J., & Alecxih, L. M. B. (2002). Home and community-based services in seven states. *Health Care Financing Review, 23*(3), 89-114.
- Xu, H., Weiner, M., Paul, S., III, J. T., Craig, B., Rosenman, M., . . . Sands, L. (2009). Volume of home- and community-based Medicaid waiver services and risk of hospital admissions. *Journal of the American Geriatrics Society, 58*(1), 109-115. doi:10.1111/j.1532-5415.2009.02614.x
- Young, H. M. (2012). County administrator perspectives on the implementation of self-directed supports. *Journal of Disability Policy Studies, 22*(4), 247-256. doi:10.1177/1044207311416595
- Young, H. M., & Sikma, S. K. (2003). Self-directed care: an evaluation. *Policy, Politics, & Nursing Practice, 4*(3), 185-195.

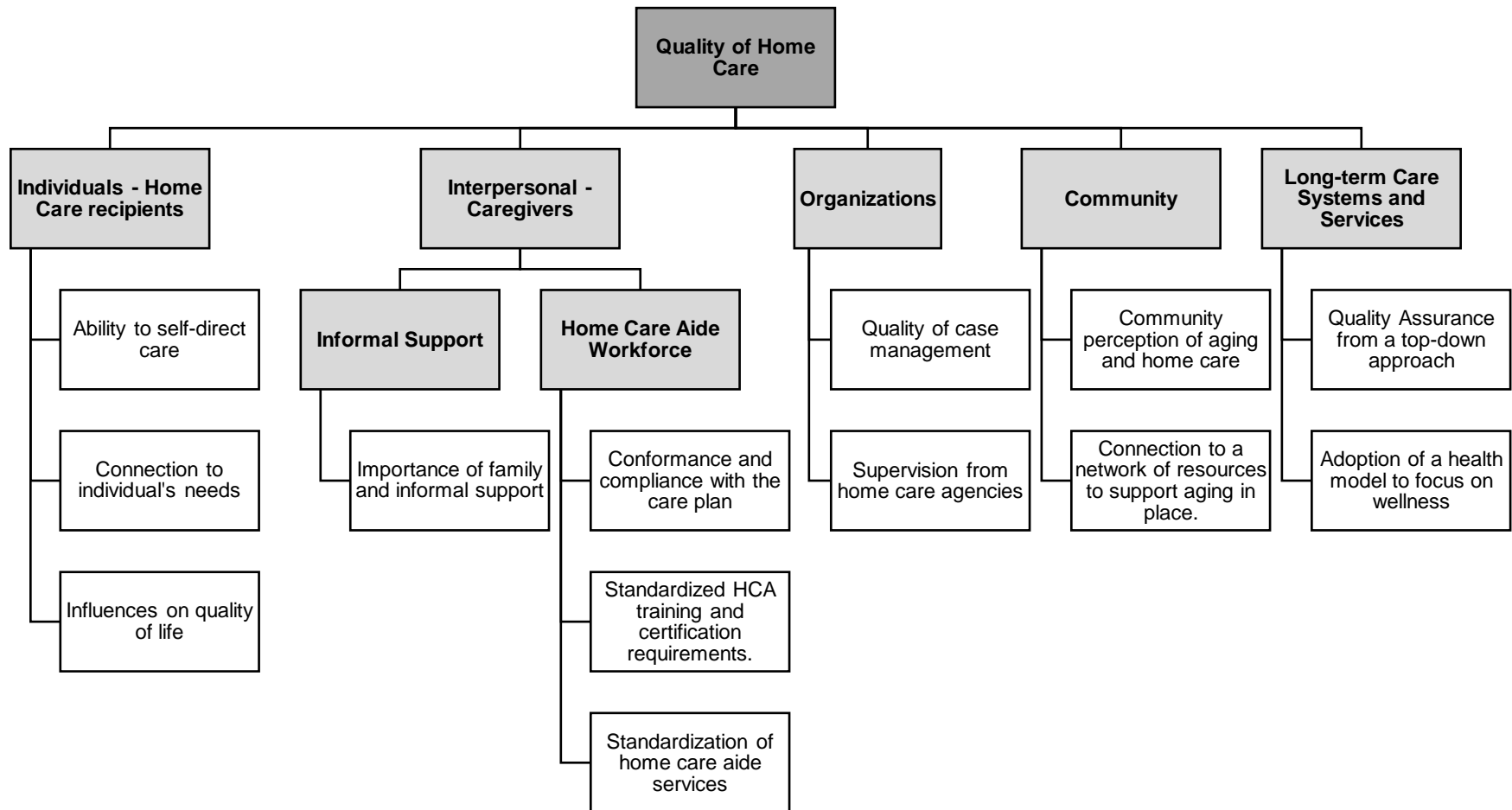
Table 1

*Semi-structured Interview Questions on Quality of Home Care Services*

<b>Questions</b>	<b>Focus Group Questions</b>
1.	How would you describe to another person what home care is/involves?
2.	How would you define home care?
3.	How would you describe quality of home care?
4.	How would you define good quality of home care? What might be an example that demonstrates good quality of home care?
5.	<p>What are the key home care services that affect the quality of care or that make it challenging to deliver high/good quality of home care?</p> <p>a) In what ways do the type of service you mentioned affect the quality of care?</p> <p>b) What is an example of how that service impacts your client in terms of health outcomes and quality of life?</p>
6.	What are the factors that affect the quality of in-home care?
7.	What data are collected in your day-to-day work that you think reflect quality of care and/or client's health outcomes and quality of life?
8.	Are there any data or information about service recipients that should be collected?
9.	In what ways does a determination/evaluation of quality of in-home care differ from typical ways that quality of care is evaluated in long-term care?
10.	Is there anything else you think I should know about home care, quality of care or the quality of life of recipients of home care?

**Figure 1**

*Themes and subthemes of quality of home care*



**Chapter III: Manuscript #2**

**The Relationship between Quality of Home Care and Health-Related Quality of Life**

To be submitted to the *Research in Gerontological Nursing*

Instructions for authors: <http://www.healio.com/nursing/journals/rgn/submit-an-article#Authors>

## Abstract

**Background:** In the United States, the aging population and increasing prevalence of chronic diseases and disabilities have contributed to a growing demand for long-term care. Long-term care services are primarily aimed at improving the quality of life of service recipients, who have temporary or permanent functional limitations affecting self-care ability and need help with activities of daily living.

**Purpose:** The purpose of this study is to explore the associations of personal care assistance by needs (met and received) with self-rated health status and well-being, as the two health-related quality of life measures, among Medicare beneficiaries.

**Methods:** Using a longitudinal, panel study design, we examined the associations of activities of daily living (ADL) and instrumental activities of daily living assistance with self-rated health (SRH) status and well-being (WB) among home-dwelling older adults. We conducted a secondary analysis of survey data derived from the National Health and Aging Trends Study (NHATS).

**Results:** Overall, our analytic models demonstrated positive associations between the number of ADL assistance tasks and the two outcomes: (a) self-rated health and (b) well-being. Significant associations were found between the number of ADL assistance needs and SRH and WB in the overall and stratified models. Our models demonstrated an increase in SRH for each increase in the number of ADL assistance tasks, and an increase in WB for each increase in the number of ADL assistance tasks provided by a formal caregiver.

**Implications:** Our findings showed that participants who had no ADL assistance need reported a higher point of SRH and WB at baseline and subsequent measurements as compared to

participants who had at least one unmet ADL assistance need. Home care should address how to fulfill the care recipient's care needs.

## INTRODUCTION

A growing interest among policy makers and consumers is to determine the effects of long-term care service on health benefits. In the United States, the aging population and increasing prevalence of chronic diseases and disabilities have contributed to a growing demand for long-term care (de Meijer, Koopmanschap, Koolman, & van Doorslaer, 2009; McAuley & Arling, 1984; Vladeck, 2005). These demographic changes suggest that many older adults with complex medical conditions need long-term care services and that they have distinctive health needs and preferences for care (de Meijer et al., 2009; Freedman & Spillman, 2014; Piering, 2007). Long-term care services are primarily aimed at improving quality of life of service recipients (Kane, 2001) who have temporary or permanent functional limitations affecting self-care ability and who therefore need help with activities of daily living. A wide variety of services is available in long-term care services and support (LTSS), ranging from institutional care (such as a nursing home) to home and community-based care (assisted living, adult family home, and home care).. These long-term care services vary in structure of care and scope of service, but they have all been established to meet care needs specific to the individual. As many people want to age in place and remain at home in their late years of life, service delivered to a recipient's home is the preferred choice of older people requiring care (Guo, Konetzka, Magett, & Dale, 2015). Home-based long-term care, also known as Personal Care Service (PCS) or Personal Assistance Service, allows service recipients to have more control of their daily living, while they remain connected to their family, friends, and the community. Home-based long-term care has been shown to improve health and quality of life of service recipients (Zubritsky et al., 2013). However, LTSS are challenged to continue providing high quality long-term care. Scientific evidence linking home-based long-term care service to health outcome is still lacking.

While most people want to be prepared for their future, further research on home care will help future long-term care users be informed about their choices. Advances in research regarding the effects of home-based long-term care on health outcomes are essential as a way to inform practice about how to measure and improve quality of care in the existing LTSS.

### **Background**

Home-based long-term care or personal care service (PCS) denotes a range of activities of daily living (ADL) assistance and instrumental activities of daily living (IADL) assistance provided to individuals with disabilities and chronic conditions, enabling them to stay in their homes and communities and to maintain independence ("Personal care services. 42 C.F.R. § 440.167.,"). A 2010 study found that about 6 million community-dwelling older adults needed long-term care in the United States (Kaye, Harrington, & LaPlante, 2010). Of those community dwellers, over 90 percent received help from an informal (unpaid) source such as family and friends, while 13 percent received formal (paid) help (Kaye et al., 2010). Formal PCS is primarily funded by Medicaid or Medicare, predominantly Medicaid (Ng, Harrington, & Kitchener, 2010). According to a study by the Henry J. Kaiser Family Foundation (2013), about 2 million people received PCS through a Medicaid waiver program or a state health plan, and the overall number of enrollment has increased 36 percent in the past decade (Ng, Harrington, Musumeci, & Ubri, 2016). Enrollment is projected to increase as the older adult population continues to grow.

Within the LTSS group, PCS is a consumer-centered service that includes a mix of ADL and IADL assistance tasks provided by a home care aide to a recipient based on the level of self-care deficit. Although PCS programs are funded and operated by individual states, the ADL and

IADL assistance tasks covered by the PCS programs are generally the same (LeBlanc, Tonner, & Harrington, 2001). ADL assistance refers to help with ambulation, repositioning in bed, and help with eating. IADL assistance refers to homemaking tasks, including meal preparation, laundry, and light housework. In the Medicaid-funded PCS programs, the PCS coverage is determined by a care recipient's needs. These needs are defined as the number and types of ADL tasks that a beneficiary reported having difficulty with or reported being incapable of performing by themselves. The service coverage also accounts for any support that would normally be provided by informal sources, as PCS is a form of supplemental service. In many state PCS programs, service reimbursement is based on the beneficiary's need and is calculated from hours of service provided by a home care aide at the beneficiary's home. Under the reimbursement requirements, a home care aide performs the ADL and IADL assistance needed by the beneficiary in the designated service hours. Unfortunately, the amount of PCS, required to fulfill the care recipient's needs is often determined from criteria that are subjective and ambiguous. This causes the overall quality of care, in terms of satisfying the beneficiary's expectations, to suffer.

Provision of PCS has been guided mainly by the assumption that high quality PCS improves health-related quality of life of the service recipients (Wilson & Cleary, 1995; Zubritsky et al., 2013). Little research has been done to examine this philosophical assumption. The main challenge for developing research in this area is a lack of benchmark measures of service quality (Applebaum & Phillips, 1990; Khatutsky, Anderson, & Wiener, 2006). In LTSS, consensus on what is good quality of care is missing. Conventional measures following the structure and process of a quality of care framework are used to measure long-term care service in congregational settings. However, these measures are not applicable for measuring services delivered to individuals at home. Another challenge is the dearth of national datasets linking

service to health outcomes. Measuring the quality of care and health outcomes experienced by service recipients is difficult. Collecting data from service recipients at home settings, which are widely dispersed by geographic locations, is extremely labor intensive, time-consuming, and expensive (Applebaum & Phillips, 1990).

Medicaid-funded PCS, mostly studied in health service research, addresses service satisfaction, with the care received as a service outcome. A few studies have indicated that service recipients had overall positive experience with the service (Eustis & Fischer, 1991; Geron et al., 2000; Khatutsky et al., 2006; Wiener, Anderson, & Khatutshy, 2009) and their relations with home care aides (Eustis & Fischer, 1991). Other studies comparing formal care to informal care showed that both formal and informal care were associated with desirable health outcomes (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Hoffman et al., 2016; Magilvy, Congdon, & Martinez, 1994). However, there is little information on how quality of care was defined and how it impacted outcomes.

Health-related quality of life (HRQOL) is a key measure in assessing health outcomes of older adults receiving health services (Dominick, Ahern, Gold, & Heller, 2002; Guyatt, Eagle, et al., 1993). HRQOL is a multi-dimensional measure that encompasses both subjective and objective evaluation of quality of life, including physical functioning, psychological well-being, social and role functioning, and health perception (Guyatt, Eagle, et al., 1993; Guyatt, Feeny, & Patrick, 1993). Research on long-term care suggests that formal care has a significant impact on HRQOL; however, little is known about how service characteristics and quality of care affect recipient outcomes. Most previous studies were done to examine long-term care service provided at institutional settings. Those studies showed that long-term care service provided in nursing

homes was associated with HRQOL (Borowiak & Kostka, 2004; Hays et al., 1996; Kanwar et al., 2013; Naylor et al., 2016).

Many factors related to older adult service recipients, such as number of chronic conditions (Kempen, Jelacic, & Ormel, 1997; Metzelthin et al., 2015; Mujica-Mota et al., 2015) and limitations in activities of daily living (Barile et al., 2013), also contributed to HRQOL. However, many service measures used for congregational long-term care settings are not applicable to measuring services delivered to homes because of vast differences in structure of care settings and process of care.

Medicaid-funded PCS is reimbursed according to the beneficiary's needs for ADL assistance. Research indicates that unmet needs for ADL for older adults with physical limitations were associated with negative health outcomes (Allen, Piette, & Mor, 2014; Freedman & Spillman, 2014; Liu, Zeng, Li, & Wang, 2013). Unmet ADL needs also increased utilization of medical services (DePalma et al., 2013; Hass, DePalma, Craig, Xu, & Sands, 2015) and was associated with mortality (Gaugler, Kane, Kane, & Newcomer, 2005; Hass et al., 2015; He et al., 2015). Studies have defined unmet needs differently and they address adverse health events as outcome measures.

Policy makers and researchers are actively searching for quantifiable service measures for benchmarking PCS and measurable health outcomes reflecting service quality (National Quality Forum, 2016). To reduce the gap between science and practice, the purpose of this study is to explore the association of PCS assistance by needs met and needs received) with self-rated health status and well-being, as the two health-related quality of life measures, among Medicare beneficiaries.

## Methods

Using a longitudinal, panel study design, we examined the associations of activities of daily living (ADL) and instrumental activities of daily living assistance with self-rated health status and well-being among home-dwelling older adults. In this exploratory study, we conducted a secondary analysis of survey data derived from the National Health and Aging Trends Study (NHATS) (Johns Hopkins University, 2011).

### Study Population

The NHATS is a longitudinal study of a nationally representative cohort of Medicare beneficiaries aged 65 and older living in the contiguous United States. The baseline (round one) interview with participants was conducted in 2011, and subsequent interviews with the same participants were done annually. Of the 8,245 participants who completed the interview survey at baseline, our study included only those who were identified as community dwellers living in their private residence. “Community dwellers” does not include participants who were residents of a nursing home or other residential care settings (such as assisted living, continuing care retirement community, group home, or adult family home), resulting in an analytical sample of 6,004 home-dwelling participants.

### Data

Our dataset integrated four rounds of the NHATS survey undertaken between 2011 and 2014 that included the data from the study participants (*sample participant files*) and the data about their caregivers identified by participants (*other person data files*) (Kasper & Freedman, 2015). Integration of the participant and caregiver data involved four steps. First, we created constructs of ADL and IADL assistance tasks and sources of ADL and IADL assistance (i.e., formal and informal), using the *other person data files* of the NHATS. Second, the caregiver data

were aggregated to the participant-specific level, such that a participant who identified more than one caregiver would be aggregated to a sum of caregivers. Constructs of ADL and IADL assistance were then developed; for example, if a participant reported receiving an ADL assistance task provided by one formal caregiver and one informal caregiver, the ADL assistance constructs would be “number of formal ADL assistance tasks” (with a value equaling one) and “number of informal ADL assistance tasks” (with a value equaling one). Third, we merged the participant data from the *sample person data files* and the aggregated caregiver data from the *other person data files* for the corresponding survey rounds. Last, we compiled the merged participant and caregiver data from all four survey rounds for our longitudinal analysis.

## Measures

**Explanatory measures.** The explanatory variables were the numbers of ADL assistance tasks provided by formal and informal caregivers. The seven ADL assistance tasks, which were considered as the basic self-care tasks, included assistance with going outside, getting around inside home, getting in and out of bed, eating, showering/taking a bath, using the toilet, and getting dressed. Each ADL assistance task was categorized into two sources: (a) formal assistance, defined as assistance provided by “someone paid to help” and (b) informal assistance, defined as assistance provided by an informal source such as family and friends.

**Outcome measures.** The two outcome measures were self-rated health status (SRH) and self-reported well-being (WB). SRH was defined as a participant’s self-rated overall health condition based on a 5-point scale (1=excellent, 2=very good, 3=good, 4=fair, and 5=poor). SRH was reverse-coded, such that a higher score indicated a higher point of self-rated health status. WB was a validated, single-factor index that was constructed by using the mean of the standardized scores of 11 well-being survey items identified in the NHATS. The single-factor

index was tested to be a reliable and valid to measure well-being of older adults (Kim, Lehning, & Sacco, 2016). The WB index included items from three well-being components: (a) positive and negative affect, (b) global life satisfaction, and (c) sense of control. Positive and negative affect were measured by four items rated on a scale of 1-5 to represent how often (i.e., number of days per week) a participant felt “cheerful”, “bored”, “full of life”, and “upset”. Global life satisfaction was measured by four items that included “My life has meaning and purpose”, “I feel confident and good about myself”, “I gave up trying to improve my life a long time ago”, and “I like my living situation very much”. Sense of control was measured by three items, which were “Other people determine most of what I can and cannot do”, “When I really want to do something, I usually find a way to do it”, and “I have an easy time adjusting to change”. A 3-point scale (agree a lot, agree a little, agree not at all) was used to measure the degree of global life satisfaction and sense of control. To adjust for items worded with reciprocal meaning, seven items such as feelings of being “cheerful” and “full of life” were reverse-coded such that a higher index indicated a higher point of well-being.

**Covariate measures.** The participant characteristics consisted of age, gender, race and ethnicity, marital status, highest degree of school completed, living arrangement (living alone or living with spouse and/or others), recent employment for pay, and military service. Participant comorbidity comprised a range of 10 medical conditions specified in the NHATS that included heart attack or myocardial infarction, any heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia/Alzheimer’s disease, and cancer. We examined health services and medical coverage, including any overnight hospital stays, availability of Medicaid benefits, Medicare Part D, Medicare supplement, nursing home coverage, assisted living coverage, and home health coverage.

Participant ADL assistance need, as a covariate, was measured by the number of ADL tasks for which a participant reported needing assistance. ADL assistance need was defined by one of three conditions that included a participant's report of performing an ADL by self with difficulty, not performing an ADL by self, and not performing an ADL because of not having help. The quality of ADL assistance for each participant was measured by number of formal and informal caregivers, whether the ADL assistance was scheduled, and whether the caregiver lived in the household. We also included the number of IADL assistance tasks provided by formal and informal caregivers as covariate measures. The eight IADL caregiver assistance tasks identified were: taking the participant to places, doing laundry, shopping for groceries, preparing meals, managing money, helping with banking, sitting with the participant doctor appointments, and helping with medications.

### **Data Analysis**

Baseline characteristics, including explanatory measures, outcome measures, and other control variables were analyzed with descriptive statistics. Outcome measures were examined for trends and changes over time. Using generalized estimating equations (GEE) population-averaged models with independent correlation matrix, we estimated the associations of ADL assistance with self-rated health status and well-being index separately and by stratification of participants. Three strata of participants were created based on their needs for ADL assistance: (a) participants who reported no need for ADL assistance, (b) participants who had need for at least one unmet ADL assistance task, and (c) participants whose needs for ADL assistance had been completely met. Our analytic models used robust standard errors, assuming cases were dependent for individual participants and independent among participants. In the NHATS, all data were estimated with sampling weights that were corrected for sample design and non-

response and for which standard errors were adjusted for clustering at the counties or groups of counties level as the primary sampling unit. A significance level of 0.05 was used for all comparisons. All analyses were conducted using Stata, version 14 software (StataCorp LP, College Station, TX).

## Results

Of the 6,004 study participants, the number who remained home-dwelling in the subsequent rounds were 4,175 (79%) in round two, 3,779 (63%) in round three, and 3,124 (52%) in round four, as shown in Figure 2. Participant attrition comprised lost to follow-up, death, illness with no proxy, refusal, and moved outside the study location. Participants who moved to nursing home or residential facilities were excluded in subsequent rounds.

The baseline characteristics of the study participants are shown in Table 2. Compared to participants who reported no need for ADL assistance ( $n=3717$ ), participants who had need for ADL assistance were fewer ( $n=2287$ ), and a higher proportion were Black, a higher proportion were widowed, and a lower proportion had worked for pay recently. Participants who had need for ADL assistance also had higher percentages in the 10 chronic illness categories. High blood pressure and arthritis were the two most frequent chronic illnesses among participants. In terms of health service utilization and medical coverage, participants who had need for ADL assistance had higher percentages of overnight hospital stays in the previous 12 months, Medicare drug coverage, and Medicaid benefits. On the other hand, this participant group was less likely to have non-governmental, long-term care insurance coverage for nursing home, assisted living, and home health services.

For those participants needing assistance, most reported having a need for some kind of mobility assistance, such as getting help with going outside ( $n=1225$ , 20%), getting in and out of

bed ( $n=1233$ , 21%), and getting around inside home ( $n=1141$ , 19%). Fewer participants needed help with getting dressed ( $n=1071$ , 18%), showering/taking a bath/wash-up ( $n=977$ , 16%), using the toilet ( $n=552$ , 9%), and eating ( $n=355$ , 6%). Participants who had a need for ADL assistance received help with going outside ( $n=626$ , 10%), getting in and out of bed ( $n=321$ , 6%), and getting around inside the home ( $n=372$ , 6%). Fewer participants received assistance with getting dressed ( $n=569$ , 10%), showering/taking a bath/wash-up ( $n=488$ , 8%), using the toilet ( $n=205$ , 3%), and eating ( $n=179$ , 3%). When we examined the differences between ADL assistance needed and ADL assistance received, the highest proportion of unmet ADL assistance needs were going outside and getting dressed. The breakdown of ADL assistance needed and ADL assistance received is shown in Table 3.

The trends of mean SRH and mean WB were relatively flat, with little variation in the three participant strata over time, as show in Figures 3a and 3b. The two strata of participants with ADL assistance needs had consistently lower SRH and WB than the participant stratum with no ADL assistance needs. Between the two strata of participants with ADL assistance needs, mean SRH of the stratum with unmet ADL assistance increased from 2.620 to 2.677, and the mean SRH of the stratum with ADL assistance needs that were met increased from 2.605 to 2.741. Mean WB of the stratum of participants with unmet ADL assistance decreased from -0.221 to -0.249, and mean WB of stratum of participants with ADL assistance needs that were met increased from -0.234 to -0.199. The trends of mean SRH and WB indicated little variation within each participant stratum; however, the variation among strata was more pronounced.

Overall, our analytic models demonstrated positive associations between the number of ADL assistance tasks and the two outcomes: (a) self-rated health status (as shown in Table 4) and (b) well-being index (as shown in Table 5), while controlling for variables that included

number of formal IADL assistance tasks, number of informal IADL assistance tasks, number of reported ADL assistance needs, age, gender, whether a participant was living alone, number of comorbid conditions, whether a participant had Medicaid coverage, and survey rounds. In the non-stratified models with all participants, we would expect an increase in SRH (coefficient estimate = 0.030, SE = 0.021,  $p > 0.05$ ) for every one unit increase in the number of ADL assistance tasks provided by a formal source, as well as an increase in SRH (coefficient estimate = 0.030, SE = 0.015,  $p < 0.05$ ) for every one unit increase in the number of ADL assistance tasks provided by an informal source. We would further expect an increase in WB (coefficient estimate = 0.030, SE = 0.021,  $p > 0.05$ ) for every one unit increase in the number of ADL assistance tasks provided by a formal source and a decrease in WB (coefficient estimate = -0.030, SE = 0.013,  $p < 0.05$ ) for every one unit increase in the number of ADL assistance tasks provided by an informal source. When stratified by needs for ADL assistance, the positive association between WB and number of ADL assistance tasks provided was insignificant.

Significant associations were found between the number of ADL assistance needs and SRH and WB in the overall and stratified models. Although the coefficient estimates were small, the findings indicated that the number of ADL assistance needs was negatively associated with SRH and WB. In other words, individuals with higher ADL assistance need would predict lowered SRH and WB.

### **Discussion**

This study examined the effects of personal care services on self-rated overall health status and well-being among Medicare beneficiaries. Our dataset was the data from the NHATS, which is a national, representative sample of participants aged 65 or over. The characteristics of the NHATS participants resemble the older adults in the general population (U.S. Census

Bureau, 2014). Comparing the demographics of the NHATS participants, which included Medicaid-funded home and community-based service beneficiaries aged 65 years and older (Anderson, Wiener, Khatuskay, & RTI International, 2005), our study sample was similar in terms of average ages and ethnic composition, but it differed somewhat in having a lower proportion of women, a higher proportion of participants who were married or with a partner, a higher proportion of people who had a college degree or higher, a higher average income, and a higher average self-rated health status.

In many states, Medicaid-funded PCS programs cover a list of ADL assistance tasks similar to the seven tasks being studied. Having considered that the LTSS has been lacking a set of benchmark measurements to measure quality of care of PCS, our study measured PCS according to the ADL assistance needed and ADL assistance received and differentiated the assistance by formal and informal sources. In terms of the seven ADL assistance tasks, each task involves a series of steps and details to be completed by a home care aide. Although ADL assistance needed versus ADL assistance received is not equivalent to service quality, quantified ADL assistance provided an operational definition of PCS.

A major assumption of differentiating ADL assistance by formal and informal sources is that formal caregivers are trained personnel and are skilled at providing ADL assistance. In Medicaid-funded PCS programs, formal home care aides are mandated to go through home care aide training and certification. Family members, unless they take care of their next of kin as a home care aide, are exempt from training and certification. Evidence supports that home care aide training improves worker competence and that it is one way to improve quality of care (Stone & Wiener, 2001). In service delivery, the same family member or non-paid helper can act as both a formal and informal caregiver to the care recipient. In the NHATS, participants

reported on whether an ADL assistance task was provided by a paid helper or a non-paid helper. In fact, the caregiving roles often overlapped and were in some cases inseparable. Many service recipients who received paid service from a family member did not consider themselves to be receiving public assistance from the government. Since there was no validation of whether a family caregiver provided only informal care or concurrently provided formal care, the ambiguity of caregiving roles created a confounding effect in our study findings. Moreover, family members (as formal caregivers) tended to provide ADL and IADL help more than the state covered, sometimes even exceeding what the service recipient needed.

Another assumption is that level of need is determined based on the number and types of ADL tasks that a beneficiary reports having difficulty with or is incapable of performing by themselves. To measure self-reported needs is difficult, because the reports can be ambiguous and can vary widely from person to person. For instance, two persons who have the same three ADL assistance needs may require various kinds of help and various amounts of time to complete the tasks. Thus, the extent of assistance and the amount of time spent providing it both factor into determining quality of care. Research on these attributes is important to inform policy development in terms of how level of care and service reimbursement are calculated.

Our study addressed self-rated health status and well-being as the two outcome measures, instead of using adverse outcomes as many studies have done. SRH and WB are two positive health outcomes that are widely accepted to be key components of health-related quality of life among older adults. Our findings showed the amount of formal ADL assistance received by recipients was positively associated with SRH and WB, though the associations were statistically insignificant. This finding suggests that a sluggish association exists between formal ADL assistance received and SRH and WB. The same positive associations were neither found

between informal ADL assistance and SRH and WB, nor between IADL assistance and SRH and WB.

Agreeing with the existing studies regarding unmet care needs associated with negative health outcomes (Acierno et al., 2010; Allen et al., 2014; Freedman & Spillman, 2014; Liu et al., 2013), our findings show that the participant stratum that had no ADL assistance need reported having higher levels of SRH and WB at baseline and subsequent measures, as compared to the stratum of participants who had at least one unmet ADL assistance need. The differences in the mean SRH and mean WB between the three participant strata suggest that the participants who had at least one unmet ADL assistance need were more likely to have physical limitations and self-care deficits that would lead to lower SRH and WB.

Another important contributor to the sluggish association between formal ADL assistance received and SRH and WB is that SRH and WB as outcome measures are general and distal to service quality. SRH and WB, which depict health-related quality of life in a global sense, can be influenced by other factors such as cultural background. In our study, the mean SRH and mean WB are population-averaged scores. A population-averaged score is insufficiently insensitive to detect individual change, because the effect of change of a small fraction of participants will be diluted in the population average. Changes in SRH and WB may take a long time to occur. Our dataset consists of only 4 years of data and thus cannot reflect any subtle changes that might surface over a longer period. Measuring outcomes related to quality of personal care should be more specific to each ADL tasks and the identified ADL assistance needs.

### **Strengths**

The strength of this study is its use of data from a national sample of Medicare beneficiaries, from the NHATS. The NHATS adopted a sophisticated sampling method that

ensured the sample selection was representative of the older adult population in the U.S. Our study findings, based as they are on the NHATS data, can be generalized to the larger population.

### **Limitations**

A limitation of this study is that the findings are limited in generalizability, since we used the NHATS data for a secondary analysis. The NHATS is a rich source of information about older adults, their lives, and their significant others. However, the NHATS survey questions were not designed to answer specific questions related to PCS. Many key variables and data were thus missing from the dataset, and that increases the challenge of applying the findings to practice.

### **Future Research**

Research on PCS is underdeveloped and will require a significant number of new studies to build the body of knowledge. Some suggestions for future research include creating a set of service measures representing quality of care in PCS, collecting clinical/administrative data from state Medicaid programs, and developing and adopting outcome measures related to quality of care.

### **Conclusion**

With little quality metrics and benchmark data to measure quality of personal care service, this groundwork study makes an important contribution to long-term care research. The study identified ways to quantify personal care service in terms of numbers of ADL assistance tasks and IADL assistance tasks, measured quality of personal care service by matching assistance needed with assistance received, and characterize assistance by formal and informal sources. This study also tested the associations of personal care services with overall health

status and well-being, which are two key domains of HRQOL. The study findings indicate a significant harmful relationship between the number of ADL assistance needs and HRQOL. These findings underscore the importance of measuring quality of care of PCS to ensure service quality and improve PCS programs nationwide in the future.

## References

- Acierno, R., Hernandez, M. A., Amstadter, A. B., Resnick, H. S., Steve, K., Muzzy, W., & Kilpatrick, D. G. (2010). Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the United States: the National Elder Mistreatment Study. *American Journal of Public Health, 100*(2), 292-297.  
doi:10.2105/ajph.2009.163089
- Allen, S. M., Piette, E. R., & Mor, V. (2014). The adverse consequences of unmet need among older persons living in the community: dual-eligible versus Medicare-only beneficiaries. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 69*(Suppl 1), S51-S58. doi:10.1093/geronb/gbu124
- Anderson, W., Wiener, J. M., Khatuskay, G., & RTI International. (2005). *Older People and Younger Persons with Physical Disabilities Who Use Medicaid Home and Community-Based Services in Six States: A Preliminary Analysis*. Retrieved from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Reports/downloads/Anderson.pdf>
- Applebaum, R., & Phillips, P. (1990). Assuring the quality of in-home care: the "other" challenge for long-term care. *Gerontologist, 30*(4), 444-450.
- Barile, J. P., Thompson, W. W., Zack, M. M., Krahn, G. L., Horner-Johnson, W., & Bowen, S. E. (2013). Multiple chronic medical conditions and health-related quality of life in older adults, 2004-2006. *Preventing Chronic Diseases, 10*, E162. doi:10.5888/pcd10.120282
- Borowiak, E., & Kostka, T. (2004). Predictors of quality of life in older people living at home and in institutions. *Aging Clinican and Experimental Research, 16*(3), 212-220.

- Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. (2016). Mixed care networks of community-dwelling older adults with physical health impairments in the Netherlands. *Health and Social Care in the Community*, 24(1), 95-104. doi:10.1111/hsc.12199
- de Meijer, C. A., Koopmanschap, M. A., Koolman, X. H., & van Doorslaer, E. K. (2009). The role of disability in explaining long-term care utilization. *Medical Care*, 47(11), 1156-1163. doi:10.1097/MLR.0b013e3181b69fa8
- Depalma, G., Xu, H., Covinsky, K. E., Craig, B. A., Stallard, E., Thomas, J., 3rd, & Sands, L. P. (2013). Hospital readmission among older adults who return home with unmet need for ADL disability. *Gerontologist*, 53(3), 454-461. doi:10.1093/geront/gns103
- Dominick, K. L., Ahern, F. M., Gold, C. H., & Heller, D. A. (2002). Relationship of health-related quality of life to health care utilization and mortality among older adults. *Aging Clinical and Experimental Research*, 14(6), 499-508.
- Eustis, N. N., & Fischer, L. R. (1991). Relationships between home care clients and their workers: implications for quality of care. *Gerontologist*, 31(4), 447-456.
- Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older Americans. *Milbank Quarterly*, 92(3), 509-541. doi:10.1111/1468-0009.12076
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *Journal of American Geriatrics Society*, 53(12), 2098-2105. doi:10.1111/j.1532-5415.2005.00495.x
- Geron, S. M., Smith, K., Tennstedt, S., Jette, A., Chassler, D., & Kasten, L. (2000). The home care satisfaction measure: A client-centered approach to assessing the satisfaction of frail older adults with home care services. *The Journals of Gerontology Series B:*

*Psychological Sciences and Social Sciences*, 55B(5), S259-S270.

doi:10.1093/geronb/55.5.S259

Guo, J., Konetzka, R. T., Magett, E., & Dale, W. (2015). Quantifying long-term care preferences.

*Medical Decision Making*, 35(1), 106-113. doi:10.1177/0272989x14551641

Guyatt, G. H., Eagle, D. J., Sackett, B., Willan, A., Griffith, L., McIlroy, W., . . . Turpie, I.

(1993). Measuring quality of life in the frail elderly. *Journal of Clinical Epidemiology*, 46(12), 1433-1444.

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life.

*Annals of Internal Medicine*, 118(8), 622-629.

Hass, Z., DePalma, G., Craig, B. A., Xu, H., & Sands, L. P. (2015). Unmet need for help with activities of daily living disabilities and emergency department admissions among older

Medicare recipients. *Gerontologist*, 00(00), 1-5. doi:10.1093/geront/gnv142

Hays, R. D., Siu, A. L., Keeler, E., Marshall, G. N., Kaplan, R. M., Simmons, S., . . . Schnelle, J.

F. (1996). Long-term care residents' preferences for health states on the quality of well-being scale. *Medical Decision Making*, 16(3), 254-261.

He, S., Craig, B. A., Xu, H., Covinsky, K. E., Stallard, E., Thomas, J., 3rd, . . . Sands, L. P.

(2015). Unmet need for ADL assistance is associated with mortality among older adults with mild disability. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 70(9), 1128-1132. doi:10.1093/gerona/glv028

Hoffman, G. J., Hays, R. D., Wallace, S. P., Shapiro, M. F., Yakusheva, O., & Ettner, S. L.

(2016). Receipt of caregiving and fall risk in US community-dwelling older adults.

*Medical Care*, 00(00), 1-8. doi:10.1097/mlr.0000000000000677

- Johns Hopkins University. (2011). *National Health and Aging Trends Study [Data file and code book]*. Retrieved from: <http://www.nhats.org/>
- Kane, R. A. (2001). Long-term care and a good quality of life: bringing them closer together. *Gerontologist, 41*(3), 293-304.
- Kanwar, A., Singh, M., Lennon, R., Ghanta, K., McNallan, S. M., & Roger, V. L. (2013). Frailty and health-related quality of life among residents of long-term care facilities. *Journal of Aging and Health, 25*(5), 792-802. doi:10.1177/0898264313493003
- Kasper, J. D., & Freedman, V. A. (2015). National Health and Aging Trends Study User Guide: Rounds 1, 2, 3 & 4 Final release. Retrieved from <http://www.nhats.org/>
- Kaye, H. S., Harrington, C., & LaPlante, M. P. (2010). Long-term care: who gets it, who provides it, who pays, and how much? *Health Affairs (Millwood), 29*(1), 11-21. doi:10.1377/hlthaff.2009.0535
- Kempen, G. I., Jelicic, M., & Ormel, J. (1997). Personality, chronic medical morbidity, and health-related quality of life among older persons. *Health Psychology, 16*(6), 539-546.
- Khatutsky, G., Anderson, W. L., & Wiener, J. M. (2006). Personal care satisfaction among aged and physically disabled Medicaid beneficiaries. *Health Care Financing Review, 28*(1), 69-86.
- Kim, K., Lehning, A. J., & Sacco, P. (2016). Assessing the factor structure of well-being in older adults: findings from the National Health and Aging Trends Study. *Aging and Mental Health, 20*(8), 814-822. doi:10.1080/13607863.2015.1037245
- LeBlanc, A. J., Tonner, C., & Harrington, C. (2001). State Medicaid programs offering personal care services. *Health Care Financing Review, 22*(4), 155-173.

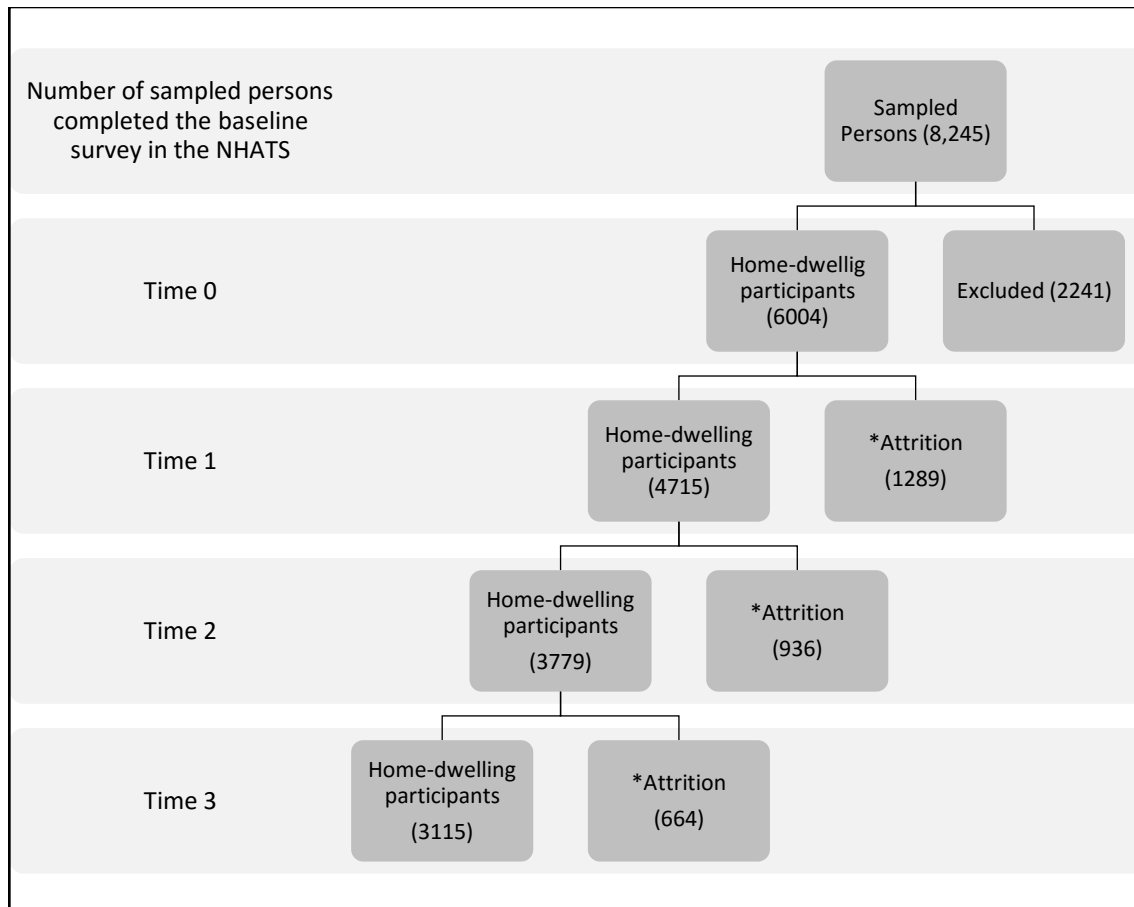
- Liu, N., Zeng, L., Li, Z., & Wang, J. (2013). Health-related quality of life and long-term care needs among elderly individuals living alone: a cross-sectional study in rural areas of Shaanxi Province, China. *BMC Public Health, 13*(313), 1-7. doi:10.1186/1471-2458-13-313
- Magilvy, J. K., Congdon, J. G., & Martinez, R. (1994). Circles of care: home care and community support for rural older adults. *Advances in Nursing Sciences, 16*(3), 22-33.
- McAuley, W. J., & Arling, G. (1984). Use of in-home care by very old people. *Journal of Health & Social Behavior, 25*(1), 54-64.
- Metzelthin, S. F., van Rossum, E., Hendriks, M. R., De Witte, L. P., Hobma, S. O., Sipers, W., & Kempen, G. I. (2015). Reducing disability in community-dwelling frail older people: cost-effectiveness study alongside a cluster randomised controlled trial. *Age Ageing, 44*(3), 390-396. doi:10.1093/ageing/afu200
- Mujica-Mota, R. E., Roberts, M., Abel, G., Elliott, M., Lyratzopoulos, G., Roland, M., & Campbell, J. (2015). Common patterns of morbidity and multi-morbidity and their impact on health-related quality of life: evidence from a national survey. *Quality of Life Research, 24*(4), 909-918. doi:10.1007/s11136-014-0820-7
- National Quality Forum. (2016). *Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Priorities for Measure Development - Interim Report*. Retrieved from [http://www.qualityforum.org/Measuring\\_HCBS\\_Quality.aspx](http://www.qualityforum.org/Measuring_HCBS_Quality.aspx)
- Naylor, M. D., Hirschman, K. B., Hanlon, A. L., Abbott, K. M., Bowles, K. H., Foust, J., . . . Zubritsky, C. (2016). Factors associated with changes in perceived quality of life among

- elderly recipients of long-term services and supports. *Journal of the American Medical Directors Association*, 17(1), 44-52. doi:10.1016/j.jamda.2015.07.019
- Ng, T., Harrington, C., & Kitchener, M. (2010). Medicare and Medicaid in long-term care. *Health Affairs (Millwood)*, 29(1), 22-28. doi:10.1377/hlthaff.2009.0494
- Ng, T., Harrington, C., Musumeci, M., & Ubri, P. (2016). *Medicaid home and community-based services programs: 2013 Data update*. Retrieved from <http://files.kff.org/attachment/Report-Medicaid-Home-and-Community-Based-Services-Programs-2013-Data-Update>
- Personal care services. 42 C.F.R. § 440.167. Retrieved from [http://www.ecfr.gov/cgi-bin/text-idx?SID=80e75e6122d39b1a79d934fc533a6bba&mc=true&node=se42.4.440\\_1167&rgn=div8](http://www.ecfr.gov/cgi-bin/text-idx?SID=80e75e6122d39b1a79d934fc533a6bba&mc=true&node=se42.4.440_1167&rgn=div8)
- Piering, P. (2007). Bracing for the boomers. *Northwest Public Health*(Fall/Winter), 6-7.
- Stone, R. I., & Wiener, J. M. (2001). *Who will care for us? Addressing the long-term care workforce crisis*. Retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/73111/lcwf.pdf>
- U.S. Census Bureau. (2014). *65+ in the United States: 2010*. Retrieved from Washington, DC: <https://www.census.gov/content/dam/Census/library/publications/2014/demo/p23-212.pdf>
- Vladeck, B. C. (2005). Economic and policy implications of improving longevity. *Journal of the American Geriatrics Society*, 53(9 Suppl), S304-S307. doi:10.1111/j.1532-5415.2005.53495.x
- Wiener, J. M., Anderson, W. L., & Khatutshy, G. (2009). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontologist*, 47(6), 763-774.

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA*, *273*(1), 59-65.

Zubritsky, C., Abbott, K. M., Hirschman, K. B., Bowles, K. H., Foust, J. B., & Naylor, M. D. (2013). Health-related quality of life: expanding a conceptual framework to include older adults who receive long-term services and supports. *Gerontologist*, *53*(2), 205-210.  
doi:10.1093/geront/gns093

Figure 2

*Flow Chart of Study Participants*

*Figure 2.* Flow chart of study participants. Attrition included individuals who were lost of contact, died, and admitted to facilities.

Table 2

*Baseline Characteristics of Study Participants*

<b>Participant Characteristics</b>	<b>All participants (n=6,004)</b>	<b>Participants who had no ADL assistance need (n= 3,717)</b>	<b>Participants who had ADL assistance need (n=2,287)</b>
<b>Age</b> year, mean(+/-sd)	77(± 7.7)	75(± 7.0)	79(± 8.1)
<b>Gender:</b> Female, n(%)	3410 (57)	1982(53)	1428(62)
<b>Race, n(%)</b>			
White, non-Hispanic	4142(69)	2708(73)	1434(63)
Black, non-Hispanic	1300(22)	705(19)	595(26)
Hispanic	340(6)	162(4)	178(8)
<b>Marital Status, n(%)</b>			
Married/Living with a partner	3333(56)	2244(60)	1089(48)
Separated/Divorced	590(10)	390(10)	200(9)
Widowed	1884(31)	973(26)	911(40)
<b>Highest Level of School Completed, n(%)</b>			
Some high school or less	1513(25)	745(20)	768(33)
High school graduate and some college	2827(47)	1323(35)	760(33)
Associate's degree or higher degree obtained	1593(27)	1613(43)	724(32)
<b>Living Arrangement, n(%)</b>			
Alone	1516(25)	970(26)	546(24)
With spouse/partner and/or others	4488(75)	2747(74)	1741(76)
<b>Participants had medical conditions, n(%)</b>			
Heart attack	887(15)	436(12)	451(20)
Heart diseases	1088(18)	491(13)	597(26)
High blood pressure	4047(67)	2341(63)	1706(75)
Osteoporosis	1183(20)	761(20)	756(33)
Arthritis	3282(55)	1686(45)	1596(70)
Diabetes	1497(25)	784(21)	713(31)
Lung disease	860(14)	428(12)	432(19)
Stroke	673(11)	272(7)	401(18)
Dementia or Alzheimer's disease	340(6)	54(1)	286(13)
Cancer	1575(26)	956(26)	619(27)

Table 2. *Continue*

Participant Characteristics	All participants ( <i>n</i> =6,004)	Participants who had no ADL assistance need ( <i>n</i> = 3,717)	Participants who had ADL assistance need ( <i>n</i> =2,287)
<b>Health Services and Medical Coverage, <i>n</i>(%)</b>			
Had any overnight hospital stay	1355(23)	606(16)	1534(67)
Was covered by state Medicaid program	734(12)	322(9)	412(18)
Had LTC insurance for nursing home	786(13)	564(15)	222(10)
Had LTC insurance for home health	671(11)	484(13)	187(8)
<b>Caregivers</b>			
Number of formal caregivers, mean (+/-sd)	0.12(± 0.42)	0.05(± 0.25)	0.23(± 0.57)
Number of informal caregivers, mean (+/-sd)	0.1.42(± 1.17)	1.17(± 0.99)	1.84(± 1.33)
ADL assistance was regularly scheduled, <i>n</i> (%)	5006(83)	2915(78)	2091(91)
A caregiver lived in the household, <i>n</i> (%)	4395(73)	2706(73)	1689(74)
<b>Number of Participants needed ADL assistance by number of ADL assistance, <i>n</i>(%)</b>			
1 ADL assistance	omitted	omitted	826(36)
2 ADL assistance			442(19)
3 ADL assistance			277(12)
4 ADL assistance			215(9)
5 ADL assistance			176(8)
6 ADL assistance			184(8)
7 ADL assistance			167(7)
<b>Participants who received ADL assistance by number of ADL assistance task, <i>n</i>(%)</b>			
1 ADL assistance task	omitted	omitted	399(17)
2 ADL assistance task			187(8)
3 ADL assistance task			131(6)
4 ADL assistance task			91(4)
5 ADL assistance task			72(3)
6 ADL assistance task			93(4)
7 ADL assistance task			45(2)
<b>Participants received IADL assistance by number of IADL assistance task, <i>n</i>(%)</b>			
1 IADL assistance task	881(15)	644(17)	238(10)
2 IADL assistance task	772(13)	524(14)	248(11)
3 IADL assistance task	932(16)	614(17)	318(14)
4 IADL assistance task	940(16)	587(16)	353(15)
5 IADL assistance task	565(9)	297(8)	268(12)
6 IADL assistance task	369(6)	141(4)	228(10)
7 IADL assistance task	441(7)	86(2)	355(16)
8 IADL assistance task	121(2)	14(<1)	107(5)

Table 3

*Number (n) and Percent (%) of Participants Identified of Having ADL Assistance Need & Participants Received ADL Assistance*

Survey Round	ADL Assistance Tasks	N	Participants had ADL assistance need		Participants Received ADL Assistance							
					No Assistance Received		Received only Informal Assistance		Received only Formal Assistance		Received Formal and Informal Assistance	
			n	%	n	%	n	%	n	%	n	%
1	going outside	6004	1225	20	599	10	532	9	42	1	52	1
	getting around inside home		1141	19	765	13	295	5	24	0	57	1
	getting in and out of bed		1233	21	912	15	251	4	31	1	39	1
	eating		355	6	176	3	132	2	18	0	29	0
	shower/take a bath/wash up		977	16	489	8	313	5	129	2	45	1
	using toilet		552	9	347	6	130	2	39	1	36	1
	getting dressed		1071	18	502	8	426	7	69	1	74	1
2	going outside	4715	946	20	464	11	379	8	42	1	56	1
	getting around inside home		828	18	528	13	203	4	38	1	55	1
	getting in and out of bed		867	18	635	15	156	3	34	1	38	1
	eating		245	5	115	3	85	2	16	0	27	1
	shower/take a bath/wash up		712	15	330	8	206	4	127	3	39	1
	using toilet		396	8	248	6	84	2	31	1	32	1
	getting dressed		782	17	360	9	279	6	82	2	57	1

Table 3 *Continue*

Survey Round	ADL Assistance Tasks	N	Participants had ADL assistance need		Participants Received ADL Assistance							
					No Assistance Received		Received only Informal Assistance		Received only Formal Assistance		Received Formal and Informal Assistance	
			n	%	n	%	n	%	n	%	n	%
3	going outside	3779	737	20	338	9	342	9	26	1	24	1
	getting around inside home		620	16	408	11	179	5	12	0	18	0
	getting in and out of bed		686	18	486	13	168	4	13	0	17	0
	eating		197	5	74	2	105	3	11	0	6	s
	shower/take a bath/wash up		557	15	252	7	247	7	37	1	16	0
	using toilet		298	8	179	5	90	2	10	0	18	0
	getting dressed		673	18	313	8	330	9	27	1	0	0
4	going outside	3115	623	20	298	10	277	9	18	1	15	0
	getting around inside home		529	17	372	12	129	4	13	0	14	0
	getting in and out of bed		591	19	453	15	110	4	16	1	12	0
	eating		149	5	59	2	70	2	12	0	7	0
	shower/take a bath/wash up		481	15	249	8	177	6	35	1	17	1
	using toilet		248	8	162	5	57	2	12	0	17	1
	getting dressed		562	18	243	8	270	9	27	1	20	1

Figure 3a and 3b

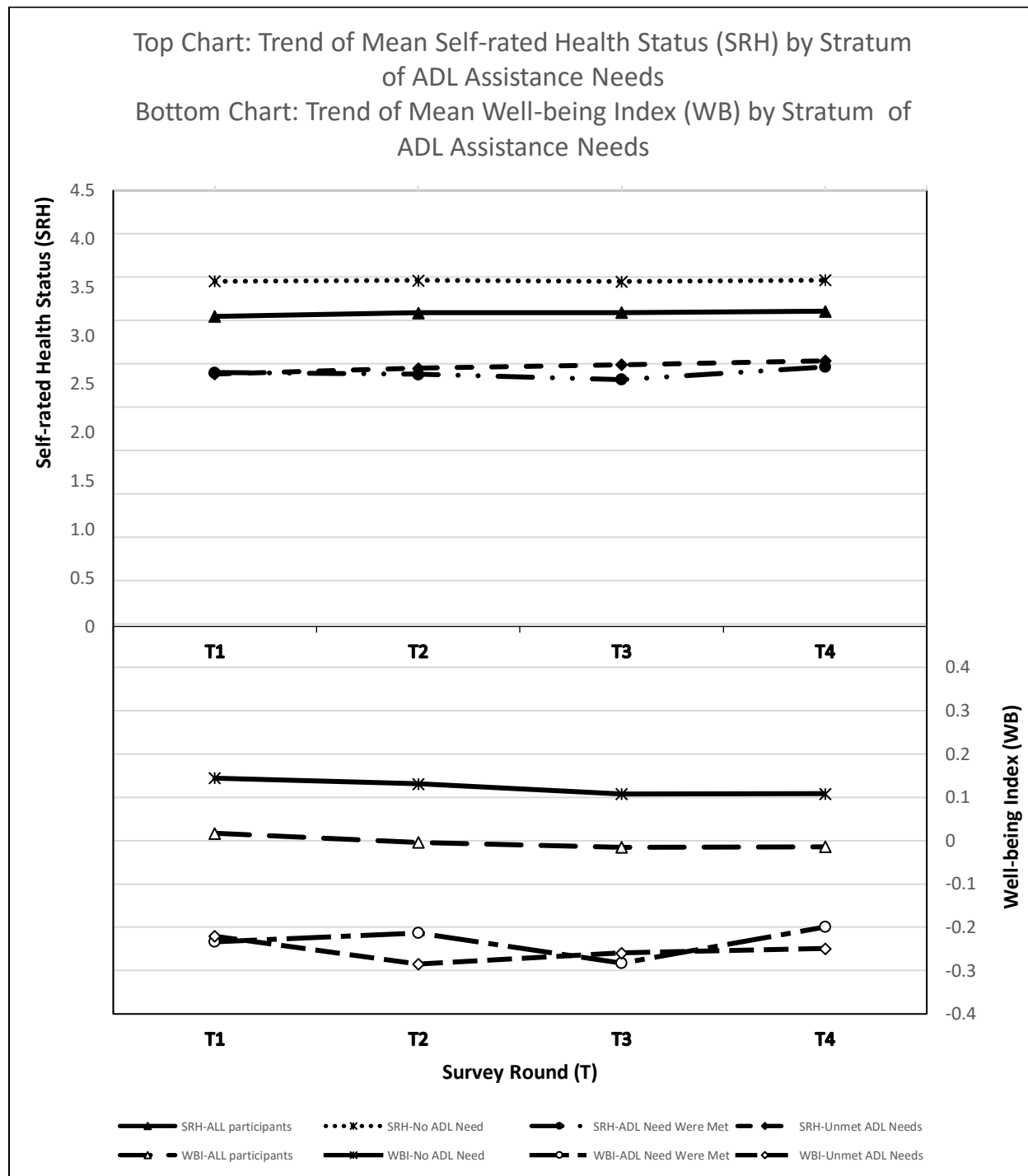


Figure 3a and 3b. Mean self-rated health status and mean well-being index by participant's overall and stratum of need for activities of daily living (ADL) assistance, (n=6,004).

Table 4

*Generalized Estimating Equation (GEE) of Relationship of ADL Assistance and IADL Assistance on Self-Rated Health Status (SRH) Among Three Stratified Groups: (1) Participants Reported of No Need for ADL Assistance, (2) Participants Whose ADL Needs Were Met, and (3) Participants Who Had at Least One Unmet Need for ADL Assistance.*

Self-Rated Health Status	Participants who reported no unmet need for ADL assistance		Participants whose ADL needs were met		Participants who had at least one unmet need for ADL assistance	
	Coefficient estimates	95% Confidence Interval	Coefficient estimates	95% Confidence Interval	Coefficient estimates	95% Confidence Interval
No. of formal ADL assistance task	(omitted)		-0.025	(-0.096, 0.047)	0.012	(-0.044, 0.068)
No. of informal ADL assistance task	(omitted)		0.040	(-0.050, 0.129)	0.003	(-0.030, 0.036)
No. of formal IADL assistance task	-0.007	(-0.059, 0.044)	0.066*	(0.011, 0.121)	-0.034	(-0.069, 0.002)
No. of informal IADL assistance task	-0.015*	(-0.029, -0.001)	0.030	(-0.009, 0.069)	-0.024*	(-0.041, -0.007)
No. of ADL need	(omitted)		-0.143**	(-0.237, -0.050)	-0.145**	(-0.169, -0.120)
Age	-0.011**	(-0.015, -0.007)	0.022**	(0.013, 0.032)	0.009**	(0.005, 0.014)
Gender: Female	0.005	(-0.048, 0.057)	0.196*	(0.033, 0.359)	0.056	(-0.013, 0.126)
Participant living alone	-0.039	(-0.099, 0.020)	-0.129	(-0.312, 0.054)	-0.056	(-0.132, 0.020)
Number of comorbidities	-0.255**	(-0.276, -0.235)	-0.173**	(-0.230, -0.116)	-0.183**	(-0.207, -0.159)
Medicaid beneficiary	-0.487**	(-0.567, -0.408)	-0.353**	(-0.502, -0.204)	-0.270**	(-0.351, -0.189)
Survey round	<i>Reference: Baseline [Round 1]</i>					
2	-0.477**	(-0.530, -0.424)	-0.536**	(-0.764, -0.307)	-0.473**	(-0.563, -0.384)
3	-0.489**	(-0.545, -0.432)	-0.576**	(-0.807, -0.345)	-0.444**	(-0.540, -0.348)
4	-0.458**	(-0.517, -0.399)	-0.443**	(-0.684, -0.203)	-0.437**	(-0.537, -0.337)
Intercept	5.036**	(4.758, 5.314)	1.465**	(0.674, 2.255)	2.964**	(2.604, 3.324)

Note: \* $p \leq 0.05$ ; \*\* $p \leq 0.01$

Table 5

*Generalized Estimating Equation (GEE) of Relationship of ADL Assistance and IADL Assistance to Well-being (WB) Index among Three Stratified Groups: (1) Participants Reported of No Need for ADL Assistance, (2) Participants Whose ADL Needs Were Met, and (3) Participants Who Had at Least One Unmet Need for ADL Assistance.*

Well-being Index	Participants reported of no need for ADL assistance		Participants whose ADL needs were met		Participants who had at least one unmet need for ADL assistance	
	Coefficient estimates	95% Confidence Interval	Coefficient estimates	95% Confidence Interval	Coefficient estimates	95% Confidence Interval
No. of formal ADL assistance	(omitted)		0.032	(-0.048, 0.113)	0.018	(-0.038, 0.075)
No. of informal ADL assistance	(omitted)		-0.025	(-0.123, 0.073)	-0.040**	(-0.068, -0.012)
No. of formal IADL assistance	-0.024	(-0.055, 0.008)	-0.016	(-0.064, 0.033)	-0.009	(-0.037, 0.019)
No. of informal IADL assistance	-0.011*	(-0.019, -0.004)	-0.008	(-0.038, 0.023)	-0.006	(-0.018, 0.006)
No. of ADL need	(omitted)		-0.097	(-0.206, 0.011)	-0.096**	(-0.114, -0.078)
Age	-0.004**	(-0.006, -0.002)	0	(-0.009, 0.008)	-0.001	(-0.004, 0.002)
Gender: Female	-0.052**	(-0.079, -0.026)	-0.103	(-0.233, 0.027)	0.006	(-0.041, 0.054)
Person lived alone	-0.039*	(-0.070, -0.007)	-0.108	(-0.243, 0.028)	-0.069*	(-0.122, -0.015)
Number of comorbidity	-0.035**	(-0.045, -0.025)	-0.042	(-0.087, 0.004)	-0.043**	(-0.060, -0.026)
Medicaid beneficiary	-0.073**	(-0.118, -0.029)	0.017	(-0.111, 0.146)	-0.079**	(-0.139, -0.019)
Survey round	<i>Reference: Baseline [Round 1]</i>					
2	-0.078**	(-0.102, -0.054)	-0.111	(-0.286, 0.064)	-0.182**	(-0.239, -0.125)
3	-0.100**	(-0.127, -0.074)	-0.164	(-0.331, 0.003)	-0.150**	(-0.211, -0.090)
4	-0.092**	(-0.121, -0.063)	-0.102	(-0.289, 0.085)	-0.160**	(-0.224, -0.097)
Intercept	0.602**	(0.463, 0.740)	0.347	(-0.275, 0.970)	0.321**	(0.076, 0.565)

Note: \* $p \leq 0.05$ ; \*\* $p \leq 0.01$

**Chapter IV: Manuscript #3**  
**Home Care and Nursing Home Placement,**  
**Accounting for Death as a Competing Risk among Home-dwelling Older Adults**

To be submitted to *Archives of Gerontology and Geriatrics*

Instructions for authors:

<https://www.journals.elsevier.com/archives-of-gerontology-and-geriatrics>

## Abstract

**Background:** Americans have been facing a critical challenge in providing high quality home-based long-term care to support the growing number of older adults and their diverse health care needs. Legislation has focused primarily on developing a more efficient and less costly system in delivering long-term care services.

**Purpose:** The purpose of this study is to address an important gap in knowledge by conducting a survival analysis from longitudinal data and examining the relationship of formal home care and the odds of transitioning from home to nursing home while accounting for death as a competing risk among home-dwelling older adults.

**Design and Methods:** In this panel study, we examined personal care as a predictor of nursing home placement while accounting for death as a competing risk, among community-dwelling Medicare beneficiaries aged 65 and older who had personal care needs. We conducted a survival analysis using the survey data derived from the National Health and Aging Trends Study (NHATS).

**Findings:** Among 6004 older adult Medicare beneficiaries, accounting for death as a competing-risk event, the incidence of nursing home placement was lower for individuals with formal ADL assistance than for individuals without formal ADL assistance (sub-distribution hazard ratio = 0.07, robust standard error = 0.05,  $p < 0.001$ ). The incidence of nursing home placement was higher for individuals with informal ADL assistance (sub-distribution hazard ratio = 5.25, robust standard error = 2.28,  $p < 0.001$ ), and higher with increasing age (sub-distribution hazard ratio = 1.07, robust standard error = 0.02,  $p < 0.001$ ), increasing ADL assistance needs (sub-distribution hazard ratio = 1.57, robust standard error = 0.08,  $p < 0.001$ ), and increasing number of morbidities (sub-distribution hazard ratio = 1.17, robust standard error = 0.08,  $p < 0.05$ ). Individuals who had ADL assistance needs were more likely to move to a nursing home for long-term care (sub-

distribution hazard ratio = 3.43, robust standard error = 2.22,  $p = 0.06$ ). **Implication:** Our study findings provide several valid and reliable predictors of nursing home placement among home-dwelling older adults, including number of ADL assistance needs, number of medical conditions, and availability of informal care. The study provides evidence to help policy makers and program administrators with planning home care services and allocating resources that may reduce institutional long-term care. A policy recommendation is to address care needs of the older adult population and identify strategies to improve home care services to better meet those needs.

## INTRODUCTION

Americans have been facing a critical challenge in providing high quality home-based long-term care to support the growing number of older adults and their diverse health care needs. Legislation has focused primarily on developing a more efficient and less costly system for delivering long-term care services. To absorb the increasing demand for long-term care and lower the high spending on institutional care, the Patient Protection and Affordable Care Act (ACA) legislation of 2010 continues to close the gap in the long-term care system by providing states with incentives to expand home and community-based services (HCBS) and reduce reliance on nursing home care (Centers for Medicare & Medicaid Services, 2014; Grabowski, Cadigan, Miller, Stevenson, Clark, & Mor, 2010; Kinosian, Stallard, & Wieland, 2007; Miller, 2012; Wiener & Anderson, 2009). The ACA provisions for expanding HCBS include providing states with incentives to expand Medicaid-funded HCBS as an alternative to institutional long-term care, increasing provision of personal care services and streamlining the enrollment process. These ACA provisions aim to lower care costs while expanding coverage (Harrington, Ng, LaPlante, & Kaye, 2012; Ng, Harrington, Musumeci, & Reaves, 2014), but they place little emphasis on improving effectiveness of service provision in HCBS programs.

Home-based long-term care, also known as Personal Care Service (PCS) or Personal Assistance Service, is designed to provide individualized services to meet the care needs specific to each service recipient. It is by far the preferred form of long-term care service (Fried, van Doorn, Tinetti, & Drickamer; Guo, Konetzka, Magett, & Dale, 2014; Keenan, 2010; Mattimore, Wenger, Desbiens, Teno, Hamel, Liu, . . . Oye, 1997). The majority of care recipients prefer home care to institutional care and other HCBS because service recipients have more choices and control over care decisions (Benjamin, 2001; Benjamin, Matthias, & Franke, 2000; Doty,

Kasper, & Litvak, 1996; Foster, Brown, Phillips, Schore, & Carlson 2003) and service satisfaction with home care is higher than that for institutional care (Khatutsky, Anderson, & Wiener, 2006). The strong preference for home care also relates to care recipient's ideation of aging in place, as many people want to remain in their own homes in the last years of life. Given such a strong preference for home care, there is a need to evaluate the types of home care services that will support an individual to remain at home as long as possible and reduce nursing home placement.

In the United States, approximately 12.7 million people need long-term services and supports. That figure includes 10.9 million community residents and 1.8 million nursing home residents (Kaye, Harrington, & LaPlante, 2010). Among community residents who receive care at home, about 13 percent (1.4 million) receive paid services funded primarily by Medicaid or Medicare (Kaye et al., 2010). The aging of the population and increasing disability prevalence continue to be the main drivers of the demand for long-term care (de Meijer, Koopmanschap, Koolman, & van Doorslaer, 2009; Griffith, Raina, Wu, Zhu, & Stathokostas, 2010; McAuley & Arling, 1984). Between 2010 and 2050, the number of Americans aged 65 years and older will double from 40.2 million to 88.5 million (U.S. Department of Health & Human Services, 2016). The fastest growing segment of the total population is the oldest old, people aged 85 years and older. The oldest old population will more than triple from 5.8 million in 2010 to 19 million by 2050 (U.S. Department of Health & Human Services, 2016). As the older population grows, the prevalence and severity of comorbidities increase (Bodenheimer, Chen, & Bennett, 2009; Griffith, Raina, Wu, Zhu, & Stathokostas, 2010; Tinetti, Bogardus, & Agostini, 2004). An estimated two of three older adults have two or more chronic conditions (Wister, Levasseur, Griffith, & Fyffe 2015; Halaweish & Alam, 2015). Nearly one fifth of adults aged 65 years and

older reported having at least one limitation in ADL that required assistance (Centers for Disease Control & Prevention, 2009; Motl & McAuley, 2010). The burden is even higher among low-income individuals and racial/ethnic minority populations (Ralph, Mielenz, Parton, Flatley, & Thorpe, 2013). These population trends suggest that a large number of older adults with complex medical conditions will receive long-term care through home care programs.

Home-based long-term care is often presumed to be an alternative to nursing home care. However, formal home care is not completely comparable to nursing home care. Home-based long-term care is an array of activities of daily living (ADL) assistance and instrumental activities of daily living (IADL) assistance provided to individuals with functional limitations to enable them to stay in their homes and communities and to maintain independence. In publicly funded PCS programs, service coverage is determined by a beneficiary's needs, where needs are defined as the number and types of ADL tasks with which a beneficiary reported having difficulty or was incapable of performing by themselves. In many state programs, PCS is provided by a trained and certified home care aide under self-direction of the beneficiary. Nursing home care can be short-term or long-term, where short-term nursing home stays are usually less 90 days and are mainly covered by Medicare Part A for purposes of post-hospital rehabilitation. Long-term nursing home care refers to custodial type of residence. In nursing homes, residents receive round-the-clock personal care and the care is often supervised by nurses (Engelhardt & Greenhalgh-Stanley, 2010).

Existing studies have explored factors predicting institutional long-term care placement among the older adult population (Fischer, Green, Goodman, Brody, Aickin, Wei, ... Leutz, 2003; Gaugler, Duval, Anderson, & Kane, 2007; Wu, Li, Oberst, & Given, 2016). Sands and colleagues' (2012) study has provided evidence of PCS (or ADL assistance) as a predictor for

nursing home placement (Sands, Xu, Thomas, Paul, Craig, Rosenman . . . , Weiner, 2012). Other studies suggested personal care assistance might affect the odds of entering a nursing home among individuals who were in home- and community-based service programs (Greiner, 2014; Mui, 2001; Wieland, 2010). However, these studies did not account for numbers of death when determining the relationship between home care and nursing home placement, despite the high mortality of the older adult population.

Informal support was studied frequently with respect to nursing home placement. A few studies showed that informal care provided by family is likely to minimize nursing home placement (Freedman & Spillman, 2014; Kuzuya, Hasegawa, Hiraakawa, Enoki, Izawa, Hirose, & Iguchi, 2011; Yaffe, Fox, Newcomer, Sands, Lindquist, Dane, & Covinsky, 2002). A few studies, however, demonstrated that having an informal caregiver was associated with an increased risk of institutionalization (Miller & Weissert, 2000; Wingard, Jones, & Kaplan, 1987).

Studies have indicated that chronic diseases such as Alzheimer's disease and other dementias (Hebert, Weuve, Scherr, & Evans, 2013; Hirono, Tsukamoto, Inoue, Moriwaki, & Mori, 2002), diabetes mellitus (Motl et al., 2010; Sands, Xu, Weiner, Rosenman, Craig, & Thomas, 2008), quadriplegia (Centers for Disease Control & Prevention, 2009), heart failure (Alonso, Mosley, Gottesman, Catellier, Sharrett, & Coresh, 2009; Centers for Disease Control & Prevention, 2009; Ieva, Jackson, & Sharples, 2015), and functional limitations (de Meijer et al, 2009; Fong, Mitchell, & Koh, 2015) have increased the demand for nursing home care. To date little is known about the utilization of long-term care services among populations with these prevalent chronic diseases (Evashwick, Rowe, Diehr, & Branch, 1984; Kuzuya, Masuda, Hiraakawa, Iwata, Enoki, Hasegawa, & Iguchi, 2006; Low & Fletcher, 2015; Wattmo, Londos, &

Minthon, 2014). One study found that access to community resources such as adult day care service did not reduce nursing home placement (Kuzuya, Izawa, Enoki, & Hasegawa, 2012).

Given the research to date, the purpose of this study is to address an important gap in knowledge by conducting a survival analysis from longitudinal data and examining the relationship of formal home care and the odds of transitioning from home to nursing home, while accounting for death as a competing risk factor, among home-dwelling older adults.

### **Methods**

In this panel study, we examined personal care, also known as formal ADL assistance, as a predictor of nursing home placement while accounting for death as a competing risk, among community-dwelling Medicare beneficiaries aged 65 year and older who had personal care needs. Adopting an exploratory study design, we conducted a survival analysis using the survey data derived from the National Health and Aging Trends Study (NHATS) (Johns Hopkins University, 2011).

### **Study Sample**

The NHATS is a longitudinal study of a nationally representative cohort of Medicare beneficiaries aged 65 and older living in the contiguous United States. Of 8,245 NHATS participants who completed the baseline interview survey in 2011, our study sample included 6,004 participants who were identified as home-dwelling individuals living in a private residence. Participants who were residents of a nursing home or another residential care setting (such as assisted living, continuing care retirement community, group home, or adult family home) at baseline and participants for whom residence data was missing were excluded.

### **Data**

Our dataset integrated the first four rounds of the NHATS survey undertaken between 2011 and 2014 and included the data from the study participants (*sample participant files*), demographic data of sample participants (*sensitive data files*), and the data about caregivers identified by participants (*other person data files*). Integration of the participant and caregiver data involved four steps. First, we created constructs of ADL and IADL assistance tasks and sources of ADL and IADL assistance (i.e., formal and informal) using the *other person data files* of the NHATS. Second, the caregiver data were aggregated to the participant level, such that if a participant identified more than one caregiver, that information would be aggregated to a sum of caregivers. Third, we merged the participant data of the *sample person data files* and the *sensitive data files* with the aggregated caregiver data of the *other person data files* for the corresponding survey rounds. Last, we compiled the merged participant and caregiver data of all four survey rounds to form a longitudinal dataset for survival analysis.

## **Measures**

**Outcome.** The event of interest was the occurrence of nursing home placement. Nursing home placement refers to a report of nursing home residence by participants or proxies at the time of interview. Given that we included only participants who lived in a private residence at baseline, nursing home placement involved a change of residential status from a private residence to a nursing home facility in the subsequent interviews. A participant's report of residing in a nursing home was considered the end-point of the study in our analysis. Participant death, as a competing risk event, obviates any nursing home placement that might occur and therefore death was not treated as censored. Censored participants were participants who neither experienced nursing home placement nor death in the study period that included home-dwellers.

**Predictor Variables.** The predictor variables were any combination of the seven ADL

assistance tasks provided by formal and informal caregivers. The NHATS defined ADL assistance tasks as help with basic self-care tasks, including help with going outside, getting around inside home, getting in and out of bed, eating, showering/taking a bath, using the toilet, and getting dressed (Kasper & Freedman, 2015). Each ADL assistance task was categorized into formal assistance, informal assistance, and no assistance available. Formal assistance was defined as assistance provided by “someone paid to help,” and informal assistance was defined as assistance provided by an informal source such as family and friends.

**Covariate measures.** Participant characteristics consisted of age, gender, race and ethnicity, marital status, living arrangement (whether a participant was living alone or with a spouse, partner, and/or others), and having Medicaid coverage. Participant comorbidity comprised a range of 10 medical conditions specified in the NHATS, which included heart attack or myocardial infarction, any heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia/Alzheimer’s disease, and cancer. The number of medical conditions is measured on a scale of 0-10, where 10 refers to a participant self-report of having all 10 of the listed medical conditions.

Participant ADL assistance *need*, as a covariate, was measured by the number of ADL tasks with which a participant reported needing assistance. ADL assistance need was defined by one of three conditions that included a participant report of performing an ADL by self with difficulty, not performing an ADL by self, and an ADL not done because of no help being available. We also included the number of IADL assistance tasks provided by formal and informal caregivers as covariates. The eight IADL tasks identified were: taking the participant places, doing laundry, shopping for groceries, preparing meals, managing money, helping with banking, sitting with the participant at doctor appointments, and helping with medications.

## Data Analysis

Participant characteristics were analyzed with descriptive statistics and by events (nursing home placement, death, and censored). We conducted a multivariate analysis of factors predictive of nursing home placement using competing-risks regression based on based on Fine and Gray's proportional sub-distribution hazards model (Fine & Gray, 1999). The competing-risks regression addressed cumulative incidence function, which indicated the probability of nursing home placement happening before a given time. Competing-risks regression is semiparametric, in that the baseline sub-distribution hazard of the event of interest is left unspecified, and the effects of covariates are assumed to be proportional. A significance level of 0.05 was used for all comparisons. All analyses were conducted using Stata, version 14 (StataCorp LP, College Station TX).

## Results

Censoring for nursing home placement included 86 participants, of which 28 participants moved to a nursing home at time 1 (round 2 of the NHATS), 32 participants at time 2 (round 3 of the NHATS), and 26 participants at time 3 (round 4 of the NHATS), as shown in Figure 4. Censoring for death as the competing-risks event included 760 participants, of which 267 participants had died at time 1, another 276 participants at time 2, and 217 participants at time 3. A total of 5,158 participants were censored at time 3.

### Sample Characteristics.

Participant characteristics are shown in Table 6. The mean age of all participants was 77 years. Among participants, 43% were male, 69% were non-Hispanic White, 25% reported living alone, 12% had Medicaid coverage, and the mean number of medical conditions was three. The

analytic sample had an average of three medical conditions, with 38% of participants having ADL assistance needs, 4.6% receiving ADL assistance from a formal source, and 19% receiving ADL assistance from an informal source. In addition, 8.1% received IADL assistance from a formal source and 82% received IADL assistance from an informal source. A total of 86 participants moved to a nursing home from a private residence. Compared to participants who remained in a private residence, those who moved to a nursing home were older, with a mean age of 86. A higher proportion were female ( $n=62$ , 72%), a higher proportion were non-Hispanic White ( $n=63$ , 73%), a lower proportion were living alone before moving to nursing home ( $n=17$ , 20%), a higher proportion had Medicaid coverage ( $n=42$ , 49%), a higher proportion had ADL assistance needs ( $n=83$ , 97%), a lower proportion had received formal ADL assistance ( $n=2$ , 2%), and a higher proportion had received informal ADL assistance ( $n=80$ , 93%) and informal IADL assistance ( $n=86$ , 100%). The censored participants were characterized similarly as the total participants. Comparing deceased participants at the time before death to the censored participants, deceased participants were older and had a higher number of ADL assistance needs and informal ADL assistance.

Among 6,004 older adult Medicare beneficiaries, accounting for death as a competing-risk event, the incidence of nursing home placement was lower for individuals with formal ADL assistance than for individuals without formal ADL assistance (sub-distribution hazard ratio = 0.07, robust standard error = 0.05,  $p<0.001$ ), as shown in Table 7. The incidence of nursing home placement was higher for individuals with informal ADL assistance (sub-distribution hazard ratio = 5.25, robust standard error = 2.28,  $p<0.001$ ), and higher with increasing age (sub-distribution hazard ratio = 1.07, robust standard error = 0.02,  $p<0.001$ ), increasing ADL assistance needs (sub-distribution hazard ratio = 1.57, robust standard error = 0.08,  $p<0.001$ ), and

increasing number of medical conditions (sub-distribution hazard ratio = 1.17, robust standard error = 0.08,  $p < 0.05$ ). Individuals who had ADL assistance needs were more likely to move to a nursing home for long-term care (sub-distribution hazard ratio = 3.43, robust standard error = 2.22,  $p = 0.06$ ).

### **Discussion**

This is one of very few studies to examine whether formal home care is predictive of nursing home placement. Our findings indicate that home-dwelling older adults who had formal home care were less likely to move to a nursing home for long-term care, while accounting for death as a competing risk. The sub-distribution hazard ratio of nursing home placement for those having formal home care compared to those having no formal home care was very small (sub-distribution hazard ratio = 0.07). The sub-distribution hazard ratio of having vs. not having formal home care as predictors of nursing home placement is potentially misleading given that the actual number of participants who had formal home care and moved to a nursing home during the 4-year study period was exceptionally small ( $n=2$ ). These findings, however, were plausible in this study of home-dwelling Medicare beneficiaries, because the participants had a relatively low number of medical conditions and a low number of ADL assistance needs. Though over one third of participants reported having ADL assistance needs, a large proportion were supported by informal caregivers.

Our study evaluated the association between formal ADL assistance and long-term nursing home placement, while accounting for death as a competing risk. Using formal home care as a predictor for nursing home placement is appropriate, even though formal home care is considered a long-term care alternative to nursing home care. Our findings are consistent with

previous studies of associations between nursing home placement and personal care services among home and community-based service recipients (Fong et al., 2015; Greiner et al., 2014; Mui, 2001; Wieland et al., 2010). The other study samples were home and community-based service recipients, and none of these studies distinguished home-based long-term care from other community-based residential care such as assisted living and adult family homes. Our study population is Medicare beneficiaries who receive their service in their homes, rather than as services provided collectively in home and community based group settings, which minimizes the possible confounding effects posed by variations in settings. The two studies that evaluated mortality as a competing risk in predicting nursing home placement suggested that accounting for death in the model yielded a more precise estimate (Sands et al., 2012; Wu et al., 2016).

Our findings indicated that several factors such as participant age, ADL assistance need, medical conditions, and availability of informal ADL assistance were predictive of nursing home placement. The odds of nursing home placement increased significantly with increasing age, number of ADL assistance needs, and number of medical conditions. In addition, participants who had informal ADL assistance showed increased odds of nursing home placement. The findings presented here are consistent with the existing studies that suggest informal ADL assistance might increase nursing home placement (Gaugler, Duval, Anderson, & Kane, 2007; Miller & Weissert, 2000).

An assumption of our study is that long-term nursing home placement referred to a custodial type of nursing home care, rather than short-term, rehabilitative type of nursing home stays. Our data did not capture those participants who moved back and forth between private residences and nursing homes. Although this may create a potential confounding effect, we

believe the confounding effect is small given that the number of nursing home placements is relatively small.

**Strengths.** This study had several strengths. First, it represented an important step in advancing health service research in publicly funded home care service. This was one of the first studies to examine personal care services and how personal care assistance influences nursing home placement among home-dwelling older adults. Second, the sample was relatively large and the study period was 4 years, which allowed us to capture the occurrence of major events. Last, this longitudinal dataset also demonstrated trends and patterns of services delivered across time and showed how a change in home care services is associated with beneficiary stays in the home care program.

**Limitations.** Limitations of this study were primarily data related. The NHATS participants were interviewed annually and thus the participant data were collected yearly. Given that there was a 1-year lag time between interviews, the timing of the event was recorded at a discrete time interval. Survival analysis using discrete time will lose the precision in calculating the time factor. For this analysis, an assumption was made that moving to a nursing home in an interval would be considered a long-term placement.

**Implications.** Our study findings provided several valid and reliable predictors of nursing home placement among home-dwelling older adults, including number of ADL assistance needs, number of medical conditions, and availability of informal care. The study provided evidence to help policy makers and program administrators with planning home care services and allocating resources that would reduce institutional long-term care. Based on this evidence, one policy recommendation is to address care needs of older adult population and identify strategies to improve home care services to better meet those needs. Variability in types of ADL assistance

tasks and quality of PCS delivered to service recipients could not be taken into account in this study; therefore, future research should focus on developing a set of quality measures specific to home care (e.g., HCA performance), as well as improving the understanding of the relationships between quality of home care and nursing home placement of home care recipients.

### **Conclusion**

In response to the Affordable Care Act and the reallocation of long-term care resources in homes and communities, this longitudinal study applied an innovative technique to predict nursing home placement among older adults who had ADL assistance needs, while accounting appropriately for death as a competing-risk event. Our findings indicate that older adults with more medical problems and higher ADL assistance needs were more likely to be admitted to a nursing home for long-term care. Home care policy should focus on supporting individuals to manage chronic diseases and providing continuing ADL assistance to meet their needs.

## References

- Alonso, A., Mosley, T. H., Jr., Gottesman, R. F., Catellier, D., Sharrett, A. R., & Coresh, J. (2009). Risk of dementia hospitalisation associated with cardiovascular risk factors in midlife and older age: the Atherosclerosis Risk in Communities (ARIC) study. *Journal of Neurology, Neurosurgery, and Psychiatry*, *80*(11), 1194-1201.
- Benjamin, A. E. (2001). Consumer-directed services at home: a new model for persons with disabilities. *Health Affairs*, *20*(6), 80-95.
- Benjamin, A. E., Matthias, R., & Franke, T. M. (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research*, *35*(1 Pt 2), 351-366.
- Bodenheimer, T., Chen, E., & Bennett, H. D. (2009). Confronting the growing burden of chronic disease: can the U.S. health care workforce do the job? *Health Affairs*, *28*(1), 64-74.
- Centers for Disease Control & Prevention. (2009). Prevalence and most common causes of disability among adults--United States, 2005. *MMWR Morbidity and Mortality Weekly Report*, *58*(16), 421-426.
- Centers for Medicare & Medicaid Services. *Balancing Long-Term Services & Supports*. Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-long-term-services-and-supports.html>
- Centers for Medicare & Medicaid Services. (2014). *Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers*. Federal Register Retrieved from

<https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>.

- de Meijer, C. A., Koopmanschap, M. A., Koolman, X. H., & van Doorslaer, E. K. (2009). The role of disability in explaining long-term care utilization. *Medical Care*, *47*(11), 1156-1163. doi:10.1097/MLR.0b013e3181b69fa8
- Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: lessons from Medicaid. *Milbank Quarterly*, *74*(3), 377-409.
- Engelhardt, G. V., & Greenhalgh-Stanley, N. (2010). Home health care and the housing and living arrangements of the elderly. *Journal of Urban Economics*, *67*(2), 226.
- Evashwick, C., Rowe, G., Diehr, P., & Branch, L. (1984). Factors explaining the use of health care services by the elderly. *Health Services Research*, *19*(3), 357-382.
- Fine, J. P., & Gray, R. J. (1999). A proportional hazards model for the sub-distribution of a competing risk. *Journal of the American Statistical Association*, *94*(446), 496-509.
- Fischer, L. R., Green, C. A., Goodman, M. J., Brody, K. K., Aickin, M., Wei, F., . . . Leutz, W. (2003). Community-based care and risk of nursing home placement. *Medical Care*, *41*(12), 1407-1416. doi:10.1097/01.mlr.0000100587.51573.7a
- Fong, J. H., Mitchell, O. S., & Koh, B. S. (2015). Disaggregating activities of daily living limitations for predicting nursing home admission. *Health Services Research*, *50*(2), 560-578. doi:10.1111/1475-6773.12235
- Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B. L. (2003). Improving the quality of Medicaid personal assistance through consumer direction. *Health Affairs, Suppl. Web Exclusives*, W3-162-175.

- Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older Americans. *Milbank Quarterly*, 92(3), 509-541. doi:10.1111/1468-0009.12076
- Fried, T. R., van Doorn, C., Tinetti, M. E., & Drickamer, M. A. (1998). Older persons' preferences for site of treatment in acute illness. *Journal of General Internal Medicine*, 13(8), 522-527.
- Gaugler, J. E., Duval, S., Anderson, K. A., & Kane, R. L. (2007). Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatrics*, 7(13), 1-14. doi:10.1186/1471-2318-7-13
- Grabowski, D. C., Cadigan, R. O., Miller, E. A., Stevenson, D. G., Clark, M., & Mor, V. (2010). Supporting home- and community-based care: views of long-term care specialists. *Medical Care Research and Review*, 67(4 Suppl.), 4.
- Greiner, M. A., Qualls, L. G., Iwata, I., White, H. K., Molony, S. L., Sullivan, M. T., . . . Setoguchi, S. (2014). Predicting nursing home placement among home- and community-based services program participants. *American Journal of Managed Care*, 20(12), e535-e536.
- Griffith, L., Raina, P., Wu, H., Zhu, B., & Stathokostas, L. (2010). Population attributable risk for functional disability associated with chronic conditions in Canadian older adults. *Age and Ageing*, 39(6), 738-745. doi:10.1093/ageing/afq105
- Guo, J. R., Konetzka, T., Magett, E., & Dale, W. (2014). Quantifying long-term care preferences. *Medical Decision Making*, 1-8. Retrieved from doi:10.1177/0272989X14551641
- Halaweish, I., & Alam, H. B. (2015). Changing demographics of the American population. *The Surgical Clinics of North America*, 95(1), 1-10. doi:10.1016/j.suc.2014.09.002

- Harrington, C., Ng, T., LaPlante, M. P., & Kaye, H. S. (2012). Medicaid home- and community-based services: impact of the Affordable Care Act. *Journal of Aging and Social Policy*, 24(2), 169-187.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, 80(19), 1778-1783.
- Hirono, N., Tsukamoto, N., Inoue, M., Moriwaki, Y., & Mori, E. (2002). Predictors of long-term institutionalization in patients with Alzheimer's disease: role of caregiver burden. *No to Shinkei [Brain and Nerve]*, 54(9), 812-818.
- Ieva, F., Jackson, C. H., & Sharples, L. D. (2015). Multi-state modelling of repeated hospitalisation and death in patients with heart failure: the use of large administrative databases in clinical epidemiology. *Statistical Methods in Medical Research*. doi:10.1177/0962280215578777
- Johns Hopkins University. (2011). *National Health and Aging Trends Study [Data file and code book]*. Retrieved from: <http://www.nhats.org/>
- Kasper, J. D., & Freedman, V. A. (2015). National Health and Aging Trends Study User Guide: Rounds 1, 2, 3 & 4 Final release. Retrieved from <http://www.nhats.org/>
- Kaye, H. S., Harrington, C., & LaPlante, M. P. (2010). Long-term care: who gets it, who provides it, who pays, and how much? *Health Affairs*, 29(1), 11-21. doi:10.1377/hlthaff.2009.0535
- Keenan, T. A. (2010). Home and community preferences of the 45+ population. Retrieved from <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf>

- Khatutsky, G., Anderson, A. R., & Wiener, J. M. (2006). Personal care satisfaction among aged and physically disabled Medicaid beneficiaries. *Health Care Financing Review*, 28(1), 69-86.
- Kinosian, B., Stallard, E., & Wieland, D. (2007). Projected use of long-term-care services by enrolled Veterans. *Gerontologist*, 47(3), 356-364.
- Kuzuya, M., Hasegawa, J., Hirakawa, Y., Enoki, H., Izawa, S., Hirose, T., & Iguchi, A. (2011). Impact of informal care levels on discontinuation of living at home in community-dwelling dependent elderly using various community-based services. *Archives of Gerontology and Geriatrics*, 52(2), 127-132. doi:10.1016/j.archger.2010.02.016
- Kuzuya, M., Izawa, S., Enoki, H., & Hasegawa, J. (2012). Day-care service use is a risk factor for long-term care placement in community-dwelling dependent elderly. *Geriatrics & Gerontology International*, 12(2), 322-329. doi:10.1111/j.1447-0594.2011.00766.x
- Kuzuya, M., Masuda, Y., Hirakawa, Y., Iwata, M., Enoki, H., Hasegawa, J., & Iguchi, A. (2006). Day care service use is associated with lower mortality in community-dwelling frail older people. *Journal of American Geriatrics Society*, 54(9), 1364-1371. doi:10.1111/j.1532-5415.2006.00860.x
- Low, L. F., & Fletcher, J. (2015). Models of home care services for persons with dementia: a narrative review. *International Psychogeriatrics*, 1-8. doi:10.1017/s1041610215000137
- Mattimore, T. J., Wenger, N. S., Desbiens, N. A., Teno, J. M., Hamel, M. B., Liu, H., . . . Oye, R. K. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatric Society*, 45(7), 818-824.

- McAuley, W. J., & Arling, G. (1984). Use of in-home care by very old people. *Journal of Health and Social Behavior*, 25(1), 54-64.
- Miller, E. A. (2012). The Affordable Care Act and long-term care: comprehensive reform or just tinkering around the edges? *Journal of Aging and Social Policy*, 24(2), 101-117.  
doi:10.1080/08959420.2012.659912
- Miller, E. A., & Weissert, W. G. (2000). Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: a synthesis. *Medical Care Research and Review*, 57(3), 259-297. doi:10.1177/107755870005700301
- Motl, R. W., & McAuley, E. (2010). Physical activity, disability, and quality of life in older adults. *Physical Medicine and Rehabilitation Clinics of North America*, 21(2), 299-308.  
doi:10.1016/j.pmr.2009.12.006
- Mui, A. C. (2001). The Program of All-Inclusive Care for the Elderly (PACE): an innovative long-term care model in the United States. *Journal of Aging and Social Policy*, 13(2-3), 53-67.
- Ng, T., Harrington, C., Musumeci, M., & Reaves, E. (2014). *Medicaid home and community-based services programs: 2010 Data Update*. Retrieved from  
Personal care services. 42 C.F.R. § 440.167. Retrieved from [http://www.ecfr.gov/cgi-bin/text-idx?SID=80e75e6122d39b1a79d934fc533a6bba&mc=true&node=se42.4.440\\_1167&rgn=div8](http://www.ecfr.gov/cgi-bin/text-idx?SID=80e75e6122d39b1a79d934fc533a6bba&mc=true&node=se42.4.440_1167&rgn=div8)
- Ralph, N. L., Mielenz, T. J., Parton, H., Flatley, A. M., & Thorpe, L. E. (2013). Multiple chronic conditions and limitations in activities of daily living in a community-based sample of older adults in New York City, 2009. *Preventing Chronic Disease*, 10, E199.  
doi:10.5888/pcd10.130159

- Sands, L. P., Xu, H., Thomas, J., 3rd, Paul, S., Craig, B. A., Rosenman, M., . . . Weiner, M. (2012). Volume of home- and community-based services and time to nursing-home placement. *Medicare Medicaid Research Review*, 2(3). doi:10.5600/mmrr.002.03.a03
- Sands, L. P., Xu, H., Weiner, M., Rosenman, M. B., Craig, B. A., & Thomas, J., 3rd. (2008). Comparison of resource utilization for Medicaid dementia patients using nursing homes versus home and community based waivers for long-term care. *Medical Care*, 46(4), 449-453. doi:10.1097/MLR.0b013e3181621eae
- Tinetti, M. E., Bogardus, S. T., Jr., & Agostini, J. V. (2004). Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *New England Journal of Medicine*, 351(27), 2870-2874. doi:10.1056/NEJMs042458
- U.S. Department of Health & Human Services. *Projected future growth of the older population*. Retrieved from [http://www.aoa.acl.gov/Aging\\_Statistics/future\\_growth/future\\_growth.aspx](http://www.aoa.acl.gov/Aging_Statistics/future_growth/future_growth.aspx) - age
- Wattmo, C., Londos, E., & Minthon, L. (2014). Solitary living in Alzheimer's disease over 3 years: association between cognitive and functional impairment and community-based services. *Clinical Interventions in Aging*, 9, 1951-1962. doi:10.2147/cia.s71709
- Wieland, D., Boland, R., Baskins, J., & Kinosian, B. (2010). Five-year survival in a Program of All-inclusive Care for Elderly compared with alternative institutional and home- and community-based care. *Journal of Gerontology Series A: Biological Sciences and Medical Sciences*, 65(7), 721-726. doi:10.1093/gerona/glq040
- Wiener, J. M., & Anderson, W. L. (2009). *Follow the money: financing home and community-based services*. Retrieved from University of Pittsburgh: [http://www.nasud.org/sites/nasud/files/hcbs/files/164/8192/Homecare\\_rp\\_09.pdf](http://www.nasud.org/sites/nasud/files/hcbs/files/164/8192/Homecare_rp_09.pdf)

- Wingard, D. L., Jones, D. W., & Kaplan, R. M. (1987). Institutional care utilization by the elderly: a critical review. *Gerontologist*, *27*(2), 156-163.
- Wister, A. V., Levasseur, M., Griffith, L. E., & Fyffe, I. (2015). Estimating multiple morbidity disease burden among older persons: a convergent construct validity study to discriminate among six chronic illness measures, CCHS 2008/09. *BMC Geriatrics*, *15*, 12. doi:10.1186/s12877-015-0001-8
- Wu, X., Li, C., Oberst, K., & Given, C. (2016). Predicting long-term nursing home transfer from MI choice waiver program. *Geriatric Nursing*, *37*(6), 446-452.  
doi:10.1016/j.gerinurse.2016.06.013
- Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*, *287*(16), 2090-2097.

Figure 4

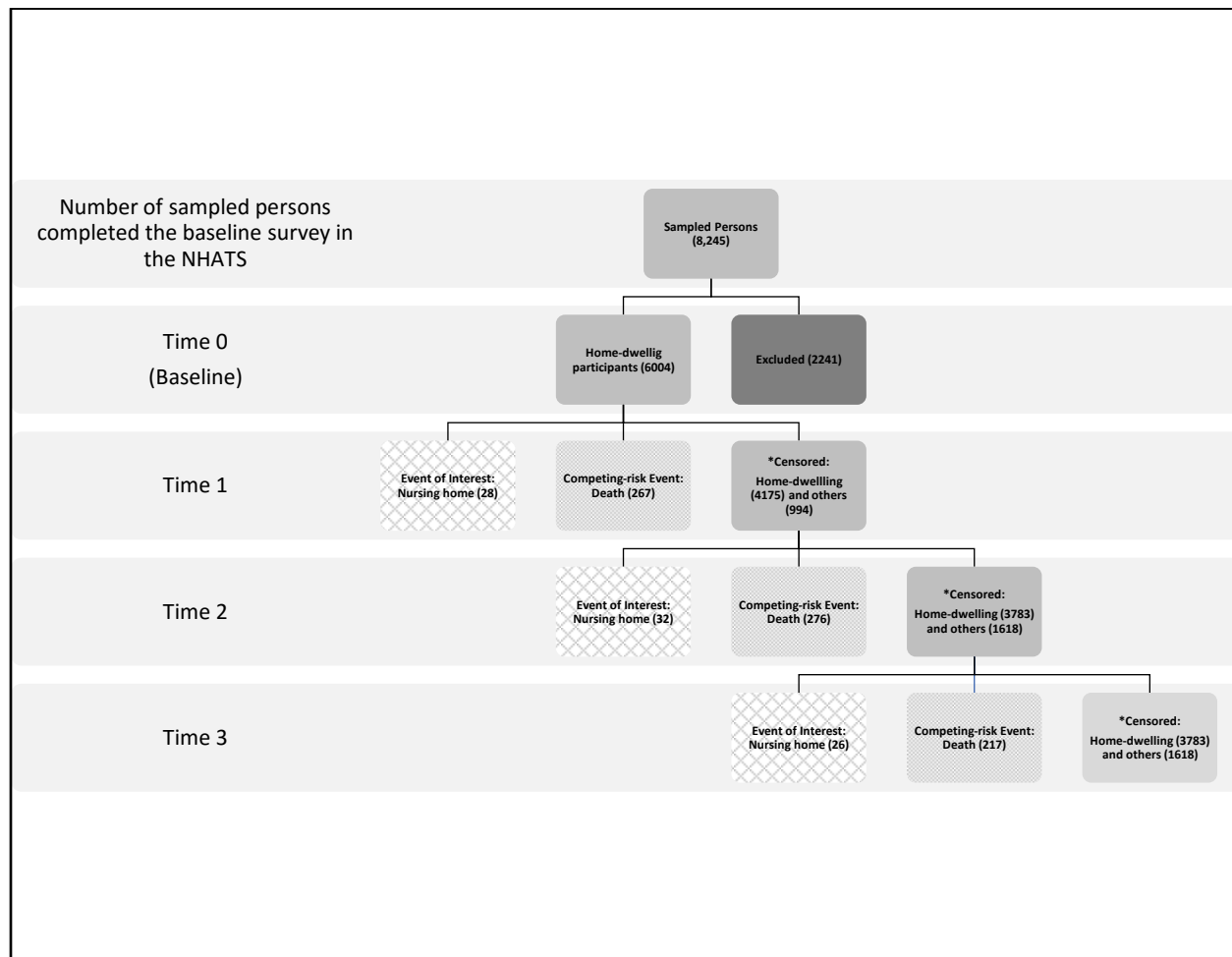


Figure 4. Flow chart of study participants. Censoring included participants who remained in homes, transitioned to residential care facilities other than nursing homes, and missing information.

Table 6

*Characteristics of Participants by Events (nursing home placement, death, and censored)*

Variables	All <sup>a</sup>	nursing home <sup>b</sup>	death <sup>c</sup>	censored <sup>d</sup>
number of participants	n=6004	n=86	n=760	n=5158
<b>Age, years, mean±sd</b>	77±7.7	86±7.4	84±9.0	78±7.5
<b>Gender, n(%)</b>				
Male	2594(43)	24(28)	363(48)	2207(43)
Female	3410(57)	62(72)	397(52)	2951(57)
<b>Race, n(%)</b>				
White, non-Hispanic	4142(69)	63(73)	506(67)	3573(69)
Black	1300(22)	21(24)	186(25)	1093(21)
<b>Living Arrangement, n(%)</b>				
Alone	1516(25)	17(20)	194(26)	971(19)
With spouse/partner and/or others	4488(75)	69(80)	566(75)	2265(44)
<b>*Number of Medical Conditions, mean±sd</b>	3±2	1±1	2±2	1±1
<b>Had Medicaid, n(%)</b>	734(12)	42(49)	144(19)	353(6.8)
<b>Had ADL Assistance Needs</b>	2287(38)	83(97)	552(73)	1247(24)
<b>‡Number of ADL Assistance Needs, mean±sd</b>	1±2	5±2	3±3	1±2
<b>Had Formal ADL Assistance, n(%)</b>	274(4.6)	2(2)	146(19)	99(1.9)
<b>Had Informal ADL Assistance, n(%)</b>	1135(19)	80(93)	649(85)	649(13)
<b>Had Formal IADL Assistance, n(%)</b>	489(8.1)	4(4.7)	94(12)	303(5.9)
<b>Had Informal IADL Assistance, n(%)</b>	4940(82)	86(100)	445(59)	2710(53)

Note: a. baseline characteristics of all study participants

b. characteristics of participants at time of nursing home placement

c. characteristics of participants at time before death

d. characteristics of censored participants at time 3

\* A list of 10 medical conditions was specified in the National Health and Aging Trends Study (NHATS) that included heart attack or myocardial infarction, any heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia/Alzheimer's disease, and cancer.

‡ A total of 7 ADL assistance tasks was identified in the NHATS that included assistance with going outside, getting around inside home, getting in and out of bed, eating, showering/taking a bath, using the toilet, and getting dressed

ADL is the abbreviation of activities of daily living.

IADL is the abbreviation of instrumental activities of daily living.

sd is the abbreviation of standard deviation

Table 7

*Model Results of Competing-risks Regression of Nursing Home Placement, Death as the Completing Risk (Participants = 6004)*

<b>Variables</b>	<b>Sub-distribution hazard ratio</b>	<b>Robust Standard Error</b>	<b>(95% Confidence Interval)</b>
<b>Had formal ADL assistance</b>	0.07**	0.05	(0.02, 0.28)
<b>Had informal ADL assistance</b>	5.25**	2.28	(2.24, 12.31)
<b>Number of ADL assistance needs</b>	1.57**	0.08	(1.42, 1.75)
<b>Age</b>	1.07**	0.02	(1.04, 1.10)
<b>Female</b>	1.27	0.30	(0.80, 2.01)
<b>Number of medical conditions</b>	1.17*	0.08	(1.02, 1.33)
<b>Had ADL assistance needs</b>	3.43	2.22	(0.96, 12.18)

Note: ADL is the abbreviation of activities of daily living.

\*  $p$ -value  $\leq 0.05$ ; \*\*  $p$ -value  $\leq 0.01$

## CHAPTER V: CONCLUSION OF THE STUDY

This study addressed three important questions related to home care provision. In response to the first question regarding factors that influence quality of home care, this study demonstrated five-levels of ecological influences on quality of home care and suggested a linkage between quality of home care and quality of life of older service recipients. To answer the second and third questions about the associations of home care provision with quality of life outcomes and nursing home placement, our study examined secondary data derived from the National Health and Aging Trends Study.

Comparing two strata of participants, those with no ADL assistance needs and those with ADL assistance needs, participants with no ADL assistance needs had higher average self-rated health and higher average well-being. Our findings showed nonsignificant, but positive associations between number of ADL assistance tasks received and self-rated health and well-being, which suggested that ADL assistance might improve service recipients' quality of life. Significant associations were found between the number of ADL assistance needs and SRH and WB in the overall and stratified models. Finally, the incidence of nursing home placement was lower for individuals with formal activities of daily living assistance than individuals without formal activities of daily living assistance, while accounting for death as a competing-risk event. The incidence of nursing home placement was higher for individuals with informal activities of daily living assistance, increasing age, and increasing number of medical conditions. Our study findings confirmed that older adults who have more ADL assistance needs are more likely to move to nursing homes for long-term care.

To our knowledge, this study is one of the few studies that explored the relationships of home care quality and quality of life among older adults. The results lay the groundwork to

develop measures for home care quality and to link home care quality to quality of life as the outcome measure. This study indicated that formal ADL assistance might lower the incidence of nursing home placement. The policy implications of our findings include older adults with high ADL assistance needs may experience poor quality of life and high nursing home placement. Thus, home care provision should address strategies to meet the ADL assistance needs of the service recipients.

As the American population continues to age, the demand for long-term care, particularly the demand for home care services, will continue to increase. To ensure good quality of home care is provided, the foremost effort is to define home care quality and to develop a set of quality measures for home care services. It is important that further research is conducted to evaluate the influences of key stakeholders on home care quality. Another important area for further research is to identify the quality of home care that will impact on service recipients' health and quality of care.