The Availability and Generosity of Medicaid Home & Community Based Services for Economically Vulnerable Older Adults: State Differences and Their Relationship to End of Life Outcomes

Hazal Erçin

A dissertation
submitted in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

University of Washington
2021

Reading Committee:
Taryn Lindhorst, Chair
Melissa Martinson
Clara Berridge
Tracy Mroz

Program Authorized to Offer Degree:
School of Social Work

University of Washington

Abstract

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Hazal Erçin

Chair of the Supervisory Committee:
Professor Taryn Lindhorst
School of Social Work

Most older adults express a wish to age and die in their own homes, yet without a support system, dying at home can be impossible due to high needs for assistance with self-care, mobility, symptom management and day-to-day functioning at the end of life. The care needs of economically vulnerable, community dwelling older adults are addressed by Medicaid 1915(c) waivers which allow Medicaid funds to be used to provide home and community–based services (HCBS). Medicaid 1915(c) waivers reach the most economically vulnerable older adults – also known as “dual eligible” older adults as they are qualified for both Medicare and Medicaid. HCBS waivers allow states to provide services that can help with symptoms, housework, daily activities, caregiver support and with home safety. There is no federal policy regulating the services provided by Medicaid waiver programs and 1915(c) waivers are offered at the discretion of the states. As a result, states vary dramatically in the availability of the suite of services provided as well as the level of funding, or generosity of these services. These state-level differences may create disparities in the end-of-life experiences among dual eligible older adults based on the state they live and die in. *Aims:* This dissertation investigated 1) state variation in Medicaid 1915(c) waiver availability and generosity of HCBS to dual eligible older adults, and 2) the association between state variation in availability and generosity and end of life experiences. *Methods:* Three papers were written to answer the aims of this dissertation. First, a policy analysis was conducted to explore availability and generosity of 1915(c) waivers utilizing three datasets: 1) waiver application documents located at CMS.Medicaid.org, 2) the Medicaid Analytic Extract - Other Services (MAX-OT) dataset, and 3) Genworth State Cost of Care Survey 2013. Analysis of these datasets resulted in summative descriptions of 8 state-level indicators for availability and generosity of HCBS. For the second and third papers, the National Health and Aging Trends Study (NHATS) (Wave 2-7, 2012-2017) was utilized in addition to state-level data summaries created for the policy analysis. For paper 2, regression analyses were used to determine the effect of waiver availability and generosity on unmet end of life needs. For paper 3, regression analyses examined the effect of HCBS on the quality of life reported at the end of life. *Results:* Substantial variation exists between states in available services, coverage for target groups, service slots available, ability to direct participants' own care and generosity of services. Paper 2 found that 40.26% of the sample had unmet needs for self-care and mobility activities Unmet need for assistance was associated with lower availability of HCBS and less generosity for homemaker services, having dementia and not having participant direction option. Paper 3 found that 56.07% of low-income respondents reported having a low quality of end of life. Lower quality at the of end of life was associated with fewer available HCBS slots, living alone, higher numbers of chronic diseases and receiving hospice during the last month of life and. *Discussion:* Community dwelling dual eligible older adults nearing the end-of-life experience unmet needs with self-care and mobility activities and low quality of end of life, such as high symptom burden and lower functioning. The findings indicated that 1915(c) waivers could tailor their services for older adults at the end of life due to their higher risk for unmet needs and lower quality of end of life. Generosity for the services and slots available for dual eligible older adults were also associated with end-of-life experiences of this sample, therefore Medicaid waivers should increase their generosity and slots to better meet the needs of economically vulnerable older adults at the end of life.

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ACKNOWLEDGEMENTS

Throughout writing this dissertation I have received a great deal of support and assistance. I would like to thank those who have helped and supported me:

Taryn Lindhorst: Thank you for sharing this journey with me since the very beginning and helping me making it real.

My Committee Melissa Martinson, Clara Berridge, Tracy Mroz and Jerald Herting: For your constant feedback, check ins and support.

Rona Levy: For your support during the long and challenging restricted data application process.

SSW Ph.D. Colleagues: Thank you Jessica Lapham, Yuanjin Zhou, Erin Harrop and Chiho Song for listening, inspiring, and brainstorming.

My Family: Sean Swearinger, Elif Yazici, Ozan Ata and Dincer Yazici for your love and belief in me.

My Friends: Cagri Kocyigit, Zuhal Cam and Charlie Blotner for being there whenever I need and bringing joy to my life.

And I would also like to acknowledge the support I received from: Carol Lamare Endowed Fellowship in Integrative Oncology and Palliative Care Social Work, West Coast Poverty Center, Center for Statistics and the Social Sciences, UW Retirement Association, Horowitz Foundation for Social Policy, and the Almgren Dissertation Award for Studies in Poverty and Health.

CHAPTER 1

END OF LIFE AND HOME AND COMMUNITY BASED SERVICES IN THE UNITED STATES

Introduction

As a result of drastic transformation in public health and medical care, the rise in life expectancy in the United States (US) over the past centuries is remarkable (Costa, 2015). The obvious consequence of a longer life expectancy is that as we live longer, how we die has changed. Contrary to a century ago, when death was usually sudden, at home and the primary cause of death was related to infectious diseases (CDC, 1999), nowadays for most people, death does not come suddenly. More people live longer with chronic and life-limiting illnesses at the end of their lives and dying happens at later ages after long term chronic conditions lasting weeks, months, or even years (Xu et al., 2018). Actually, 3 out of 4 older adults who are 65 and older have multiple chronic conditions and comorbidities, including Alzheimer's disease, diabetes, arthritis, cancer, and cardiovascular disease; these diseases are incurable and persist until the very end of life, (Ward 2017). Closer to a person's death, it is common to see a steep rise in impairment and a period of progressive decline (Cohen-Mansfield et al., 2018; Gill et al., 2010; Verbrugge et al., 2017), resulting in limitations with daily activities and a potential impact on the quality of life in our last days, particularly if a person has limited access to necessary supports at home (Cohen-Mansfield et al., 2018).

Limitations with Self-care Activities and Mobility

Older ages are often characterized by substantial deteriorations across a variety of Activities of Daily Living (ADL) domains, including eating, showering/taking a bath/washing up, getting to or using the toilet, dressing and mobility activities such as getting out of bed, moving in one's home and leaving the house[1] (Freedman & Spillman, 2014; Kasper et al., 2014). During the last 3 months of life, decline in ADLs is the greatest (Chen et al., 2007). Among those 65 and older, only 31.5% were fully able to engage in self-care and mobility activities; the need for assistance increased by age with only 3.9% being fully able to carry out all ADLs in the 90 and older age group (Freedman & Spillman, 2014).

Functional limitations typically increase in the last months of life (Gerlach et al., 2017; Chen et al., 2007; Stabenau et al., 2015; Chen et al., 2007), which may create changes in routine daily behaviors (Williamson, 1998) and leave older adults dependent on caregivers. Approximately 45 million Americans are 65 and older today and more than half of them are projected to need long term caregiver services and assistance for their activity limitations at some point before they die (Favreault & Dey, 2016). When there is a lack of or inadequate assistance with needed activities, older adults may experience adverse consequences like not getting dressed, going without food when hungry, wetting or soiling clothes and attendant diminishment of health because of these unmet caregiving needs (Freedman et al., 2014). The prevalence of adverse consequences due to unmet needs is 40% among economically vulnerable older adults, who are eligible for both Medicare and Medicaid, also known as dual eligible older adults (Allen et al., 2014). Adverse consequences due to unmet needs are also socially

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[1] According to the measure constructed by Kasper et al, 2014, self-care activities include bathing, dressing, eating, and toileting. Mobility-related activities include getting out of bed, getting around inside one's home or building, and leaving one's home or building. Taken together, self-care and mobility activities correspond to activities of daily living (ADLs).

stratified. For example, black older adults are more likely to experience an unmet need (Berridge & Mor, 2018) as are women (LaPlante et al., 2004).

Research on unmet needs experienced by older adults at the end of their lives is limited. Studies have found an association between unmet needs and risk of death among dementia patients (Gaugler et al., 2005), higher rates of falls (Allen & Mor, 1997), burns (LaPlante et al., 2004), depressive symptoms (Xiang et al., 2018), anxiety (Zuverink et al., 2020), emergency department visits (Hass et al., 2017), potentially preventable hospitalizations (Schussler-Fiorenze Rose et al., 2017; Xu et al., 2012) and hospital readmission (DePalma et al., 2013). While these studies point to problems that can occur when assistance with ADLs is not met, none of this research focused on the particularly vulnerable period of the last month of a person's life.

Quality of End of Life

Quality of life is defined in relation to each individual's goals, expectations, standards and concerns (World Health Organization [WHO], 1998). End of life, especially the last month of life, is typically characterized by terminal decline and steep deteriorations in well-being, including elevated symptom burden and ever decreasing functioning (Lee et al., 2020). Therefore, quality of life at the end of life has typically been conceptualized as a person's functional status (being alert, able to get out of bed) and symptom burden (pain, trouble breathing, and anxiety/sadness) (Teno et al., 2015; Sharma et al., 2017; Lee et al., 2020). In the US, it is estimated that only 20% of people have high quality of life in the month before their death (Lee et al., 2020).

Symptoms are an expression of distress of the whole person (Singer et al., 2016) and the most commonly reported symptoms at the end of life are pain (Paice, 2018), breathing troubles (Bausewein, et al., 2007) and psychosocial distress like anxiety and depression (Kozlov et al., 2019). Although there are differences based on diagnosis (Bausewein et al., 2010), studies show common pathways in symptom severity closer to death regardless of one's disease (Solano et al., 2006). Also, despite effective treatment for each of these symptoms, caregivers report a high prevalence of unmet needs in terms of symptom control. (Makaroun et al., 2018).

Mobility and self-care also become more limited during the last month of life, including being able to get out of bed and being alert. Getting out of bed may be more difficult for older adults due to increased weakness, fatigue (Lynch, 2013), declines in global motor function (Wilson et al.,2012) and weight decline (Alley et al., 2010). As a result of physical deterioration, older adults are likely to be confined to bed during the last month of their lives. Pronounced decline in alertness is also be expected during the end of life, which in turn may contribute to worse quality of life by decreasing the ability of older adults to report and describe symptoms and side effects of interventions (Kehl & Kowalkowski, 2012; Lynch, 2013). Functioning at the end of life is a critical indicator of quality of end of life, with some suggesting that being confined to bed in severe distress or being unconscious could be described as worse than death (Farsides et al., 2001).

End of Life Care

End of life is a time period with difficulties of self-care and mobility activities, functioning and high symptom severity, thereby requiring high levels of caregiver assistance (Cohen-Mansfield et al., 2018). Due to accumulated, multiple chronic conditions and comorbidities, an increasing number of older adults live with functional limitations and require personal assistance and support with symptoms to age and die in place (Broad et al., 2015). End-of-life care encompasses care for patients that are considered to be in the last stage of their life. Longer-term care with functional limitations and quality of life is crucial for older adults to be able to stay in their own homes through the end of their life, however end of life care is highly fragmented, poorly coordinated and out of reach for many Americans without some kind of financing or support system in place (Favreault & Dey, 2015). Care needs can be addressed informally (by family and friends) or formally via nursing facilities, home and community-based services and hospice/palliative care services.

Informal caregivers play a vital role in the care needs of older adults at the end-of-life (Schulz & Eden, 2016). Most of the care an older adult receives is delivered by informal, unpaid caregivers, such as family or friends[2] (Buchanan et al., 2009; Schulz & Eden, 2016). According to the 2020 caregiving report of AARP (Prudencio & Young, 2020), an estimated 41.8 million family caregivers provided, on average, 24 hours per week of unpaid care to older adults in 2020, a dramatic increase since 2015 when 34.2 million provided this kind of care. Taking care of someone near the end of life is often difficult and may remain limited due to the high care needs required. In addition to providing assistance with self-care and mobility activities (National Alliance for Caregiving, 2015), caregivers also undertake additional challenging tasks at the end of life, such as symptom management, support with functioning and decision-making (Institute of Medicine, 2015) which may cause higher levels of depression and anxiety

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[2] AARP does not define family caregivers exclusively related to the person they are providing care to; they include any adult who provides unpaid care or support to a family member or friend.

among caregivers (Pottie et al., 2014). However, demographic, and social changes are making it more difficult for informal caregivers to be the only resource for care. These changes include longer life spans and subsequent need for longer periods of caregiving help; higher rates of chronic conditions creating more complex care (Commission on Long-Term Care, 2013); and the increased participation of women in the workforce while they are still expected to shoulder most of the work of providing care in the family (Reinhard et al., 2015). As a result of these changes, older adults may need to receive care from formal sources in addition to family and friends as they age and approach the end of life.

Older adults receive formal care at either a residential care setting or at one's home. Residential care settings are facilities like nursing homes, assisted living facilities or adult family homes that provide safety, care, assistance, meals, and supervision. Despite the fact that dying at home is the preference of the majority of older adults (Lacas, 2019; Khan et al., 2014; Gomes et al., 2013; Higginson & Sen-Gupta, 2000; Ratner et al., 2001; Arnold et al., 2015), older adults are often forced to move to nursing facilities as death approaches if they do not have access to resources to meet their rising care needs (Harris-Kojetin et al., 2016). There are around 1.4 million older adults living in nursing homes across the US (CDC, 2015) with 41.6 percent of them identified as the oldest-old (age 85+; CMS, 2015). The number of older adults using nursing home (NH) care has steadily declined from a high of 1,628,300 in 1999 to 1,369,700 in 2014 (Harris-Kojetin et al., 2016). Length of stay in NHs is also declining which indicates that older adults are either being discharged to home care or that older adults are using NHs primarily for end-of-life care when they do not have resources to support their own care at home (Harris-Kojetin et al., 2019).

The other option for older adults to receive formal long-term care is through home care services. However, the out-of-pocket payments for caregiving help at home are costly and beyond the economic means of economically vulnerable and even middle-class persons. In 2015, the median cost of home health aide services was $20 per hour (Genworth 2015; Berridge, 2018). In cases where a person requires 24-hour care such as is often true at the end of life, formal costs are substantial. Private health insurances, Medicare and Medicaid only cover home-based caregiving partially and conditionally. First, private health insurance plans generally do not cover long term care services at home or in institutions (Thompson et al., 2013). It is possible to purchase private long-term care insurances that may cover home caregiving services, but the costs for these policies are also high and unaffordable for economically vulnerable older adults, so only a small portion of people have private long-term care insurance (Khatutsky et al., 2016).

Second, despite the general assumption that Medicare pays for long-term care needs, it plays a relatively minor role in funding these services (Robison et al., 2014). Medicare provides payment for short-term rehabilitative services at home for those who are recovering from acute events if the beneficiary is homebound (Medicare Interactive, 2020; Volpp et al., 2020). End of life care is not rehabilitative; therefore, Medicare the alternative program of hospice was developed for those at the end of life. Hospice care, "catered to [the] cultural model of 'good' death," (Livne, 2019, pg.113) and aims to provide comfort and supportive care at home, in a nursing home, or at one of the few inpatient hospice settings in the US. Hospice is limited to patients with less than six months to live and who agree to end treatment and life-sustaining interventions (Meier, 2011). Because of these constraints, hospice referral, if it occurs, happens very late in the course of a person's condition, with more than one-third of hospice patients dying within seven days of admission (Yim et al., 2017). Even for those who are eligible and accept hospice, hospice does not provide assistance for self-care and mobility activities and caregiver respite services are severely limited (Cagle et al., 2020; Muramatsu et al., 2008). To summarize, Medicare does not cover the personal care needs of older adults with functional limitations nearing end of life.

Medicaid is the primary funder for nursing home care and the only source of potential support for low-income older adults in need of home-based caregiving services[3] (Colello, 2013; Ng et al., 2011). Historically, public financing of long-term services and supports has focused on institutional long-term care, as opposed to home- and community-based services ([HCBS] Ng et al., 2011). Federal law requires that Medicaid pays for care for individuals who require nursing home care, including room and board, nursing care, personal care, and therapy services, if they are unable to pay for this care themselves. Motivated by the recognition that older adults and other individuals with disabilities often prefer to remain and die in their own home and community, and potential cost savings of HCBS compared to nursing home care (Reaves & Musumeci, 2015), Congress authorized states to experiment with the provision of HCBS through a waiver system. Under this system, states apply to use Medicaid funds to provide HCBS to persons who might otherwise be forced to move to a nursing home. Medicaid funded HCBS have grown substantially over the past few decades (Segelman et al., 2017). In 1995, only 18% of national Medicaid long term services and support

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[3] Older adults enroll in Medicare automatically at the age 65, but to be eligible for Medicaid older adults must meet income guidelines or state-specific decisions on eligibility rules like who qualifies as medically-needy (Feng, 2018).

(LTSS) spending was devoted to HCBS (Eiken et al., 2017). By 2015, HCBS accounted for 55% of total national Medicaid LTSS spending (Eiken et al., 2015).

Congress has allowed states to experiment with new policies that focus on less-restrictive, lower-cost HCBS alternatives to institutional care. The Social Security Act reauthorization of 1981 created 1915(c) waivers, through which states have the option to use Medicaid funding to provide recipients who qualify for NH care with a variety of HCBS [4] (Kapp, 2014; Anderson et al., 2018). Medicaid HCBS waivers provide funds for approximately 11 million older adults and their family members each year that would otherwise be used to pay for NH care (National Association of Area Agencies on Aging, 2016). The rapid expansion of 1915(c) waiver programs has explained most of the increase in the HCBS portion of Medicaid long-term care expenditures, because they are the major tool for states to provide HCBS (Wang, 2019).

Waivers are also the source of variation in programs across states because they allow states to waive federal regulations and to target services to specific populations -- such as those at risk for institutionalization -- and to demonstrate new methods for providing services. The federal government sets certain standards but gives the states considerable flexibility about the services they provide. There are more than 300 HCBS waiver programs currently operating in the US. These waivers differ dramatically in terms of the availability and generosity of services.

Availability and Generosity of 1915(c) Waivers

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[4] 1915(c) waivers are not the only mechanisms that Medicaid use to provide HCBS. Medicaid can provide HCBS under three primary authorities, (1) mandatory home health care services, (2) optional state plan amendments (i.e., 1915(i),(j),(k) HCBS state plans), and (3) optional Medicaid authorities (1915(c) HCBS waivers and 1115 waivers).

The availability of services varies greatly from state-to-state resulting in inequities based on where economically vulnerable older adults live (Meucci et al., 2018). Standard services suggested by CMS include but are not limited to home-delivered meals, home-based services (like home-based habilitation, home health aide, personal care, companion, homemaker), non-medical transportation, interpreter, and housing consultation. HCBS may also provide support with case management, nursing (private duty nursing, skilled nursing), mental health, or behavioral services. The most frequently provided service categories under HCBS waivers are specialized medical equipment and assistive technology; personal care, transportation, homemaker, and chore services are offered in fewer than half of the states (Friedman et al., 2019).

States can set parameters for particular target groups that impose additional limitations to the availability of services. In 2015, older adults and nonelderly adults with physical disabilities made up the largest Medicaid HCBS enrollment group (54%), followed by people with intellectual and developmental disabilities (I/DD) (42%) (Watts and Musumeci, 2018). Similarly, states may define the maximum number of participants that each waiver can serve annually. Limitations on the number of participants served at any point in time permits states to specify enrollment numbers which limits the maximum number of participants served during the waiver year (Cooper, 2017). In contrast to institutional care, states are not required to provide waiver services to everyone who is eligible and can implement controls such as cost limits and reserved waiver capacity which may lead to long waiting lists. More than three-quarters of states report waiting list for their HCBS waivers with an average wait time of 39 months (Musumeci et al., 2020).

States also vary in the generosity of HCBS waivers, such as the number of participants per state population and expenditures per capita (Kitchener et al., 2003; Rizzolo et al., 2013). For instance, Medicaid HCBS participation rates ranged from 3 per 1,000 population in Georgia to 15 per 1,000 in Washington, D.C. in 2007 (Ng et al.,2011). In 2016, the average spending per capita was $20.70 across the older adult-only waivers; generous states such as for Connecticut, and for Pennsylvania, spent on average $71.74 and $58.97 respectively per capita, while less generous states such as Oklahoma and Alabama spent $0.57 and $0.53 respectively per capita. (Friedman et al., 2019). The proportion of LTSS spending on HCBS ranged from 27% in Mississippi and New Jersey to 78% in Oregon in 2012 (Eiken et al., 2014).

The variation between the states in terms of the availability and generosity of HCBS may lead to inequitable outcomes based on where a recipient resides. Understanding the effects of HCBS on the end-of-life experiences of economically vulnerable community-dwelling older adults with functional limitations may hold particular promise for promoting the better end of life outcomes. No systematic examination has yet occurred on the impact of HCBS on end-of-life outcomes of older adults, other than its effect on place of death, namely higher likelihood of dying at home (Muramatsu, et al. 2008). Research is needed that would help identify policy pathways that could be strengthened to help this population achieve a higher quality end of life experience.

Social Justice Considerations at the End of Life

Disparities in end-of-life experience are well documented, hence death is not a great equalizer anymore (Moodie, 1853). Economically vulnerable older adults who are at the end of their lives are one of the most medically complex and marginalized groups in the US (Hayes et al., 2016; Hurd et al., 2013). According to the CDC, 59% of people who were dually enrolled in the Medicare and Medicaid programs were 65 years or older (Medicare Medicaid Coordination Office, 2017). Dual eligible older adults experience several disadvantages that may put them at risk for worse end of life experiences compared to rest of the population. For example, Cumulative Advantage/Disadvantage (CAD) theory, based on the life course perspective, examines how health disparities in later ages can be traced back to differential and cumulative inequality and disadvantage that began early in life, such as the deleterious effects of inequalities experienced by racial minorities and those experiencing poverty (Taylor et al., 2020). Early exposure to risks continues affecting individuals systematically over the life course through the end of life (Dannefer, 2003). For instance, patterns of racial health disparities across the life course are one of the most common factors associated with cumulative disadvantage in later ages (Dannefer, 2003; Taylor, 2008; Brown, 2018). Although the majority of the dual eligible population were non-Hispanic White (57%), dual eligible individuals who are older than 65 were less likely to be than dual eligible individuals under age 65 to be non-Hispanic White (53% vs. 61%) (Feng, 2018). Dual eligible recipients were also less likely than non–dual Medicare beneficiaries to be White (Feng, 2018).

The other common pattern in cumulative disadvantage is socioeconomic status (Hu et al., 2020). The poverty rate for older Americans (10%) is lower than for other age groups (Johnson & Lindner, 2017) because of guaranteed income floors provided via the Social Security or Supplemental Security Income programs, but poverty in older age disproportionately affects people of color (Proctor et al., 2016) and women (Feng, 2018). For example, poverty rates are 2.5 times higher for African American older adults, and 3 times higher among Hispanic older adults than white older adults (Cubanski et al., 2015). The majority of dual eligible population is female (61%), and the proportion of females among dual eligible older adults was higher than among younger dual eligible or among non–dual Medicare beneficiaries (Feng, 2018). Poverty rates for older women (12 percent) are almost twice that of older men (7 percent) (Cubanski et al., 2015) and women are expected to need more years of long-term services (4.4 years) compared to men (3.2 years) on average (Favreault & Dey, 2016). These patterns show that people with lifetimes of lower access to social determinants of good health have greater long-term care needs (Ferraro & Shippee, 2009; Ferraro et al., 2016).

Disparities increase with age as the effects of earlier disparities accumulate across the life course (Dannefer, 2003, Guilley & D'Epinay, 2008), suggesting the years approaching death may be a particularly vulnerable adverse experience because of unmet needs for assistance with ADLs and lower quality of end of life. End of life is a time period associated with health deterioration (Brown et al., 2012) that leads to skyrocketing health care needs and expenditures (Fassbender et al., 2009). Older adults—especially those with limited economic resources—have substantial late-life care needs (Freedman & Spillman, 2014). These needs are much more expensive for older adults than for the younger population (Alecxih et al., 2010; Reuben & Tinetti, 2012) and much of these costs are incurred near the end of life (Cubanski et al.,2016). Further, a greater share of dual-eligible older adults had three or more activities of daily living limitations than those under age 65 (36% vs. 22%) (Feng, 2018). And almost half of dual eligible older adults have unmet care needs (Allen et al., 2014). Interestingly, a recent study showed that, although racial inequalities in functional disparities decrease among older adults, they increase again significantly closer to death, the years surrounding death may be a particularly vulnerable period for health inequality (Tylor et al., 2020).

To summarize, dual eligible older adults who are at the end of their lives are a vulnerable segment of the population that experiences relatively higher disparities at the end of life compared to the rest of the society. Due to the high proportion of women and people of color in this population, the disadvantage may be reflective of the cumulation of disadvantage across the life course and the uneven policy response to these disadvantages. One way to address this disparity among people who are approaching the end of life is well-tailored long-term care services. However, there remains a gap in empirical research on how disparities are patterned in end of life to inform long term service policies.

The Current Study

This dissertation has two main aims: (1) to identify between-state variation in availability and generosity of Medicaid home- and community-based services for economically vulnerable community-dwelling older adults, (2) to examine the relationship between this state variability and end of life experiences defined as (1) unmet care needs and (2) quality of end of life the end of life for economically vulnerable community-dwelling older adults. Aims of the 3 papers are below.

Aims of Paper One. The aim of this paper is to identify between-state variation in availability and generosity of Medicaid HCBS over the 2011 – 2015 year period.

Aims of Paper Two. The aim of paper 2 is to understand (1) to what extent do economically vulnerable community-dwelling older adults experience unmet care needs at the end of life and (2) what is the association between unmet care needs and state variation in the availability and generosity of HCBS waivers.

Aims of Paper Three. This paper investigates the association between HCBS availability and generosity and quality of end of life among economically vulnerable older adults by examining (1) to what extent do economically vulnerable community-dwelling dual-eligible older adults experience a lower quality of end of life and (2) whether variation in quality at the end of life is associated with differences in availability and generosity of states' HCBS waivers.

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CHAPTER 2

STATE DIFFERENCES IN THE AVAILABILITY AND GENEROSITY OF MEDICAID HCBS FOR OLDER ADULTS

Abstract

Medicaid 1915(c) waivers are cost-effective and preferred platforms to provide home and community–based services (HCBS) to the economically vulnerable older adults. However, there is no federal policy regulating Medicaid waiver programs by mandating the services to be provided, 1915(c) waivers are offered at the discretion of the states therefore states are allowed to vary in their expenditure, available services, coverage for target, service slots and ability to direct participants' own care.

Aims: The aim of this paper is to identify between-state variation in availability and generosity of Medicaid HCBS over the 2011 – 2015 year period for socioeconomically vulnerable community-dwelling older adults.

Methods: This paper conducted a policy analysis on availability and generosity of 1915(c) waivers utilizing three datasets, namely waiver application documents located at CMS.Medicaid.org, the Medicaid Analytic Extract - Other Services (MAX-OT) dataset, and Genworth State Cost of Care Survey 2013.

Results: Frequency of available types of services showed variation between the states, with equipment, technology, and modifications services being the most likely to be offered and family training being the least frequent service provided. Participant direction was not available in 10 states.

Discussion: In parallel to the previous literature, this study showed that states do not provide family training service as frequent as other services. Although most states decided to have participant direction option available, 10 states do not have this option. There is a variation in waivers allowing participant direction by their target population. The waivers specifically tailored for HIV/AIDS provide this option less commonly than the other target populations.

Keywords: home and community-based services, 1915(c) waivers, economically vulnerable older adults, state policies

CHAPTER 2

STATE DIFFERENCES IN THE AVAILABILITY AND GENEROSITY OF MEDICAID HCBS FOR OLDER ADULTS

Introduction

Home and community–based services (HCBS) are some of the fastest-growing and most cost-effective programs for service delivery to economically impoverished older adults with functional limitations in the United States (U.S.) (Harris-Kojetin et al., 2016; Sullivan et al., 2016). Medicaid can provide HCBS under three primary authorities. First, they can use mandatory home health care services. Second, optional state plan amendments can be used to provide HCBS, and these amendments are known as 1915 (i) 1915(j) and 1915(k) HCBS state plans. And third, optional Medicaid authorities provide these services under two options namely 1915(c) HCBS waivers and 1115 waivers. States mostly use Medicaid 1915(c) waiver programs to provide HCBS - 55% of all HCBS expenditures in 2013 was for 1915(c) waivers (Eiken et al., 2017). 1915(c) waivers provide these services to recipients who qualify for a level of care that would normally be provided in a nursing home setting. Created by the Social Security Act reauthorization of 1981, 1915(c) waivers allow states to petition (WHO?) to use Medicaid funds to provide a variety of HCBS, including services like nursing and home health, chore and homemaker services, personal care, caregiver respite and assistive technology, environmental adaptations, specialized medical equipment and personal emergency response systems.

There is no federal policy mandating states about the services to be provided under each waiver programs (Eiken et al., 2017). 1915(c) waiver services are optional and authorize states to waive certain Medicaid rules such as furnishing services to all eligible individuals on a statewide basis (Rizzolo et al., 2013). Currently, there are more than 300 1915(c) waiver programs operating in nearly every state; those states with waivers have unique names (e.g. Ohio named their waiver "PASSPORT"), organizing, financing, and delivery of HCBS services (Wysocki et al., 2015). As a result, states vary in expenditures (Musumeci, 2019), available services (Friedman et al., 2019), coverage for target groups (e.g., older adults, individuals with brain injury etc.) (Musumeci et al., 2018), service slots available (Miller & Kirk, 2016) and ability of the person needing care to hire their own caregivers (known as participant direction) (Ng et al., 2015). Therefore, 1915(c) waivers, are one of the primary sources of variation between the states in terms of HCBS.

Despite Medicaid HCBS waivers can address care needs of economically vulnerable older adults, research on the topic has been hampered (Ng et al., 2015). Most studies have focused on HCBS in general (including various authorities together) instead of a focusing on 1915(c) waivers specifically (Walsh et al., 2012; Muramatsu et al., 2007; Wysocki et al., 2014; Muramatsu, et al. 2008) or have focused on waivers for younger adults with disabilities (Friedman, 2018; Friedman, 2017; Friedman & Rizzolo, 2017; Friedman & Rizzolo, 2016).

The studies focusing on broad HCBS (not only 1915(c) waivers) have shown that higher HCBS expenditure is associated with a lower risk of institutionalization and hospitalization (Walsh et al., 2012; Muramatsu et al., 2007; Wysocki et al., 2014), lower depression among older adults with low levels of functioning (Muramatsu et al., 2010), and higher likelihood of dying at home (Muramatsu, et al. 2008). Research focused on waivers available for younger adults have shown that waivers for people with intellectual and development disabilities (IDD) have a huge variation in their services between the states, with most waivers providing transportation for people with IDD (Friedman & Rizzolo, 2016) and adult day health, education and recreation being the least frequent services (Friedman, 2017).

Although the literature on HCBS in general and on 1915(c) waivers with younger target groups provide important information, little is currently known about how states differ in their 1915(c) waivers available for older adults. Recent studies have examined the Medicaid HCBS for older adults, but they did it in combination with waivers for younger adults with physical disabilities (Musumeci & Young, 2017; Meucci et al., 2018; Musumeci et al., 2019) or combining 1915(c) waivers with other state programs (Ng et al., 2015). Most of these research operationalized HCBS as per enrollee spending and found that per enrollee spending for older adults ($13,249) is 4 times higher than per enrollee spending for non-elderly adults ($3,247) partially due to greater use of long-term care services (Musumeci & Young, 2017). They also found that per enrollee spending significantly varied between states due to state choices about eligibility and services, with $10,518 in North Carolina and $32,199 in Wyoming (Musumeci & Young, 2017). Meucci and colleagues (2018) have also explored waivers for older adults and people with physical disabilities and identified 6 key service categories that are the most critical to support community living: are case management, nursing, home-based services, health/therapeutic services, equipment, and non-medical transportation. The literature also showed that Medicaid HCBS programs provide flexibility with options like participant direction to their consumers (Ng et al., 2015).

A recent study has specifically focused on the waivers for only older adults and developed an older adult waiver taxonomy to describe the availability of service categories by state (Friedman et al., 2019). They found that there is variation between the states in terms of frequency of service categories, with specialized medical equipment and adult day health being the most commonly provided service categories, and companion/supervision and family training being the least provided service categories. However, the authors excluded waivers that target various population groups that a waiver could target from their analysis, such as waivers targeting individuals with brain injury, technology dependent and HIV/AIDS, which could also be used by older adults. Therefore, there is a need for research to comprehensively address the availability and generosity of HCBS services across waivers with different target groups that may provide generous services to some, while only offering limited or no services to others with the same level of need (Low et al., 2011; Kaye & Williamson, 2014). The aim of this paper was to identify between-state variation in the availability and generosity of Medicaid HCBS over the 2011 – 2015 year period for socioeconomically vulnerable community-dwelling older adults.

Design and Methods

Data

Three data sets were used to measure availability and generosity of 1915(c) waivers for older adults. Availability of services was extracted using information obtained from state-submitted approved waiver application documents located at CMS.Medicaid.org. Generosity was identified from two datasets. The Medicaid Analytic Extract - Other Services (MAX-OT) dataset, which is based on the Medicaid HCBS Taxonomy (Truven Health (at that time Thomson Reuters), 2012; Peebles & Bohl, 2014), was used to identify state expenditure on services, including home health, adult day care and personal care services. Genworth State Cost of Care Survey 2013 was utilized to identify median hourly rate for homemaker services, home health aide services and adult day health care services in each state (Genworth 2013 Cost of Care Survey, 2013) and then used to adjust the state expenditure accordingly.

Sample

The analytical sample of this study is 1915(c) waivers which were (1) available for Medicaid beneficiaries, aged 65 and older, and (2) available between the years of 2011 and 2015. Under the waiver of Section 1902(a)(10)(B) of the Social Security Act of 1981, states can limit waiver services to one or more groups or subgroups of individuals. Waivers were included in the sample if they specified older adults and/or older adults and other population combined groups (i.e., physical disability, brain injury, HIV/AIDS etc.) in their waiver target group in their approved waiver application. After excluding waivers that did not target older adults or were out of the year range, the final sample included 125 waivers from a total of 45 states (including District of Columbia). 6 States were not included because they either did not have any 1915(c) waivers (Arizona, Rhode Island, Vermont); or had 1915(c) waivers but not for older adults or no waivers for older adults (Hawaii, Delaware, Tennessee). Arizona, Delaware, Rhode Island, and Vermont provided HCBS to Medicaid participants through 1115 waivers and not 1915(c) HCBS waivers. Figure 1 shows the waiver inclusion flow diagram and can be found at the end of this chapter.

Measures

1915(c) HCBS waivers were assessed for two main indicators: availability and generosity of services. For the availability analysis, I coded each waiver downloaded from CMS.Medicaid.org. For the number of slots in each waiver, I summed the maximum number of unduplicated participants of the waivers available for older adults to create the total number for each state. To standardize available slots according to the state dual eligible population, I used annual Medicaid/Medicare Dual Enrollee State County Snapshots obtained from Medicare-Medicaid Coordination Office (MMCO) Statistical & Analytic Reports (MMCO, 2019) and calculated the average dual eligible population for the years between 2011 and 2015 in each state. I used this average to standardize the rate of the total number of available slots. Availability of waivers was measured in 4 ways:

1. *Target population:* Waivers have flexibility to serve different target groups or serve combined target groups. Waivers were classified based on their target groups; namely older adults, individuals with physical disabilities, individuals with brain injury, technology dependent, medically fragile or individuals with HIV/AIDS.

2. *Types of services provided:* States could elect to provide various services. Based on a recently developed HCBS 1915(c) waiver service taxonomy (Friedman et al., 2019), I have identified whether states provided the following service categories: adult day health, assistive technology, care coordination, chore, community transition and integration supports, companion and supervision, environmental adaptations, family training, financial support services, health and professional services, homemaker, individual goods and services, meals, personal care, personal emergency response system, residential habilitation, respite, specialized medical equipment and assistive technology, transportation and other. Definitions of the service categories can be seen in Table 1.

< Insert Table 2. 1 >

3. *Participant direction:* States may use 1915(c) waivers to provide self-directed

HCBS if participant direction is allowed in their approved waiver documents. Participant Direction offers enrollees the ability to determine which employees or vendors will be hired to deliver their services, provide supplies or additional support. States were identified as allowing participant direction if they specified participant direction opportunities.

4. Available slots: States have flexibility to decide the maximum number of unduplicated participants who are served in each year that the waiver is in effect. Available slots of states were measured as the rate of the total number of available slots to the average number of Medicaid/Medicare dual eligible individuals in each state, obtained from Medicare-Medicaid Coordination Office (MMCO) Statistical & Analytic Reports. Detailed information can be found in Appendix A Table 1.

Generosity of waivers was assessed based on average expenditure of each state for hours of (1) Homemaker services, (2) Home health services, and (3) Adult Day services[5]. For the generosity analysis, data were obtained from MAX OT and Genworth State Cost of Care Survey. First, the mean reported cost for each service type per user between the years between 2011-2015 was calculated separately for each state using the

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[5] I have limited the types of services to these three main types of services due to the data limitations. Medicaid MAX (Medicaid Analytic Extract) Other Services (OT) files have data for various Medicaid expenditures for dual eligible enrollees, such as outpatient services, clinic services, home health services, lab/x-ray services, prescription drugs, transportation, personal care, targeted case management, rehabilitation, nurse practitioner, durable medical equipment, residential care services, adult day care and other services. Home health, personal care and adult day services were the types of services that Genworth annual cost of survey report included in their long-term care service types. To be able to standardize the state expenditures by average cost of care by service types in each state, we limited the service types only to these 3 types of services.

MAX OT data set. Then using the median hourly rate for each service type of each state from the Genworth data, I calculated the ratio of average expenditure to hourly rate to identify the generosity in hours for each state.

Generosity for Homemaker services: The generosity for homemaker was identified in hours for each state and measured as the ratio of average expenditure per user for personal care services to state mean expenditure for hourly rate of homemaker services. While MAX OT had data for personal care services, Genworth annual cost of care survey had homemaker services. The definition of these two services were comparable[6].

Generosity for Home Health services: The generosity for home health was identified in hours for each state and measured as the ratio of average expenditure per user for home health services to hourly rate of state mean expenditure for home health services.

Generosity for Adult Day Care services: The generosity for adult day was identified in hours for each state and measured as the ratio of average expenditure per user for adult day services to hourly rate of state mean expenditure for adult day services.

Analysis

To report the descriptive analysis of each indicator of availability and generosity

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[6] MAX OT's definition of personal care services is that type of service including assistance with IADLs, the supports offered in companion and homemaker if these supports are provided along with assistance with ADLs and/or health-related tasks. On the other hand Genworth Annual survey defines homemaker services as types of services that provide hands-off care such as helping with cooking and running errands and mentions that it is often referred to as "Personal Care Assistants" or "Companions."

in detail, first, I prepared the descriptive table of the waivers by target groups in each state (Table 2.2) that shows the sum of waivers for each state according to their target population. Then I prepared the table showing the availability of waivers for older adults by states that summarizes the number of types of services provided with the waivers, number of waivers in each state with participant direction option, number of waivers specifically tailored for older adults in each state with participant direction option and available slots in these waivers by dual eligible population in each state (Table 2.3). And the last table showed generosity of state 1915(c) waivers for dual Medicaid-Medicare enrollees as measured in hours of service provided (Table 2.4)

Findings

There were 125 approved waivers for 45 states (including District of Columbia). States varied in the number of waivers they obtained, with Florida having the highest number of waivers (N=8) and 6 states having no waivers available for older adults (Arizona, Rhode Island, Vermont, Hawaii, Delaware and Tennessee). Waivers had different target groups (see Table 2.2). While only 11 of the waivers identified older adults as their sole target population, 72 of the waivers were focused on specific medical problems, regardless of the age of the beneficiary. For example, 20 waivers targeted individuals with brain injury, 11 of the waivers targeted individuals with HIV/AIDS, 11 of the waivers targeted individuals who were medically fragile and technology dependent (MF/TD).

< *Insert Table 2. 2* >

Availability of Services for Older Adults

Frequency of available types of services showed variation between the states. The most frequently provided services were specialized medical equipment and assistive technology (SMEAT) (43 of the 45 states), personal care (41 of the 45 states), adult day health (41 of the 45 states), respite (40 of the 45 states), and health and professional services (40 of the 45 states). The least frequently provided services were family training (16 of the 45 states), companion and supervision (19 of the 45 states), chore assistance (20 of the 45 states), homemaker (25 of the 45 states) and transportation services (28 of the 45 states). Florida, Iowa, Minnesota and Utah provided all types of services, while Oregon provided only care coordination and Wyoming provided only personal care and residential habilitation. Detailed information on the type of services can be seen in the Appendix A Table 2.

Availability of participant direction also showed variation between the states (see Table 2.3). Participant direction was available in 35 states; 10 states did not have the participant direction option. Among the 11 waivers with waivers for only older adults, 5 had participant direction; 40 of the 72 waivers with combined target populations, 12 of the 20 waivers for individuals with brain injury, 4 of the 20 waivers for individuals with HIV/AIDS and 5 of the 11 waivers for individuals who are MF/TD had participant direction.

< *Insert Table 2. 3* >

As can be seen in the Table 2.3, the total number of available slots to average Medicaid/Medicare dual eligible in each state also varied between states. Wyoming (1.90%), California (2.27%), Texas (2.38%), Maine (3.18%), Louisiana (3.19%) and New York (3.19%) had the lowest proportion of available slots in the 1915(c) waivers for the state dual eligible enrollees. Wisconsin (48.73%), Oregon (40.74%), Pennsylvania (37.75%), Colorado (33.93%), Idaho (32.83%) and Washington (31.59%) had the highest proportion of available slots for state Medicaid/Medicare dual eligible enrollee population.

Generosity of the Waivers for Older Adults

Generosity of state 1915(c) waivers for dual Medicaid-Medicare enrollees was examined with a special focus on service types, namely the number of hours available for homemaker, home health and adult day services, as well as total generosity across these 3 categories (Table 2.4). Average generosity for homemaker services was 404.15 hours and seven states provided zero hours. Minnesota was the most generous state for homemaker services, providing 1,166 hours, followed by New Hampshire (1,158 hours), New York (1,150 hours) and DC (1,138). The average generosity for home health services was 244.73. The most generous states for home health services were Indiana (967 hours), Nevada (951 hours), Maryland (759 hours) and Texas (619 hours), while the least generous states were Wisconsin (16 hours), Oregon (32 hours), Michigan (34 hours) and Minnesota (35 hours). The average generosity for adult day services was 176.84 hours with the most generous states being South Carolina (626 hours), Alabama (464 hours), North Dakota (440 hours) and North Carolina (416 hours); the least generous states were Maine (5 hours), Idaho (27 hours), Oregon (43 hours) and South Dakota (57 hours). Total generosity of state 1915(c) waivers for dual eligible enrollees ranged between 1,978 hours (New York) to Georgia (157 hours).

< *Insert Table 2. 4* >

Discussion

Medicaid HCBS waivers are the fastest growing and preferred platform for service delivery to older adults with functional limitations by providing services in their homes and communities that can help with supporting beneficiaries to remain in their own home. The flexibility offered under the Social Security Act of 1981 resulted in states showing marked variation between states in the availability and generosity of HCBS services for older adults, similar to previous studies which included younger persons (Wysocki et al., 2015). The findings of this study revealed that between the years of 2011-2015, 45 states provided 125 waivers for older adults, but only 11 of these waivers were specifically tailored to older adults. States show different patterns in the availability and generosity of services provided through these waivers, where some states offered fewer services, had low numbers of available slots, or opted out of providing beneficiaries with the opportunity of participant direction.

The most frequently provided types of services were SMEAT, personal care and adult day health, while family training, companion and supervision, and chore are the least frequent service types. This finding was similar to the previous research by showing SMEAT and adult day health were the most commonly provided service categories and companion/supervision and family training being the least provided service categories (Friedman et al., 2019). Their study was different the current study by limiting their sample to only 61 waivers which are only targeting older adults as their target groups and not including the other target populations that can include older adults. Our study also revealed the states that provided the least number of service types within these waivers, like Wyoming and Oregon.

Previous research provided the number of unduplicated participants in each state (Miller & Kirk, 2016; Friedman et al., 2019); this study standardized the number of participant numbers to the dual eligible population in each state to better compare the availability of the slots. The findings showed that states such as Wisconsin, Oregon, and

Pennsylvania had the highest number of slots available for the population while states such as Wyoming, California and Texas had the lowest ratio of total number of available slots.

Participant direction was another policy that differed among waivers and states. Similar to the previous literature (Ng et al., 2015), most states decided to have a participant direction option available. The waivers had varying availability of participant direction by their target population. While more than half of the waivers for individuals with brain injury and with combined populations provided participant direction, only 20% of the waivers specifically tailored for HIV/AIDS had this option. This difference is particularly important, because having access to participant-directed services can be critical not only due to its flexibility, but also it makes the services more accessible because it creates a larger pool of workers and worker shortage can be an access limitation (Mahoney et al., 2014).

In addition to these differences, the generosity of 1915(c) waivers for older adults also showed variance between the states. As evidenced by our findings, this variation showed different patterns by service types across homemaker, home health and adult day services. Previous research had operationalized generosity in the form of expenditure in dollars. This study added to this literature by standardizing this expenditure to the state median hourly rates of services, which made the generosity of each state more comparable to each other and less affected by local differences in costs. According to this analysis, states provided the most hours' worth of expenditure for homemaker services, followed by home health services and provided the least hours for adult day services.

States had varying generosity levels for different service types. For instance, while

Minnesota was the most generous state for homemaker services, it is the least generous state for home health. Similarly, Oregon was one of the least generous states for home health and adult day services, while spending more than the average of all states for homemaker services.

To summarize, this study explored and mapped the variation in Medicaid HCBS available for economically vulnerable older adults in the US. Findings revealed that states show different patterns in their availability and generosity of the waivers, also varying by their target population. The evidence that was revealed by the findings can help improve the policy pathways that need to be strengthened in order to better support the needs of the high-need economically vulnerable older adults for home and community-based services. The findings can inform federal policymakers to develop meaningful measures and identify key policy strategies to examine state-based policies and to reduce disparities caused by modifiable state differences experienced by poor and near-poor older adults.

Limitations and Future Research

The first limitation that must be acknowledged is that our study only focused on 1915(c) waivers. However, it is known that states use various mechanisms to provide HCBS authorities to Medicaid recipients. Therefore, states that are low in ranking in 1915(c) waivers are not necessarily providing lower quality or less HCBS in reality. Besides the mandatory home health services that all states must provide under their state plans, states were also utilizing multiple options that are optional, such as 1915(i),(j),(k) authorities and 1115 demonstration waivers. States that are not providing 1915(c) waivers to dual eligible older adults are mostly utilizing 1115 waivers, such as

Arizona, Delaware, Rhode Island and Vermont. However, approved application documents of 1115 waivers are not standardized like the 1915(c) waivers, so they do not provide clear description of availability of their services. Also, MAX OT data does not have information about 1115 waivers for the state generosity. Therefore, our study has mainly focused on the 1915(c) waivers. As a result, these findings do not provide a comprehensive national picture of the funding of HCBS to low-income older adults, but rather are limited to those states that use 1915 c waivers.

Another limitation that should be noted is that the information provided in waiver documents on participant direction does not specify who is allowed to be hired and under which regulations. For example, some states allow beneficiaries to hire family members to provide care while others require services go through credentialed agencies. Although findings of this study provided important insight on variation of the availability of this policy option, who can be hired under this policy could also have important implications for beneficiaries and states.

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Table 2.1.

Service Category Definitions

Category	**Definition**
Adult day health	Provides daytime supervision in a community-based setting and provides snacks and meals, personal care assistance and social activities.
Assistive technology	Means an item, piece of equipment, service animal or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants. Assistive technology service means a service that directly assists a participant in the selection, acquisition, or use of an assistive technology device.
Care coordination	Services that assist participants in gaining access to needed waiver and other state plan services, as well as medical, social, educational, and other services, regardless of the funding source for the services to which access is gained.
Chore	Services needed to maintain the home in a clean, sanitary, and safe environment. This service includes heavy household chores such as washing floors, windows, and walls, moving heavy items of furniture in order to provide safe access and egress.
Community transition and integration supports	Services involve non-recurring set-up expenses for individuals who are transitioning from an institutional or another provider-operated living arrangement to a living arrangement in a private residence where the person is directly responsible for their own living expenses. It also aids people in developing, retaining, or improving skills to attend social events, recreational activities and volunteering.
Companion and supervision	Companions may assist or supervise the participant with such tasks as meal preparation, laundry, and shopping. Providers may also perform light housekeeping tasks that are incidental to the care and supervision of the participant.
Environmental adaptations	Home modifications/adaptations include the installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or the installation of specialized electric and plumbing systems that are necessary to accommodate the medical equipment and supplies that are necessary for the welfare of the participant.
Family training	Instructions about the treatment regimens and other services included in the service plan, use of equipment specified in the service plan, and includes updates as necessary to safely maintain the participant at home, specifically for unpaid family.
Financial support services	Includes services which help the older adult or family members manage and direct the disbursement of funds contained in the participant-directed budget.

Health and professional services	Provided by a registered nurse, or licensed practical or vocational nurse under the supervision of a registered nurse, licensed to practice in the State.
Homemaker	Services that consist of the performance of general household tasks (e.g., meal preparation and routine household care) provided by a qualified homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home.
Individual goods and services	Services, equipment or supplies that increase the participant's safety in the home environment.
Meals	Includes preparation and delivery of meals for people unable to prepare their own food.
Personal care	A range of assistance to enable waiver participants to accomplish tasks that they would normally do for themselves if they did not have a disability. This assistance may take the form of hands-on assistance (actually performing a task for the person) or cuing to prompt the participant to perform a task.
Personal emergency response system	PERS is an electronic device that enables waiver participants to secure help in an emergency. The participant may also wear a portable "help" button to allow for mobility. The system is connected to the participant's phone and programmed to signal a response center once a "help" button is activated.
Residential habilitation	Supports that assist with the acquisition, retention, or improvement in skills related to living in the community. These supports include adaptive skill development, assistance with activities of daily living, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his or her needs. Residential habilitation also includes personal care and protective oversight.
Respite	Services provided to participants unable to care for themselves that are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the participant. Federal financial participation is not to be claimed for the cost of room and board except when provided as part of respite care furnished in a facility approved by the state that is not a private residence.
Specialized medical equipment and assistive technology	Medical equipment includes: (a) devices, controls, or appliances, specified in the plan of care, that enable participants to increase their ability to perform activities of daily living; (b) devices, controls, or appliances that enable the participant to perceive, control, or communicate with the environment in which they live; (c) items necessary for life support or to address physical conditions along with ancillary supplies and equipment necessary to the proper functioning of such items; (d) such other durable and non-durable medical equipment not available under the state

	plan that is necessary to address participant functional limitations; and, (e) necessary medical supplies not available under the state plan.
Transportation	Services in the form of transportation escorts or rides that enable waiver participants to gain access to waiver and other community services, activities and resources.

Source: Disabled and Elderly Health Programs Group et al. (2015), Friedman, C., Caldwell, J., Rapp Kennedy, A., and Rizzolo, M. C. (2019).

Table 2.2.

Descriptive Table of the Waivers by Target Groups in Each State

		Total # of States	**Combined waivers**	**Older adults**	**Brain injury**	**HIV/AIDS**	**MF/TD[a]**
Total states with waivers		45	41	9	16	11	10
Total number of waivers		125	72	11	20	11	11
Rank	**State**	**Total # of Waivers**	**Combined waivers**	**Older adults**	**Brain injury**	**HIV/AIDS**	**MF/TD**
1	Florida	8	3	2	1	1	1
2	California	6	2	1	0	1	2
3	Massachusetts	6	3	0	3	0	0
4	Ohio	5	5	0	0	0	0
5	Kentucky	5	2	0	2	0	1
6	Utah	4	2	1	1	0	0
7	Alabama	4	2	0	0	1	1
8	Colorado	4	2	0	1	1	0
9	New Mexico	4	2	0	0	1	1
10	Illinois	4	2	0	1	1	0
11	Mississippi	4	3	0	1	0	0
12	Maine	4	3	0	1	0	0
13	Iowa	3	0	1	1	1	0
14	Connecticut	3	0	1	2	0	0
15	Nevada	3	1	2	0	0	0
16	Oklahoma	3	1	1	0	0	1
17	South Carolina	3	1	0	0	1	1
18	Missouri	3	1	0	0	1	1
19	Maryland	3	2	0	1	0	0
20	Virginia	3	2	0	0	0	1
21	Wisconsin	3	2	0	1	0	0
22	New Jersey	3	2	0	0	1	0
23	New York	3	2	0	1	0	0
24	Pennsylvania	3	2	0	0	1	0
25	Washington	3	3	0	0	0	0
26	West Virginia	2	1	0	1	0	0
27	Indiana	2	1	0	1	0	0
28	North Dakota	2	1	0	0	0	1
29	New Hampshire	2	1	0	1	0	0

30	Arkansas	2	2	0	0	0	0
31	Louisiana	2	2	0	0	0	0
32	Michigan	2	2	0	0	0	0
33	South Dakota	2	2	0	0	0	0
34	Kansas	1	0	1	0	0	0
35	Minnesota	1	0	1	0	0	0
36	DC	1	1	0	0	0	0
37	Georgia	1	1	0	0	0	0
38	North Carolina	1	1	0	0	0	0
39	Texas	1	1	0	0	0	0
40	Alaska	1	1	0	0	0	0
41	Idaho	1	1	0	0	0	0
42	Montana	1	1	0	0	0	0
43	Oregon	1	1	0	0	0	0
44	Wyoming	1	1	0	0	0	0
45	Nebraska	1	1	0	0	0	0
46	Arizona	0	0	0	0	0	0
47	Rhode Island	0	0	0	0	0	0
48	Vermont	0	0	0	0	0	0
49	Hawaii	0	0	0	0	0	0
50	Delaware	0	0	0	0	0	0
51	Tennessee	0	0	0	0	0	0

Notes: [a] MF/TD stands for waivers with the target population of older adults who are medically fragile or Technology dependent.

Table 2. 3.

Availability of Waivers for Older Adults by States

States	Number of types of services [a]	# of Waivers with PD [b]	Older Adults Waivers with PD [c]	Available slots
Florida	13	0	0	18.94%
Iowa	13	3	1	15.02%
Minnesota	13	1	1	30.99%
Utah	13	4	1	10.40%
California	12	2	0	2.27%
Connecticut	12	2	0	12.53%
Massachusetts	12	2	-	7.98%
Montana	12	1	-	11.18%
New Jersey	12	1	-	7.66%
North Dakota	12	0	-	3.93%
Idaho	11	1	-	32.83%
Ohio	11	3	-	24.99%
Oklahoma	11	3	1	20.78%
South Dakota	11	1	-	12.75%
Colorado	10	4	-	33.93%
Indiana	10	1	-	20.88%
Kentucky	10	4	-	10.67%
Maine	10	2	-	3.18%
Michigan	10	2	-	8.34%
Nevada	10	1	0	9.18%
New Hampshire	10	2	-	16.48%
New York	10	0	-	3.19%
Pennsylvania	10	2	-	37.75%
South Carolina	10	3	-	15.56%
Wisconsin	10	3	-	48.73%
Alabama	9	3	-	5.56%
Alaska	9	0	-	18.70%
DC	9	1	-	16.86%
Louisiana	9	1	-	3.19%
New Mexico	9	1	-	6.04%
Arkansas	8	0	-	10.44%
Illinois	8	2	-	37.73%
Maryland	8	0	-	9.87%
Mississippi	8	2	-	19.30%

Missouri	8	0	-	16.12%
North Carolina	8	1	-	4.40%
Washington	8	1	-	31.59%
Georgia	7	1	-	12.19%
Nebraska	7	0	-	18.19%
Virginia	7	1	-	25.46%
Texas	6	1	-	2.38%
West Virginia	6	2	-	9.81%
Kansas	4	1	1	10.12%
Wyoming	2	0	-	1.90%
Oregon	1	0	-	40.74%

Notes: [a] Maximum number of services is 13.

[b] PD: Participant direction.

[c] 1 for waivers targeting only older adults with participant direction, 0 for waivers targeting only older adults without participant direction, - for states without waivers targeting only older adults.

Table 2. 4.

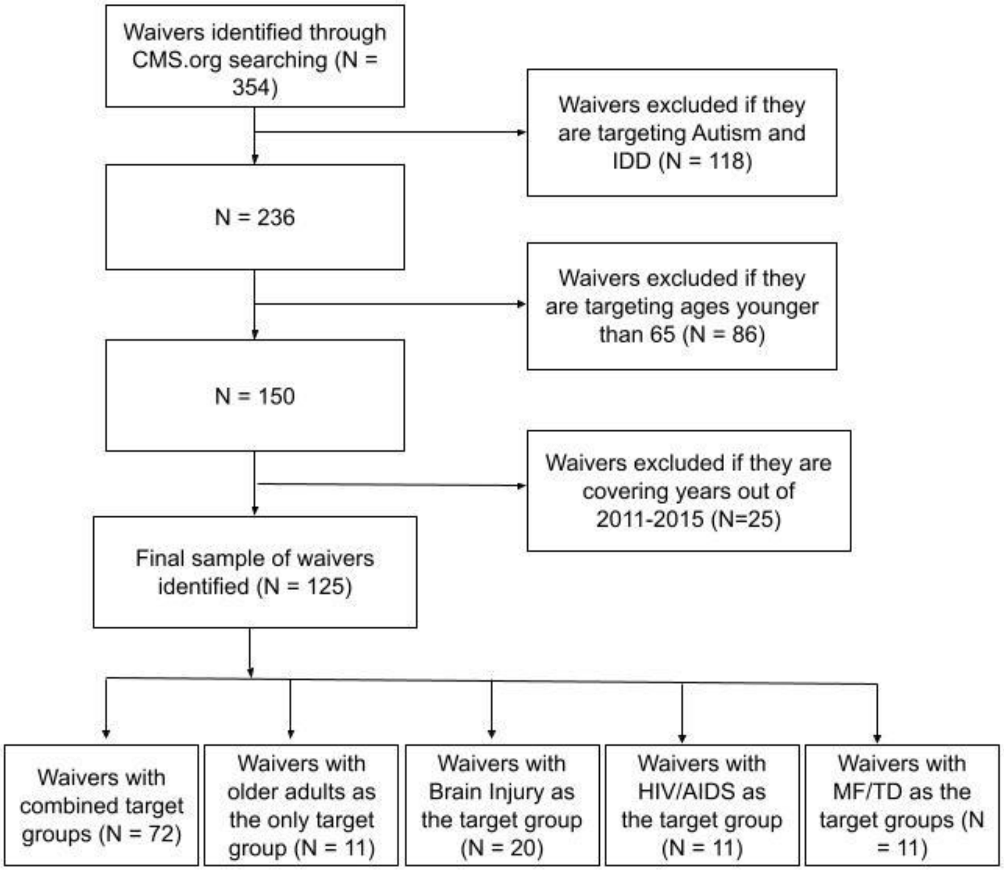
Generosity of State 1915(c) Waivers for Dual Medicaid-Medicare Enrollees as Measured in Hours of Service Provided

States	Homemaker services [a]	Home health services [a]	Adult day services [a]	TOTAL
New York	1,150	531	297	1,978
Nevada	506	951	127	1584
New Hampshire	1,158	97	233	1,488
Minnesota	1,166	35	214	1,415
DC	1,138	79	151	1,368
Connecticut	782	293	222	1297
Maryland	326	759	195	1280
Alaska	921	208	124	1253
Louisiana	786	329	123	1238
Virginia	917	108	127	1152
South Carolina	450	67	626	1143
North Dakota	521	154	440	1115
Indiana	0	967	73	1040
North Carolina	465	149	416	1030
Illinois	775	139	105	1019
Nebraska	321	474	208	1003
Texas	46	619	313	978
California	452	396	122	970
Mississippi	778	50	108	936
Pennsylvania	243	414	269	926
Montana	501	72	302	875
Washington	551	50	184	785
West Virginia	547	88	117	752
Utah	260	253	204	717
Massachusetts	36	507	158	701
Wyoming	35	388	205	628
Arkansas	332	163	128	623
Oregon	539	32	43	614
Alabama	0	142	464	606
New Jersey	364	156	78	598
Maine	376	211	5	592
Colorado	0	477	114	591
Missouri	420	40	126	586
Ohio	0	407	176	583

Iowa	135	282	145	562
South Dakota	332	48	57	437
Oklahoma	245	52	87	384
Michigan	248	34	90	372
Kansas	49	206	109	364
Kentucky	0	152	182	334
Wisconsin	158	16	142	316
New Mexico	75	73	122	270
Idaho	83	154	27	264
Florida	0	143	91	234
Georgia	0	48	109	157

Notes: [a] Generosity is the Expenditure for the type of services in hours

Figure 2. 1. Methodology tree: Waiver inclusion flow diagram.



APPENDIX A

Appendix A Table 1

Total Number of Unduplicated Participants and Dual Eligible Enrollees by State

State	Total Number of Unduplicated Participants [a]	Yearly average Medicare-Medicaid Dual Eligible Enrollees [b]	Available Slots
Alabama	11236	202051.8	5.56%
Alaska	2860	15293.2	18.70%
Arkansas	12820	122852.8	10.44%
California	28953.6	1277217.8	2.27%
Colorado	31522.4	92908.4	33.93%
Connecticut	19478.8	155409.8	12.53%
DC	4646	27558.6	16.86%
Florida	134186.6	708472.2	18.94%
Georgia	34826	285733	12.19%
Idaho	12441.2	37900.4	32.83%
Illinois	127196.2	337156.4	37.73%
Indiana	34471.6	165070.4	20.88%
Iowa	12104	80585.8	15.02%
Kansas	6258	61828.6	10.12%
Kentucky	18254	171140.2	10.67%
Louisiana	6240	195582.6	3.19%
Maine	2893	90920.8	3.18%
Maryland	12296.2	124617.8	9.87%
Massachusetts	22073	276686.6	7.98%
Michigan	23368.2	280230	8.34%
Minnesota	40178.8	129643	30.99%
Mississippi	29350	152035.6	19.30%
Missouri	27366	169734.4	16.12%
Montana	2580.2	23069.6	11.18%
Nebraska	6940	38144	18.19%
Nevada	4236.2	46148	9.18%
New Hampshire	5179.8	31437.2	16.48%
New Jersey	15509.6	202525.6	7.66%
New Mexico	4459.4	73824.2	6.04%
New York	25212.8	789289.6	3.19%
North Carolina	13588	308962.6	4.40%
North Dakota	540.4	13762.6	3.93%

Ohio	79459.8	318026.6	24.99%
Oklahoma	23028	110799.2	20.78%
Oregon	45117	110735.6	40.74%
Pennsylvania	155035.2	410710	37.75%
South Carolina	22981.6	147679	15.56%
South Dakota	2421.2	18992.6	12.75%
Texas	14921.5	626560.4	2.38%
Utah	3330.6	32027.4	10.40%
Virginia	45451.4	178508.6	25.46%
Washington	54617.4	172903.2	31.59%
West Virginia	7722	78687	9.81%
Wisconsin	75780.6	155512	48.73%
Wyoming	197	10360.8	1.90%

Notes: [a] The mean for each state is calculated for the years of 2011-2015.

[b] Source: Annual release of Enrollment Snapshots from Medicare-Medicaid Coordination Office Statistical and Analytic Reports. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Analytics

Appendix A Table 2

Availability of Types of Services by State

State	**Total # of services**	**Waivers with**												
		Personal Care	**Care Coordination**	**Respite**	**Homemaker**	**Companion**	**Adult Day**	**Meals**	**Health and Professional**	**SMEAT**	**Residential Habilitation**	**Transportation**	**Chore**	**Family Training**
Florida	13	8	8	5	5	5	5	6	7	7	4	1	5	5
Iowa	13	3	2	3	2	1	3	2	2	2	1	2	1	1
Minnesota	13	1	1	1	1	1	1	1	1	1	1	1	1	1
Utah	13	4	3	3	3	2	3	2	3	4	2	3	3	1
California	12	6	6	3	3	1	1	2	6	5	5	2	0	2
Connecticut	12	2	1	3	3	3	2	2	3	3	3	3	3	0
Massachusetts	12	3	0	4	4	5	6	1	5	6	4	6	3	3
Montana	12	0	1	1	1	1	1	1	1	1	1	1	1	1
New Jersey	12	2	3	1	1	0	1	1	3	2	1	1	1	1
North Dakota	12	2	2	1	1	1	1	1	1	2	1	2	1	0
Idaho	11	1	0	1	1	1	1	1	1	1	1	1	1	0
Ohio	11	4	0	3	2	1	4	4	3	4	2	3	2	0
Oklahoma	11	3	3	3	0	1	2	3	3	3	2	1	0	1
South Dakota	11	2	1	2	1	1	1	1	2	2	1	0	1	0
Colorado	10	4	0	3	3	3	4	3	2	4	1	4	0	0
Indiana	10	2	2	2	2	0	2	2	2	2	2	2	0	0
Kentucky	10	2	4	4	2	0	4	1	5	4	4	0	0	3
Maine	10	3	4	1	2	0	1	1	2	4	1	2	0	0
Michigan	10	1	1	2	0	0	2	2	2	2	0	2	2	1
Nevada	10	3	3	2	2	1	1	1	0	2	1	0	2	0
New Hampshire	10	2	1	2	1	0	1	1	1	2	2	1	0	0
New York	10	3	2	3	2	1	3	2	3	3	0	3	0	0
Pennsylvania	10	3	1	2	0	0	2	2	3	3	1	2	0	1
South Carolina	10	3	3	2	0	2	1	3	2	3	1	1	0	0
Wisconsin	10	2	3	3	0	0	3	3	3	3	3	3	0	3
Alabama	9	4	3	3	3	3	2	2	3	2	0	0	0	0
Alaska	9	0	1	1	0	0	1	1	1	1	1	1	1	0
DC	9	1	1	1	1	0	1	0	1	1	1	0	1	0
Louisiana	9	1	2	1	0	0	2	1	1	1	1	1	0	0
New Mexico	9	1	3	3	2	0	1	0	4	3	2	1	0	0

Arkansas	8	1	0	1	0	1	1	1	1	1	2	0	0	0
Illinois	8	2	0	2	3	0	3	2	3	3	1	0	0	0
Maryland	8	1	1	1	0	0	3	0	1	1	2	0	0	1
Mississippi	8	3	2	2	0	0	1	1	1	2	1	0	0	0
Missouri	8	2	0	1	1	0	1	1	3	2	0	0	1	0
North Carolina	8	1	1	1	0	0	1	1	0	1	0	0	1	1
Washington	8	2	0	0	0	0	2	1	3	3	2	1	0	3
Georgia	7	1	1	1	0	0	1	1	1	1	0	0	0	0
Nebraska	7	0	0	1	0	0	1	1	0	1	1	1	1	0
Virginia	7	2	1	2	0	0	1	0	2	2	1	0	0	0
Texas	6	1	0	1	0	0	0	1	1	1	1	0	0	0
West Virginia	6	2	2	0	0	0	0	0	1	2	0	2	2	0
Kansas	4	1	0	0	0	0	1	0	1	1	0	0	0	0
Wyoming	2	1	0	0	0	0	0	0	0	0	1	0	0	0
Oregon	1	0	1	0	0	0	0	0	0	0	0	0	0	0

Notes: [a] Maximum number of services is 13.

Appendix A Table 3

Availability of Participant Direction by Target Population and State

	Waivers with PD [a]	Older Adults Waivers with PD [b]	Combined Waivers with PD	BI Waivers with PD	HIV/AIDS Waivers with PD	MF/TD Waivers with PD
Alabama	3	-	2	-	0	1
Alaska	0	-	0	-	-	-
Arkansas	0	-	0	-	-	-
California	2	0	0	-	0	2
Colorado	4	-	2	1	1	-
Connecticut	2	0	-	2	-	-
DC	1	-	1	-	-	-
Florida	0	0	0	0	0	0
Georgia	1	-	1	-	-	-
Idaho	1	-	1	-	-	-
Illinois	2	-	0	1	1	-
Indiana	1	-	1	0	-	-
Iowa	3	1	-	1	1	-
Kansas	1	1	-	-	-	-
Kentucky	4	-	2	2	-	0
Louisiana	1	-	1	-	-	-
Maine	2	-	2	0	-	-
Maryland	0	-	0	0	-	-
Massachusetts	2	-	2	0	-	-
Michigan	2	-	2	-	-	-
Minnesota	1	1	-	-	-	-
Mississippi	2	-	1	1	-	-
Missouri	0	-	0	-	0	0
Montana	1	-	1	-	-	-
Nebraska	0	-	0	-	-	-
Nevada	1	0	1	-	-	-
New Hampshire	2	-	1	1	-	-
New Jersey	1	-	1	-	0	-

New Mexico	1	-	1	-	0	0
New York	0	-	0	0	-	-
North Carolina	1	-	1	-	-	-
North Dakota	0	-	0	-	-	0
Ohio	3	-	3	-	-	-
Oklahoma	3	1	1	-	-	1
Oregon	0	-	0	-	-	-
Pennsylvania	2	-	2	-	0	-
South Carolina	3	-	1	-	1	1
South Dakota	1	-	1	-	-	-
Texas	1	-	1	-	-	-
Utah	4	1	2	1	-	-
Virginia	1	-	1	-	-	0
Washington	1	-	1	-	-	-
West Virginia	2	-	1	1	-	-
Wisconsin	3	-	2	1	-	-
Wyoming	0	-	0	-	-	-

Notes: [a] PD: Participant direction. [b] 1, 2, 3 for number of waivers with participant direction, 0 for waivers without participant direction, - for states without waivers.

CHAPTER 3

PREVALENCE OF UNMET NEEDS AT THE END OF LIFE: DO MEDICAID HCBS WAIVERS HELP?

Abstract

Most older adults eligible for both Medicare and Medicaid (dual eligible) have poor health, a high prevalence of multiple chronic conditions and higher rates of difficulty with performing self-care and mobility activities that require increasing caregiving assistance until the very end of life. The care needs of community dwelling dual eligible older adults are be addressed via 1915(c) waivers which allow states to propose a suite of services for low-income older adults, however HCBS are not readily recognized to be a resource for end-of-life care. These services can help with symptoms, housework, daily activities, caregiver support and home safety, however states vary greatly in the availability and generosity of the services offered through under these waivers.

Aims: This paper assesses unmet care needs among community dwelling older adults at the end of life, and the association between unmet care needs and state variation in the availability and generosity of services provided through 1915(c) waivers.

Methods: Utilizing the National Health and Aging Trends Study dataset; this paper estimated frequencies of outcome variables, conducted bivariate analysis by sample characteristics and state policies, and carried out hierarchical multivariate logistic and linear regression models to understand the function of state-level policy domains and individual level variables on unmet needs at the end of life.

Results: In this sample, 40.26% had any unmet need at the end of life; 22.39% had any unmet need with self-care activities; 28.98% had any unmet need with mobility activities. Having a participant direction option available, more waivers and increased generosity for homemaker services were significantly associated with decreased risk for unmet needs at the end of life. Individuals with a dementia diagnosis had higher levels of unmet need for assistance with self-care and mobility activities.

Discussion: Almost half of dual eligible older adults experienced any unmet need at the end of life. For states to decrease unmet need, offering participant direction, providing more waivers options, and increasing generosity for homemaker may all be policies choices that can better meet the needs of older adults at the end of life. The service needs of older adults with dementia require further investigation to identify policy choices that would be most effective in supporting these persons in a home environment.

Keywords: unmet needs, end of life, dual eligible older adults, home and community-based services, 1915(c) waivers

CHAPTER 3

PREVALENCE OF UNMET NEEDS AT THE END OF LIFE: DO MEDICAID HCBS WAIVERS HELP?

Background and Research Problem

The majority of individuals who receive both Medicare and Medicaid (known as dual-eligible beneficiaries) are older adults (MMCO, 2017) and often have poor health and high prevalence of multiple chronic conditions commonly resulting in significant long-term care needs (Young et al., 2015; Neuman et al., 2012). Compared to older adults who are eligible for Medicare only, Medicare/Medicaid dual eligible older adults have a higher prevalence of difficulty with performing self-care and mobility activities: 43.57% of dual eligible older adults needed assistance with one or more self-care activities compared to 22.28% of Medicare-only older adults; 53.39% of dual eligibles needed assistance with one or more mobility tasks compared to 27.72% of Medicare only recipients[7] (Allen et al., 2014). Older adults having difficulty with activities of self-care and mobility require increasing caregiving assistance.

Unmet need is defined as the absence or inadequate caregiving assistance with needed self-care and mobility activities (Freedman & Spillman, 2014). Studies on unmet needs have found patterns in prevalence by socio-demographic factors such as

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[7] Allen, Piette and Mor found that dual Medicare/Medicaid recipient older adults have higher needs with assistance with all self-care and mobility activities compared to Medicare only recipient older adults, such as such as eating (15.21% vs. 5.67%), showering/taking a bath/washing up (32.80% vs. 13.24%), getting to or using the toilet (18.34% vs. 7.47%), dressing (31.89% vs. 15.78%), getting around inside the home (34.90% vs. 16.17%), getting out of bed (35.75% vs. 17.34%) and going outside of home (39.72% vs. 16.74%) (2014).

race/ethnicity and gender, and by health factors such as dementia and chronic diseases. Black older adults (Berridge & Mor, 2018) and women (LaPlante et al., 2004) have higher rates of unmet needs compared to white older adults and men. Probable dementia was also significantly associated with more unmet needs among Medicaid and Medicare eligible older adults (Berridge & Mor, 2018). Higher numbers of chronic conditions make care needs more complex and challenging (Schulz & Eden, 2016) and increase risk for unmet needs among community dwelling older adults (Beach & Schulz, 2016). Also, most of dual eligible beneficiaries experience multiple chronic conditions (Fox & Reichard, 2013). Difficulties experienced with self-care and mobility activities significantly increase in the last year of life (Chaudhry et al., 2013) with unmet care needs for self-care activities particularly pronounced near the end of life compared to low-need older adults, such as older adults without chronic conditions or without dementia (Beach et al., 2020).

Unmet needs for assistance with self-care and mobility may result in adverse consequences such as failure to eat, wetting or soiling clothes; dually eligible older adults experience higher rates of adverse consequences of unmet needs compared to Medicare-only older adults (Allen et al., 2014; Desai et al., 2001). Unmet needs increased risk of hospitalization and readmissions (Sands et al., 2006; Xu et al., 2012; DePalma et al., 2013), emergency department admissions (Hass et al., 2017) and premature mortality (Gaugler et al., 2005). Despite the fact that most older adults express a preference to die at home in their own communities (Higginson & Sen-Gupta, 2000; Arnold et al., 2015; Khan et al., 2014; Gomes et al., 2013), this goal may be challenging to meet as greater difficulty with self-care activities also increased the risk for nursing home admissions among older adults (Gaugler et al., 2005).

The care needs of economically vulnerable community dwelling older adults can be addressed via Medicaid Home and Community-Based Services (HCBS). Medicaid uses three main authorities to provide HCBS, namely mandatory state plan benefits, optional state plan amendments, and optional 1915(c) HCBS waivers. Optional 1915(c) waivers can address needs for self-care and mobility activities by providing services that help with symptoms (home health), with housework (homemaker), with daily activities (personal care), with caregiver support (respite) and with home safety (specialized medical equipment). The majority of Medicaid HCSB expenditures are related to 1915(c) waivers (Eiken et al., 2017) making them an important policy pathway for additional support for older adults approaching the end of life.

Because Medicaid 1915(c) waivers are optional and driven by state (not national) policy choices, the availability and generosity of these waivers vary (Eiken et al., 2017; Wysocki et al., 2015). An extensive literature has developed on states' HCBS generosity and its influence on health outcomes of older adults. States with more generous HCBS programs were found to have lower depression rates among older adults with self-care difficulties (Muramatsu et al., 2010). Use of HCBS was also associated with better life satisfaction among older people who are both homebound and low-income (Chen et al., 2019). Research on HCBS has generated conflicting findings about hospitalization. While higher state HCBS spending as percent of total long-term care spending was found to reduce risk of all cause hospitalizations and potentially avoidable hospitalizations among dually eligible individuals (Walsh et al., 2012; Segelman et al., 2019), another study reported that compared to dual eligible nursing home residents, dual eligible HCBS user older adults had an increased probability of experiencing both a preventable and non-preventable hospitalization (Wysocki et al., 2014).

Current studies demonstrated important findings for the association between state generosity for HCBS and care location among older adults which may be insightful for the rising care needs throughout aging until the end of life. For instance, living in a state with higher HCBS expenditures was associated with lower risk of nursing home admission among childless older adults (Muramatsu et al., 2007). Similarly, another study on dual eligible waiver recipients living in 24 states showed that higher HCBS spending for waiver enrollees was associated with a lower risk of long-term nursing home admissions and greater functional impairment at nursing home admissions for those waiver enrollees who enter a nursing home for a long-term stay (Segelman et al., 2017). Another study found that living in a state with more generous HCBS - measured as total HCBS expenditures per older adult population and as percentage of long-term care expenditures spent for HCBS rather than nursing homes- increased the chance of dying at home via lowering the risk of end-of-life nursing home relocation (Muramatsu et al., 2008). To summarize, HCBS appears to decrease nursing home relocation in the aggregate, however, the association between different services packages under 1915(c) waivers and unmet needs at the end of life is not yet understood.

Addressing the caregiving needs of economically vulnerable community-dwelling older adults with functional limitations with services tailored to be provided in home and communities may hold particular promise in meeting end of life goals to remain at home through death. Currently, it is unclear which particular HCBS services may be most beneficial for dual eligible older adults. Therefore, this paper is guided by two research questions: (1) To what extent do economically vulnerable community-dwelling older adults experience unmet care needs in the last month of life? (2) What is the association between unmet care needs and state variation in the availability and generosity of HCBS waivers?

Conceptual Framework

Under the auspices of the Section 1915(c) of the Social Security Act of 1981 - passage of Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981-, states are allowed to apply for exceptions to standard Medicaid requirements to provide HCBS through submitting 1915(c) waivers. States vary dramatically in their HCBS expenditures (Musumeci, 2019), available services (Friedman et al., 2019), coverage for target groups[8] (Musumeci & Watts, 2019), service slots available[9] (Miller & Kirk, 2016) and ability to direct participants' own care (Ng et al., 2015). Studies that have focused on state generosity for HCBS have analyzed the entire eligible population and not specifically older adults.

Given the fact that the end of a person's life has a progressive decline in functioning which requires increasing caregiving assistance (Cohen-Mansfield et al., 2018), analyzing availability and generosity together can provide important evidence to identify key policy strategies to reduce health disparities experienced by poor and near-poor community dwelling older adults at the end of life. This paper investigates the following research question: *Is the availability and generosity of HCBS associated*

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[8] 1915(c) waivers can target populations that they are providing the services exclusively. The target populations can be older adults, individuals with brain injury, Autism Spectrum Disorder, developmental disabilities/physical disabilities/intellectual disabilities/other disabilities, HIV/AIDS, serious emotional disturbances, and technology dependent individuals or medically frail (TDMF) individuals.

[9] 1915(c) waivers identify the total maximum number of unduplicated individuals participating in the program during the waiver year which defines the available slots for the population in each state.

with less unmet needs for self-care and mobility activities in the last month of life? The conceptual model can be seen on Figure 3.1.

Methods

Data

This paper used the National Health and Aging Trends Study (NHATS) (Wave 2-7, 2012-2017); (a) Public data, (b) Restricted data to identify the state of residence for each individual, and (c) the Last Month of Life review data to examine the proxy responses about the last month of life of the older adult. The NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG032947) through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health. NHATS was designed to follow nationally representative cohorts of persons 65 and older and enrolled in Medicare, with an oversampling for non-Hispanic Blacks and those aged 85 and older. NHATS participants were administered annual, in-person interviews designed to collect detailed information on the aging process and its consequences. The Last Month of Life data included interviews conducted with proxies, who were a family member and where a family member could not be identified, another surrogate such as facility staff responded (Kasper, & Freedman, 2020).

The analytic sample is limited to older adults who died between 2012-2017, who were dual eligible for Medicaid and Medicare and also living in the community or group living arrangement during the last wave before they died. The sample excluded those (1) who were alive, and (2) who were residing in various types of nursing homes, (3) who were not Medicaid recipients, and (4) lived in a state where 1915(c) waivers were not available (6 states). The original NHATS sample was 19,530. After excluding participants who were alive (n= 16,088), died before 2012 or after 2017 (n=771), were not Medicaid recipients (n=2,197), residing in nursing homes during the last wave of data collection (n=134), had missing data in the outcome variables (n=7), or lived in a state without 1915(c) waivers (n=18), the final sample size was 315.

Measures

The main outcome variable of this paper was unmet needs with self-care and mobility activities which was operationalized with combination of activity limitations and care received for self-care and mobility activities during the last month of life.

Activity limitations. This paper used Freedman and Spillman's measure of activity limitation and unmet need (2014). NHATS included the following self-care and mobility-related activities: bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, and leaving one's home or building. For each activity, proxies were asked if the deceased older adult had difficulty performing the activity during the last month of life. Each activity was dichotomized so that 1 = deceased older adults who had difficulty performing the activity, or 0 = those who did not have difficulty.

Care received for self-care and mobility activities. This outcome was measured based on the deceased older adult's proxy responses. Each activity (bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, and leaving one's home or building) was coded as follows: 0 = without difficulty or with difficulty and assistance from another person, or 1 = with difficulty when carried out alone but without assistance (Kasper, Freedman and Spillman, 2014; Freedman & Spillman, 2014). Unmet need for assistance was identified for each activity separately when the deceased older adult did not receive any assistance despite having difficulty with the activity during the last month of life.

Summary measure of unmet need with assistance. Based on the scores for each of the seven indicators (bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, and leaving one's home or building), I created the dichotomized summary measure based on a two-step process. First, I summed the total number of unmet needs with assistance to have a total score of unmet needs for assistance ranging between 0 and 7, where 0 means no unmet needs for assistance with any activities and 7 means unmet needs for assistance with all activities (Kasper et al., 2014; Freedman & Spillman, 2014). And then, I created a dichotomous measure of unmet need for assistance where 0 = no unmet need for assistance with any activities and 1 = any unmet need for assistance with activities.

State Level Variables. HCBS were measured under two indicators: availability and generosity and they were coded for each state based on the findings of a recent analysis of 1915(c) waivers for older adults between states (Ercin-Swearinger, et al., 2021). This paper operationalized availability of state HCBS waivers using indicators of types of services, target groups, limits in participant number and participant direction. States show a dramatic variation in the services that they provide for older adults (Meucci et al., 2018; Friedman et al., 2019). I measured available types of services by utilizing the older adult waiver taxonomy designed by Friedman specifically tailored for HCBS 1915(c) older adult waivers (2019). States can also target different population groups, so that target groups are another source for variation between the states. I measured states' target population by examining whether they have a waiver specifically designed and targeted for older adults only. States also have flexibility to decide the maximum number of unduplicated participants who are served in each year that the waiver is in effect. Total number of available slots are calculated for each state and standardized by state dual eligible population to identify the population who are in need of and can benefit from the services through the 1915(c) waivers. And participant direction was another policy option for Medicaid waivers that offers enrollees the ability to determine which employees or vendors will be hired to deliver their services and provide supplies and additional support (Friedman, 2018). States were identified as allowing participant direction if they specified participant direction opportunities.

Due to dataset limitations, generosity of waivers was measured by average expenditure of states for various service types, such as homemaker, home health and adult day services[10]. Generosity was measured for each state as average Medicaid expenditure per users for service types for the years between 2011 and 2015 using MAX OT data set. Then this rate was standardized according to the median hourly rate for the types of services that were pulled from Genworth State Cost of Care Survey 2013 separately for each state. This ratio of average expenditure was used in hours to make them more comparable between the states. After coding all availability and generosity variables, I recoded them separately to examine each policy decision separately.

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[10] Adult day care includes a wide array of services with an ultimate goal of allowing participants to remain in their communities while ensuring their needs are met. It must be noted that the nature of the services provided within adult day services do not necessarily align with priorities of end of life, therefore older adults may not use these services at the very end of their lives – last month of their lives. However, I included adult day health as one of the service types to measure generosity of states for 1915(c) HCBS waivers as a proxy.

Continuous variables were standardized and were coded into dichotomous measures. Dichotomous measures were created in the following fashion. First the frequency of the sample for each variable was checked; the data was strongly skewed to the left and thus, dichotomous variables were created based on median values.

Covariates. Choice of individual-level covariates were informed by prior research on predictors of unmet needs with assistance. Covariates that were used were as follows: Sociodemographic characteristics were categorical age groups: 65-74, 75-79, 80-84, 85-89 and 90+; gender (LaPlante et al., 2004); categorical race/ethnicity as White/Non-Hispanic, Black/Non-Hispanic, Hispanic/Other (Berridge & Mor, 2018). Severity of illness and impairment characteristics were dementia status (Gaugler et al., 2005) and having chronic diseases (including heart disease, arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer) (Xiang et al., 2018). End of life indicators were hospice use and place of death (1 = home, 2 = hospital, 3 = nursing facility/hospice/other).

Data Analysis

Since a change in a policy variable may have a lagged effect on the end-of-life experiences of older adults over several years, I examined a 1-year lagged effect of HCBS policies. Analytical model of lagged effect of HCBS availability and generosity on unmet needs can be seen on Figure 3.1. This analytical model was set up to establish a time order between and determine the lagged association between unmet needs and HCBS availability and generosity. To explore the lagged association between the two indicators, I used the policy environment of states from year t and unmet needs from year t + 1.

Descriptive summary tables were prepared of frequencies of outcome variables; by state level policy variables such as availability and generosity; and by individual level variables such as sociodemographic characteristics, severity of illness, impairment characteristics and end of life indicators. Then I analyzed the bivariate associations with the independent t-test for continuous variables and the chi-square test for binary and categorical variables to compare sample characteristics and prevalence rates of unmet needs accounting for NHATS complex survey design (Montaquila et al., 2012). I set the weights using *pweight* commend and run the analysis using the *svy subpopulation* code.

All analyses considered the sample weights and sample design variables available in NHATS to generate weighted, nationally representative estimates, and 95% confidence intervals (CIs). Sample weights and design variables were provided to users at each round for each cohort (Freedman and Kasper, 2019), but NHATS does not include state weights available since NHATS is not designed to be representative at the state level (Freedman et al., 2020). Use of survey weights for multilevel analysis nested under states required complex survey data analysis, which means scaling design weights and fitting the multilevel models using scaled-weighted data (Carle, 2009). Following the guidance of Carle (2009), I scaled the weights based on the entire sample of individuals with weights, which achieves nearly identical weighted results across the fixed and random effects (Asparouhov, 2006). To scale the weighted data, I created new weights that sums to the effective cluster size.

The final step in the analysis was the construction of a hierarchical multivariate logistic regression model for the dependent variables of unmet needs at the end of life as a function of state-level policy domains and individual level variables. The models accounted for the two-level hierarchical structure of the data, with individuals (level 1) nested within states (level 2). This approach allowed for the decomposition of the variance in the dependent variable into individual level (t + 1) and state level variance in policy domains (t). All variables were entered simultaneously in the hierarchical multivariate logistic regression models using the following equation:

Level 1:

$$\text{Unmet Needs}_{ij(t+1)} = p_{oj} + p_{1j}\ \text{Individual level covariates}_{ij(t)} + e_{ij}$$

Level 2:

$$p_{oj} = g_{oo} + g_{o1}\ \text{State level covariates}_{ijt} + r_{oj}$$

$$p_{1j} = g_{10} + g_{11}\ \text{State level covariates}_{ijt} + r_{1j}$$

Where,

Unmet Needs EOL $_{ij}$ = Dependent outcome variable for older adult i in state j

Individual level covariates $_{ij}$ = Individual level socio-demographic and health indicators

State level covariates $_{ij}$ = State policy indicators for availability and generosity for state 1915(c) waivers

p_{oj} = The slope of the intercepts varying across states

p_{1j} = The slope for each covariate across states

t = Time in terms of the year

g_{jo} = Group mean

g_{j1} = Between-group regression coefficient

r_{oj} and r_{1j} = Residual error

All the analyses were conducted using the STATA 16 software program.

Sensitivity Analysis

After completing the primary analysis, two sensitivity analyses were conducted to account for decisions about the measures. As a part of the first sensitivity analysis, I controlled for the alternative cut points of the mean rather than the median level for the state policy measures. Sensitivity analysis of the weighted bivariate analysis of unmet need measures that used mean scores as the threshold values to create dichotomous variables for state level factors provided similar results with the current analysis. Therefore, I kept using median threshold in the rest of the analysis.

With the second sensitivity analysis, I also conducted additional sensitivity analysis using the same measures for the sample including the states that do not have any 1915(c) waivers (n=18). I repeated all analyses to compare the findings between states with and without 1915(c) waivers. In this analysis, I defined all state level policy variables as zero for the states without any 1915(c) waivers. Unmet needs showed similar patterns in both samples by sociodemographic characteristics, severity of illness and impairment characteristics, end of life indicators and state policies on HCBS in both bivariate analysis and multilevel models. The results have not changed therefore I limited sample only states with 1915(c) waivers.

Results

Table 3.1 presents the weighted prevalence of the sample for full demographic characteristics and patterns in unmet need for self-care and mobility activities. Total sample description showed that most of the sample is female (58.51%), living alone (73.71%) and non-Hispanic white (52.17%). Their age at death varied between 65 to greater than 90, with the majority group being in the 80-84 age category group (21.53%). 18.54% of the sample had dementia and on average the sample had 2.49 chronic diseases. Most of the sample were not on hospice when they died (60.42%). The place of death was mostly hospital (40.33%), followed by home (39.53%) and nursing facility/hospice (20.13%) (Table 3.1).

<Insert Table 3. 1 here >

Unmet Needs in Total Sample and by States

In this sample, 40.26% had any unmet need, composed of 22.39% who had any unmet need with self-care and 28.98% had any unmet need with mobility (Table 3.2). On the other hand, 59.74% of the sample had no unmet needs during the last month of their lives. Among self-care activities, eating (11.53%) and toilet use (11.53%) had the highest prevalence of unmet need, and among mobility activities, unmet need with getting in/out of bed had the highest prevalence (16.45%).

<Insert Table 3.2 here >

Unmet Needs by Sociodemographic, Health and End-of-Life Indicators

Results of the bivariate analysis of unmet needs with self-care and mobility activities (Table 3.1) can be seen above. Bivariate analysis showed that level of unmet need with self-care and mobility activities was significantly associated with dementia status and chronic diseases (Table 3.1). Older adults with dementia (p-value=0.021) and older adults with higher number of chronic diseases (p-value=0.013) were found to have more likelihood of having any unmet need during the last month of their lives.

Unmet Needs by Generosity and Availability of State HCBS

Table 3.3 indicates the availability and generosity of HCBS in this sample. Less than a quarter of the sample lived in a state where a waiver targeting only older adults existed (23.71%), while more than three quarters lived in a state with participant direction (78.69%). Sample mean for available waivers in a state was 3.38, with a range of 0 to 8 and the mean number of available services for the current sample was high, 9.62, with a range of 0 and 13. Generosity of HCBS showed variation by type of services. 48.03% of the sample lived in a state with generosity for homemaker services that was higher than national median; 57.37% of the sample were in a state with generosity for homemaker services higher than national median; and 61.53% of the sample were in a state with generosity for adult day services higher than national median.

<Insert Table 3.3 here >

Weighted bivariate analysis of summary unmet need measures by state level factors can be seen in Table 3.4. Bivariate analysis did not provide statistically significant results in this sample by state level HCBS factors.

<Insert Table 3.4 here >

Regression Results

The results of the multilevel models of unmet need for assistance summary measures can be seen in Table 3.5. Multilevel models showed that having a participant direction option available was found to be associated with significantly less risk for unmet needs at the end of life (β=-0.69, p-value=0.010), as well as more generosity for homemaker services (β=-0.46, p-value=0.050). It was also found that being in the age groups of 75-79 (β=1.00, p-value=0.022) and 85-89 age group (β=0.81, p-value=0.038), were associated with higher levels of unmet need for assistance for self-care and mobility activities compared to being in the 65-74 age group. Additionally, having more than 2 chronic diseases was found to be associated with higher risk for having any unmet need for assistance during the last month of life compared to having 0 or 1 chronic diseases (β=0.71, p-value=0.017). Having a dementia diagnosis was found to be on the margins of significance for higher risk for having any unmet needs at the end of life (β=0.48, p-value=0.090).

<Insert Table 3.5 here >

Discussion

This study aimed to examine whether state variation in HCBS availability and generosity could be associated with unmet needs experienced by economically vulnerable community-dwelling older adults at the end of life. Almost half of the dual eligible Medicare/Medicaid receiving older adults experienced any unmet need at the end of life (40.26%), with 22.39% having any unmet need with self-care, and 28.98% having any unmet need with mobility. Contrary to the findings of Komisar and colleagues (2005) who found 58% of dual-eligible older adults had unmet needs for personal care needs, lower rates of unmet needs were found at the end of life. The difference of the findings of this study from the previous literature may be due to the exclusive focus of this study on end of life. Community-dwelling older adults at the end of life may be unique because when there is a lack of care or higher levels of care are needed closer to the end of life, older adults may be moved to care. When the supportive care resources are not available in home or community, dual-eligible older adults may have to move to nursing facilities closer to the end of their lives because Medicaid covers institutional care when there is a need for nursing home level of care. Therefore, one can assume that the sample of community-dwelling older adults at the end of life could be the individuals who already had access to care to help them stay in their home and community.

Lower risks for unmet needs experienced at the end of life were found to be associated with certain availability of the HCBS pathways, such as participant direction option. Older adults who died in states where participant direction was available tended to have fewer risk for having any unmet needs for assistance during the last month of life. These findings were consistent with the previous research showing that having a participant direction option to direct support and services decreases unmet needs among adults with significant intellectual and developmental disabilities (Gross et al, 2013) and among people with intellectual and developmental disabilities (Heller et al., 2012). HCBS waiver literature showed that having an option of hiring family or friends for personal care can be more reliable and flexible than agency workers and they can be more sensitive to the consumers' needs (San Antonio et al., 2006; Friedman & Rizzolo, 2016). They also showed that hiring family members via participant direction may create less embarrassment for intimate needs like toileting (San Antonio et al., 2006). Although this study did not check for policies on hiring family members specifically, participant direction still indicates older adults' ability to hire and manage their own caregivers. Care needs at the end of life can also be very intimate, hence participant direction is a critical resource to address this time of life.

The results of this paper demonstrated that state generosity for homemaker services can support self-care and mobility care needs of economically vulnerable community dwelling older adults during the last month of their lives. Homemaker services may include assistance with light housekeeping, meals preparation, companion, and personal care. The findings showed that states that were more generous to provide these services were doing better at targeting care needs of Medicaid/Medicare receiving dual eligible older adults during the last month of life. This was similar to the previous findings on HCBS generosity and how it improves health outcomes among older adults. These findings added to this previous literature by showing how it also may be a resource to support care needs for assistance with self-care and mobility activities. These results cast a new light on association between state HCBS policies and unmet needs experienced at the end of life. The results of the analysis on state level policies on availability and generosity of HCBS waivers found clear support that HCBS waivers can be important resources for support with assistance for self-care and mobility limitations at the end of life.

Informed by previous research on unmet needs, this study also explored various factors that may be associated with the level of unmet needs at the end of life, such as sociodemographic characteristics, severity of illness and impairment and end of life indicators. Certain health and demographic factors were associated with higher levels of unmet need, such as older age, dementia diagnosis and chronic diseases. Therefore, states can consider tailoring heir services for older adults who are older, with dementia or with more numbers of chronic diseases given their higher risk for unmet needs.

Implications for Policy and Practice

HCBS are not readily recognized to be a resource for end-of-life care. The findings of this paper suggest several important reasons that HCBS policies may contribute to improved end of life outcomes. First, the findings provide evidence to help improve the policy pathways for 1915(c) HCBS waivers that better support the care needs for assistance with self-care and mobility activities of the growing population of high-need older adults at the end of life. The policy pathways that needed to be strengthened to better support economically vulnerable community dwelling older adults were participant direction and homemaker. States may tailor these services to better meet care needs of the older adults living at home through death.

The findings also showed that economically vulnerable community-dwelling older adults with dementia may significantly benefit from HCBS at the end of their lives. Tailored services and support for older adults with dementia who want to stay in their homes and community can be a vital support to meet care needs for assistance with self-care and mobility activities. Such specialized HCBS specifically designed for economically vulnerable older adults with dementia could help them stay home while their care needs are met.

Limitations

While this paper had important findings, results should be interpreted considering several limitations. A limitation of this study was the time frame of the analysis. Information on HCBS policies was derived from data for 2011 and 2015, while the NHATS data covered the years between 2012 and 2017, so there was an overlapping period preventing causal analyses. This lagged approach aimed to cover this limitation but some of the policies put in effect may not have had adequate time to impact care needs at the end of life. Second, although this study tried to account for all confounders based on the previous research, there still may be other confounders that were not included in the analysis.

Another limitation of this study was the measure of generosity. Although this paper improved the previous measurement of generosity (expenditures) by using ratios of average expenditures per user to the hourly rate of state mean expenditures for services, this measure could not account for quality of care, as states do not obtain these data. Future research should consider ways to include quality of care in the operationalization of generosity. Potential proxy measures might include the level of training of the workforce and turnover.

Use of aggregated data to measure 1915(c) HCBS waivers was another limitation. 1915(c) waivers were operationalized on the state level, not on the individual level. Therefore, it was possible to identify the economically vulnerable older adults who were utilizing the 1915(c) waivers and who were not. Due to this limitation, I could not identify the waiver users who benefitted from these services with their self-care and mobility activities.

Last but not least, the use of proxy responses to measure care received during the last month of life was a limitation. This paper utilized the last month of life dataset composed of responses by a proxy respondent, typically a family member describing the decedent's end-of-life experience. Although the use of proxy response is a common approach for assessing end of life care where self-reports are not possible, issues with response validity and accuracy among proxies can present challenges (Fowler et al., 1999). Proxy responses can be biased due to the fear of being stigmatized or marginalized (Tourangeau & Yan, 2007). Feelings of social desirability may be especially common among caregivers of people with dementia as reflection on their caregiving practices (Bou Malham & Saucier, 2016; Sadak et al., 2017) due to strong cultural norms particularly around caregiving (Sadak et al., 2018). To avoid response distortion by social desirability bias that can threaten the validity of measures (Bou Malham & Saucier, 2016), questions that detail the measures as much as possible are preferred in this study (Lietz, 2010). However, due to the unique nature of end of life, proxy respondents are currently the only ways to measure end of life experiences of older adults on the experience of dying.

Conclusion

In this study, I examined the patterns of unmet care needs experienced by economically vulnerable community-dwelling older adults at the end of life and explored whether there is any association between state variation in the availability and generosity of HCBS waivers and unmet care needs experienced by older adults during the last month of their lives. Results demonstrated that having unmet needs with self-care and mobility activities were a common experience for older adults at the end of life. Older age, dementia diagnosis and not receiving hospice were found to be associated with higher levels of unmet needs. The findings of study showed that there was a between state variation in levels of unmet needs experienced at the end of life. State policies also showed certain patterns in a way that availability and generosity of HCBS waivers may protect older adults from having higher levels of unmet needs with self-care and mobility activities at the end of life, like participant direction option and generosity of services like homemaker and adult day.

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Table 3.1

Weighted Description and the Bivariate Analysis Between Unmet Need for Assistance with Self-Care and Mobility Activities and Sociodemographic Characteristics, Severity of Illness and Impairment and End of Life Indicators

	Total sample	Unmet Needs	No Unmet Needs	p-value [a]
	N = 315	N = 130	N = 185	
Sociodemographic characteristics				
Age groups (%)				0.476
65-74	34.22	30.55	36.69	
75-79	12.90	15.18	11.37	
80-84	21.53	20.41	22.28	
85-89	16.71	21.19	13.70	
90+	14.64	12.67	15.96	
Gender (%)				0.059
Female	58.51	66.75	52.96	
Male	41.49	33.25	47.04	
Marital Status (%)				0.788
Living together	26.29	25.19	27.03	
Living alone	73.71	74.81	72.97	
Race/Ethnicity (%)				0.454
White, Non-Hispanic	52.17	50.44	53.35	
Black, Non-Hispanic	24.74	22.32	26.41	
Hispanic/Other	23.09	27.24	20.24	
Dementia status (%)				0.021
No dementia	81.46	74.46	86.14	
Dementia	18.54	25.54	13.86	
Chronic Disease status (%)				0.013
0/1 chronic diseases	22.63	14.13	28.37	
2 + chronic diseases	77.37	85.87	71.63	
Hospice use (%)				0.307
No hospice	60.42	64.81	57.47	
Hospice	39.58	35.19	42.53	
Place of death				0.143
Home	39.53	36.36	41.66	
Hospital	40.33	48.33	34.96	
Nursing Facility/Hospice	20.13	15.31	23.37	

Notes: All the results are weighted using the appropriate year weights. [a] P values represent the results of the chi-squared test for the null hypothesis of no difference in the unmet need for assistance by sociodemographic characteristics, severity of illness and impairment characteristics and end of life indictors.

Table 3.2

Weighted Prevalence of Unmet need for Assistance with Self-care and Mobility Activities

	Prevalence
Self-Care Activities	
Unmet Need with Eating (%)	11.53
Unmet Need with Dressing (%)	9.71
Unmet Need with Bathing (%)	6.07
Unmet Need with Toilet Use (%)	11.53
Any Unmet Need with Self Care (%)	22.39
Mobility Activities	
Unmet Need with Getting in/out of bed (%)	16.45
Unmet Need with Moving inside (%)	13.74
Unmet Need with Going outside (%)	6.5
Any Unmet Need with mobility (%)	28.98
Summary measures	
No unmet needs (%)	59.74
Any Unmet Need (%)	40.26

Notes: All the results are weighted using the appropriate year weights.

Table 3.3.

Weighted Sample Characteristics for State-Level Factors of Generosity and Availability of the Home and Community-Based Services

	Prevalence
Generosity	
Homemaker - More than median (%)	48.03
Home Health - More than median (%)	57.37
Adult Day - More than median (%)	61.53
Availability	
Only older adult waivers (%)	23.71
Participant direction (%)	78.69
Available slots more than median (%)	51.24
Number of waivers (mean, range)	3.38; [0 - 8]
Number of services (mean, range)	9.62; [0 - 13]

Table 3.4.

Weighted Bivariate Analysis Between State Level Factors and Unmet Needs

State-level factors	Any Unmet need (%)	p-value [a]
Only older adult waivers		
Available	40.09	0.977
Not available	40.31	
Participant direction		
Available	37.7	0.172
Not available	49.71	
Available slots		
% slots more than median	42.37	0.540
% slots less than median	38.04	
Number of waivers		
# of waivers more than median	43.38	0.588
# of waivers less than median	39.12	
Number of services		
# of services more than median	39.24	0.832
# of services less than median	40.79	
Generosity for Homemaker		
More than Median	35.44	0.154
Less than Median	45.47	
Generosity for Home Health		
More than Median	41.05	0.796
Less than Median	39.2	
Generosity for Adult Day		
More than Median	39.07	0.673
Less than Median	42.16	

Notes: All the results are weighted using the appropriate year weights. [a] P values represent the results of the bivariate analysis for the null hypothesis of no difference in unmet needs by state level policies on HCBS.

Table 3.5.

Weighted Multilevel Models of Unmet Need for Assistance Summary Measure

	Level of Unmet Need for Assistance		
	Coef.	[95% C.I.]	p-value
Sociodemographic characteristics			
Age groups [a]			
75-79	1.00	[0.14 – 1.87]	0.022
80-84	0.31	[-0.54 – 1.16]	0.471
85-89	0.81	[0.05 – 1.57]	0.038
90+	-0.06	[-0.65 – 0.53]	0.838
Female [b]	0.62	[-0.15 – 1.38]	0.113
Married/Living together [c]	0.09	[-0.82 – 1.00]	0.843
Race/Ethnicity [d]			
Black, Non-Hispanic	-0.23	[-0.98 – 0.52]	0.554
Hispanic/Other	0.23	[-0.55 – 1.01]	0.565
Severity of illness and impairment			
Dementia [e]	0.48	[-0.07 – 1.03]	0.090
Has more than 2 chronic diseases [f]	0.71	[0.13 – 1.30]	0.017
End of life indicators			
Received Hospice [g]	-0.19	[-0.96 – 0.58]	0.627
Place of death [h]			
Hospital	0.57	[-0.19 – 1.33]	0.142
Nursing Facility/Hospice	-0.15	[-1.20 – 0.91]	0.784
State-level factors			
Availability			
Has waiver for only older adults [i]	-0.07	[-0.98 – 0.84]	0.883
Has participant direction [j]	-0.69	[-1.23 - -0.17]	0.010
Available slots [k]	0.35	[-0.19 – 0.90]	0.211
# of services more than median [l]	-0.30	[-1.29 – 0.69]	0.550
# of waivers more than median [m]	0.26	[-0.58 – 1.11]	0.544
Generosity			
Homemaker spending > median [n]	-0.46	[-0.93 - -0.00]	0.050
Home health spending > median [n]	0.36	[-0.33 – 1.05]	0.307
Adult Day spending > median [n]	-0.27	[-0.85 – 0.31]	0.361
Constant	-1.29	[-2.36 - -0.21]	0.019

Notes: [a] Reference age group is age group 65-74. [b] Referent category is male. [c] Married/Living together includes married and living with a partner. The referent category is not living together and includes separated, divorced, widowed, and never married. [d] Referent category is non-Hispanic White. [e] Referent category is not having dementia diagnosis. [f] Referent category is having 0 or 1 chronic diseases. [g] Referent category is those who did not received hospice during the last month of life. [h] Referent category is home death. [I] Referent category is living in a state without any waivers designed for only older adults. [j] Referent category is living in a state without participant direction policy option. [k] Referent category is living in a state with less than median slots. [l] Referent category is states with available services less than median. [m] Referent category is states with available number of waivers less than median. [n] Referent category for all expenditure variables is living in a state with spending less than median.

Figure 3. 1. Analytical Model of Lagged Effect of HCBS Availability and Generosity on Unmet Needs

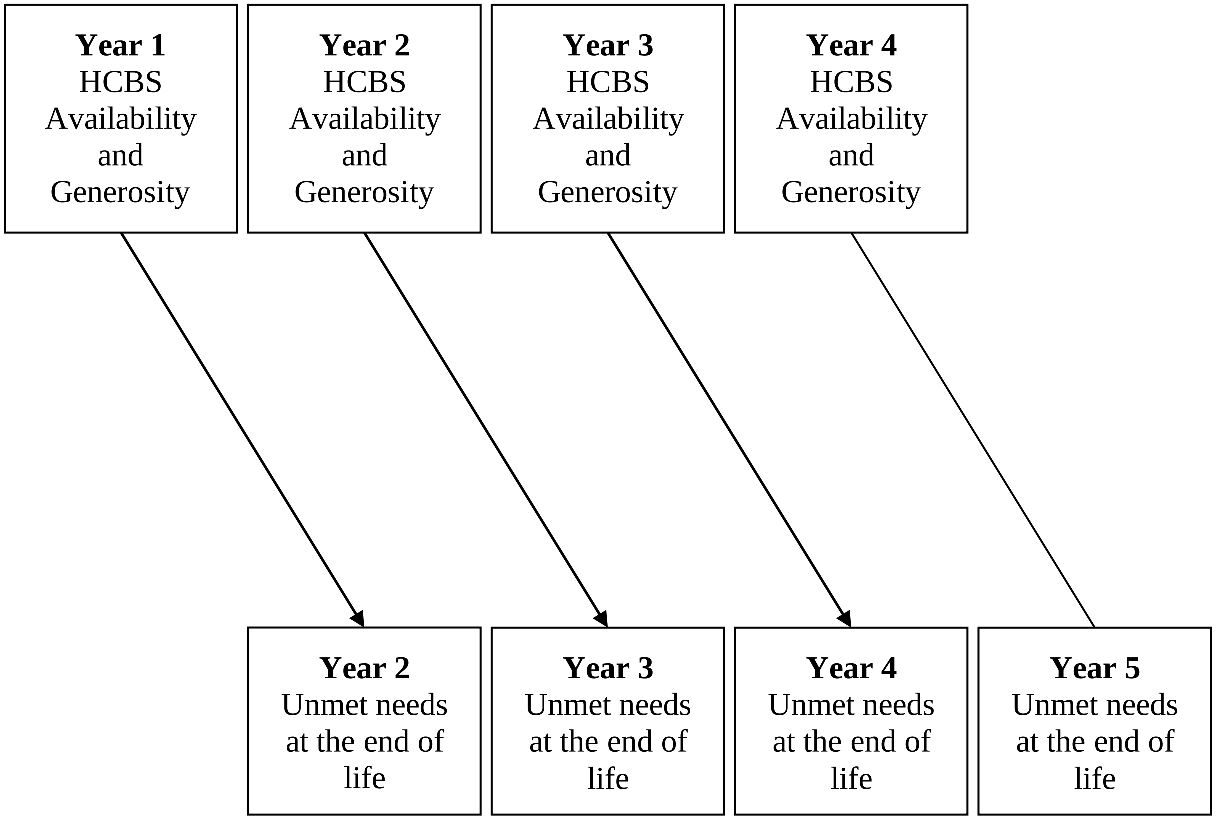
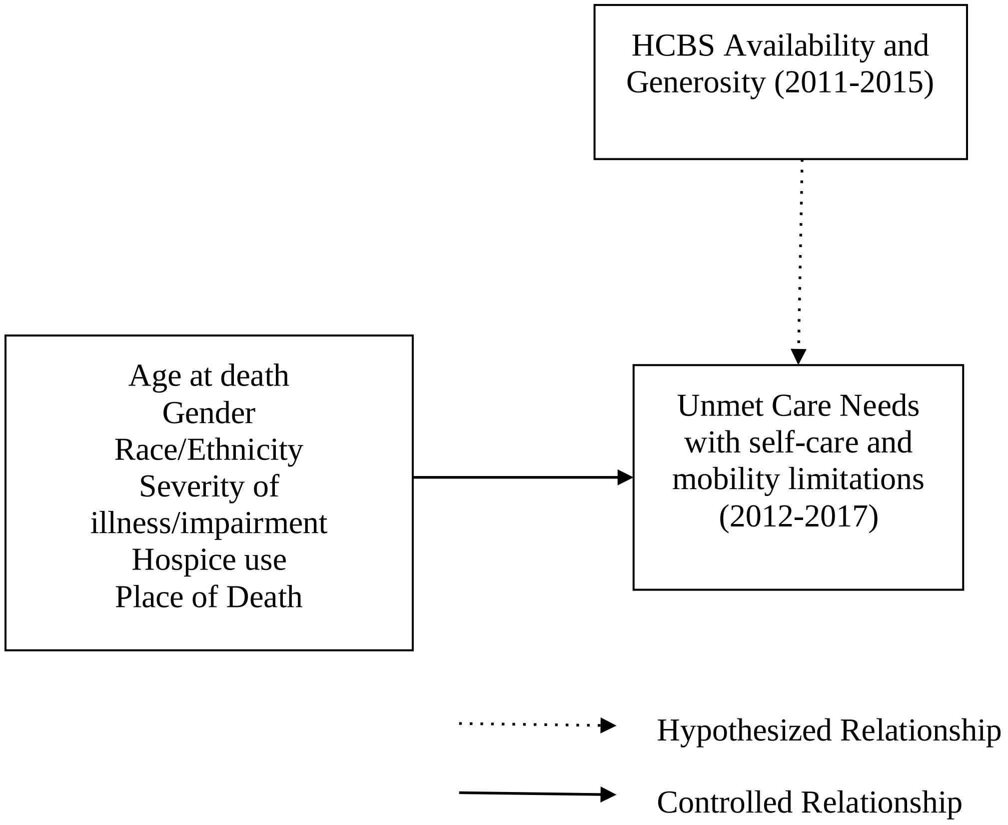


Figure 3. 2. Conceptual Model



CHAPTER 4

QUALITY OF END OF LIFE OF ECONOMICALLY VULNERABLE OLDER AMERICANS: EFFECTS OF HOME AND COMMUNITY-BASED SERVICES

Abstract

Although dying at home is preferred by most older adults, older adults may end up moving to institutional care facilities or being hospitalized due to decreased functioning and intense symptom severity near the end of life. Quality of end of life among older adults is often assessed by level of symptom burden (pain, breathing troubles and depression/anxiety) and the ability to maintain functioning (being alert and being able to get out of bed) as much as possible. Medicaid 1915(c) waivers provide home and community-based services (HCBS) that may be critical for older adults to achieve death at home. However, states vary in the availability and generosity of the services they provide which may affect the quality of end of life experienced among community-dwelling dual eligible older adults.

Aims: This paper examined quality of end of life among community dwelling older adults, and the association between quality of end of life and state variation in the availability and generosity of 1915(c) waivers.

Methods: Utilizing the National Health and Aging Trends Study; this paper estimated frequencies of outcome variables, ran bivariate analysis by sample characteristics and state policies and used hierarchical multivariate logistic and linear regression models to assess the effects of state-level policy domains and individual level variables on quality of end of life.

Results: 43.93% had a high quality of end of life, with a mean score of 2.25

between the ranges of 0 and 5. Functioning score was 1.02 between the range of 0 and 2, and symptom control was 1.23 between the range of 0 and 3. Living alone, being non-Hispanic White, higher numbers of chronic diseases, receiving hospice and moving to nursing facilities during the last month of life were associated with low quality of end of life. Higher numbers of available slots for the 1915(c) waivers were found to be linked to higher quality of end of life.

Discussion: Compared to the previous research with Medicare only older adults, this study found similar patterns in symptoms, but lower functioning levels among Medicaid-Medicare dual eligible older adults. Findings also demonstrated higher levels of symptoms and low functioning at the end of life is associated with older adults moving to a nursing facility during the last month of life.

Keywords: home and community-based services, 1915(c) waivers, dual eligible older adults, quality of end of life, symptoms, functioning

CHAPTER 4

QUALITY OF END OF LIFE OF ECONOMICALLY VULNERABLE OLDER AMERICANS: EFFECTS OF HOME AND COMMUNITY-BASED SERVICES

Introduction

Quality of end of life is often addressed by minimizing symptom burden and maintaining functioning as much as possible (Lee et al., 2020). According to the framework developed by the Institute of Medicine, death is not strictly a medical event, and the end-of-life is a time period marked with low functioning and high symptom severity. Approximately 80% of older adults were found to have low quality of life during the last month of their life which refers to not being alert, not being able to get out of bed, and symptoms like pain, breathing troubles and depression/anxiety (Lee et al., 2020).

Many older adults at the end-of-life experience difficulties in functioning, such as not being alert and not being able to get out of bed. A recent study found that 9% were not alert and 29% were not able to get out of bed during the last month of life (Lee et al., 2020). Not being alert is one of the most prevalent and critical cognitive problems that can impede communication and independence (Stewart et al., 1999). Decreased alertness during the end of life may also create adverse consequences such as problems with self-care (feeding, toileting, etc.) and decreasing the patient's ability to report and describe symptoms and side effects of interventions (Kehl & Kowalkowski, 2012; Lynch, 2013). Being confined to bed is also a common difficulty experienced at the end of life. Due to increased weakness and fatigue, older adults may end up spending most of their time in bed and feeling unable to leave bed without any help (Lynch, 2013).

Symptom severity is another common experience at the end of life and intensifies sharply in the 2 months before death (Murtagh et al., 2011). Among people who died and who were identified as receiving “too little” care, the predominant concern was inadequate symptom management (Teno et al., 2021). The most reported symptoms at the end of life are pain, breathing troubles and sadness/depression (Singer et al., 2016; Hasegawa et al., 2021; Doorenbos et al., 2006; Kutner et al., 2001). Between the years 2011-2013, 67% of community-dwelling older adults had pain (25.2% had unmet care with pain), 55.8% had anxiety/sadness (55.8%% with unmet need) and 56.2% had breathing trouble (21.4% with unmet need) during the last month of their life (Teno et al., 2015). Compared to symptoms experienced at the end of life in 2000, unmet needs for care with pain and anxiety/sadness were higher in 2011, which suggests that quality of end-of-life care may not have improved but rather may have worsened over a decade (Teno et al., 2015). A more recent study on community dwelling older adults has found that 29% of older adults had no pain, 45% had no trouble breathing and 43% had no anxiety/sadness during the last month of life (Lee et al., 2020).

In the United States (US), both palliative and hospice care services are designed to address decreased functioning and higher symptom severity, especially closer to the end of life, however both services remain underused. Access to palliative care is variable and often limited, especially in the outpatient setting (Donlon et al., 2018; Meier, 2011). Also, palliative care knowledge is generally low and less common among older ages (Boakye et al., 2020). Consequently, many patients who could benefit from palliative care services either receive them too late in their illness or do not receive them at all

(Kozlov et al., 2015; Gidwani et al., 2016). Hospice is more commonly used among people at the end of life, yet only 45% of people who died in the US were receiving hospice services at the time of death (Keegan & Drick, 2011; NHPCO, 2013), and within this population, the median duration of services is estimated to be only 24 days (NHPCO, 2018), with one-third of hospice patients with lengths of stays of less than a week (NHPCO, 2018). This underutilization of hospice may be due to late referrals to hospice (Diamond et al., 2015; Rickerson et al., 2005) or strict eligibility criteria of the Medicare hospice program such as having a prognosis of less than 6 months, agreement with ending treatment and life-sustaining interventions, or due to the stigma associated with the end-of-life care. Even for those who are on hospice, hospice services can be highly limited (Cagle et al., 2020; Muramatsu et al., 2008) and there is a wide range of quality of care that is provided depending on the hospice's profit status, size and rural/urban location (Anhang Price et al., 2020).

Although dying at home is preferred by most older adults (Khan et al., 2014; Gomes et al., 2013; Higginson & Sen-Gupta, 2000; Ratner et al., 2001; Arnold et al., 2015). Hospice services are the primary national policy available to support this goal, yet hospice does not provide in-home caregiving so, home death may not be possible without the addition of other resources, such as homemaker or personal care services (Burge et al., 2015). Due to decreased functioning and intense symptom severity, older adults may experience a decline in their preference for home death closer to death (Higginson & Sen-Gupta, 2000). For instance, older adults who experience uncontrolled pain at the end of their lives might prefer to die in a hospital where pain can be medically managed (Pollock, 2015). As a result, despite the recent rise in home deaths in the US (Lei et al., 2021; Teno et al., 2018), most older adults still die in institutions like hospitals and nursing facilities (Cross & Warraich, 2019).

Many older adults who cannot stay at home enter nursing homes. Recent trends indicate that the length of stay in nursing facilities is declining - most nursing home residents stay for fewer than 3 months (Fox-Grage, 2017). Older adults enter nursing facilities older (CMS, 2015), with higher levels of care needs (Gomez-Batiste et al., 2014) and closer to death (Currow & Hegarty, 2006). These trends suggest that older adults' use of nursing facilities for end-of-life care has a similar pattern to late use of hospice care. However, the quality of care in nursing facilities at the end-of-life has been shown to be remain limited to provide a comprehensive care (Andersson et al., 2017; Di Giulio et al., 2008) and most nursing facility residents suffer from uncontrolled symptoms (Fleming et al., 2017; Mitchell et al., 2009; Teno et al., 2004). Nursing facility care, on average, represents the most expensive type of long-term care (Konetzka et al., 2020) and is largely financed through Medicaid.

Medicaid, a means-tested, needs-based social welfare program, reaches high-cost, high need economically vulnerable older adults (Favreault & Dey, 2015) and pays for long-term care in two settings: institutional settings and home-and community-based services (HCBS) (Ng et al., 2011). Medicaid HCBS commonly provide assistance that is critical to staying home, including but not limited to services that can help with symptoms like nursing and home health; with housework like chore and homemaker; with daily activities like personal care; with supporting caregivers like respite; and with safety at home like assistive technology, environmental adaptations, specialized medical equipment and personal emergency response system[11] . HCBS are more affordable than nursing home care (Genworth Financial, 2016). Therefore, HCBS are alternatives to nursing facilities through the support they provide to economically vulnerable older adults at the end of their lives. However, states vary in terms of the availability and generosity of HCBS which may result in disparities in the quality of end of life experienced based on the state in which they reside.

States use three authorities to provide HCBS through Medicaid, namely mandatory state plan benefits, optional state plan amendments, and optional 1915(c) HCBS waivers, which represent the majority of HCBS expenditures (Eiken et al., 2017). 1915(c) waivers, developed at the discretion of the states, are one of the primary sources of variation between the states in terms of HCBS. States vary in their expenditures on HCBS (Musumeci, 2019), available services (Friedman et al., 2019), coverage for target groups (e.g., older adults, individuals with brain injury, etc) (Musumeci, 2019), service slots available (Miller & Kirk, 2016) and ability for participants to direct their own care (Ng, Stone and Harrington, 2015). State HCBS generosity lowers the risk of end-of-life nursing home relocation (Muramatsu et al., 2008), but little is currently known about the effects of these waivers on the quality of end of life.

Medicare-Medicaid recipients (commonly known as dual-eligible individuals) are known to have a high prevalence of multiple chronic conditions (Boersma et al., 2020). Care and support services in place can be critical at older ages due to extended periods of physical and functional decline, increasing symptoms and low functioning

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[11] Although HCBS 1915(c) waiver do not provide palliative care services among their services yet, Texas defines palliative care services in the context of its home and community-based services regulations (Donlon, Purington, and Williams, 2018).

experienced until the end of life (Komisar & Feder, 2011; Eiken et al., 2017). This study investigated the association between HCBS availability and generosity and quality of end of life among economically vulnerable older adults. This paper is guided by two research questions: (1) To what extent do economically vulnerable community-dwelling dual-eligible older adults experience a lower quality of end of life? (2) Is state variation in availability and generosity of HCBS services associated with quality at the end of life?

Methods

Data

This paper used the National Health and Aging Trends Study (NHATS) (Wave 2-7, 2012-2017); (a) Public data, (b) Restricted data to identify the geography-state variable for each individual, and (c) the Last Month of Life review data to examine the proxy responses about the last month of life of the older adult. The NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG032947). NHATS was designed to follow nationally representative cohorts of persons ages 65 and older and enrolled in Medicare, with an oversampling of non-Hispanic Blacks and those aged 85 and older. NHATS participants were administered annual, in-person interviews designed to collect detailed information on the aging process and its consequences. The Last Month of Life data includes interviews conducted with proxies, who were preferably a family member, but where a family member could not be identified, were facility staff (Kasper, & Freedman, 2020).

Study Cohort

The analytic sample is limited to deceased older adults who were dual eligible for Medicaid and Medicare and living in the community or group living arrangement during the last wave before they deceased [12]. The sample excluded those (1) who were alive, and (2) who were residing in various types of nursing homes, (3) who were not Medicaid recipients, and (4) lived in a state where 1915(c) waivers are not available. The original sample was 19,530, and after excluding participants who were alive (n= 16,088), died before 2012 or after 2017 (n=771), not a Medicaid recipient (n=2,197), residing in nursing homes during the last wave the participant attended the survey before they died (n=134), had missing data in the outcome variables (n=25), or lived in a state without 1915(c) waivers (n=18) the final sample size was 309.

Measures

The main outcome of this study was a summary measure of quality of end of life composed of two subcategories of functional and symptom status, which was developed by Lee et all, 2020. This measure broadens our understanding of how older persons function before dying and whether there were certain patterns of end of life (EOL) daily experiences in this older population.

EOL Functional Status. Functional status at the end of life was measured as whether the deceased (a) was alert during the last month of life and (b) was able to get out of bed during the last month of life. Indicators of functional status used 4-point response categories from “always” to “never.” I dichotomized answers into “always” versus all other categories informed by previous studies analyzing the NHATS data (Lee et al., 2020; Sharma et al., 2017; Teno et al., 2015). Using the indicators of functional

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[12] We defined location of living until the last month of life. Therefore, even though I excluded the older adults living in nursing facilities, our sample still had older adults who died in nursing homes. This group of older adults represents those whose functioning or symptoms could not be controlled at home, so they needed to move to a nursing home during the last month of their life.

status, a count variable for EOL functional status was created ranging from 0 to 2 by counting “yes” responses to the two items.

EOL Symptom Status. Symptom status at the end of life was measured as whether the deceased older adult experienced any of three symptoms during the last month of life: (1) pain, (2) breathing troubles, and (3) anxiety/sadness (Lee et al., 2020). Indicators of symptom status used binary response categories including “yes” and “no.” Indicators of symptom status were kept as dichotomous variables and a count variable for EOL symptoms was created ranging from 0 to 3 by assessing “no" responses to the three items, which indicated better symptom status. EOL symptoms were used to measure as an indicator of good care (Lee et al., 2020).

Quality of End of Life. Quality of end of life (QEOL) was operationalized as functioning and symptom status (Lee et al., 2020; Teno et al., 2001). QEOL was identified as low when the deceased older adults experienced less functional status and worse symptom status during the last month of life. Summary measure for QEOL was created as a count variable ranging from 0 (low QEOL) to 5 (high QEOL) summing EOL functional status and EOL symptoms, including the variables namely whether the older adult was alert, able to get out of bed, had no pain, had no breathing troubles, and had no sadness/anxiety. Due to restricted dataset limitations, I could not use the continuous variable of QEOL, so I created the dichotomous measures of high quality of end of life for those with less than 2 symptoms or difficulties with scores 3-5 and low quality of end of life for those with 3 and more symptoms or functioning difficulties with scores 0-2 (Lee et al., 2020).

State Level Variables. Availability and generosity of HCBS were coded for each state based on the findings of a recent analysis of 1915(c) waivers for older adults between states (Ercin-Swearinger, et al., 2021).

Availability of state HCBS waivers was measured using indicators of types of services, target groups, available slots for waivers and participant direction. Availability of types of services was measured by utilizing the older adult waiver taxonomy designed by Friedman et al which was specifically tailored for HCBS 1915(c) older adult waivers (2019). Target groups [13] were measured as to whether they have a waiver specifically designed and targeted for older adults only. Available slots for waivers[14] were calculated for each state and standardized by the state's dual eligible population. Participant direction[15] was measured by whether states allowed participants to direct their own care.

Generosity of waivers was examined by average expenditure of states for various service types, such as homemaker, home health and adult day services. Generosity was measured for each state as the average Medicaid expenditure per users for service types for the years between 2011 and 2015 using MAX OT data set. Then this rate was standardized according to the median hourly rate for the types of services which was obtained from the Genworth State Cost of Care Survey 2013 separately for each state. This ratio of average expenditure by state-specific cost was used make hours of care

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[13] States can target different population groups like brain injury, technology dependent and HIV/AIDS, so that target groups are another source for variation between the states.

[14] States also have flexibility to decide the maximum number of unduplicated participants who are served in each year that the waiver is in effect.

[15] States can have participant direction option that offers enrollees the ability to determine which employees or vendors will be hired to deliver their services and provide supplies and additional support.

provided more comparable between the states.

The dichotomous variables were used as binary variables, such as availability of only older adult waivers and participant direction. The continuous state level variables were used as continuous measures after being standardized and also were coded into dichotomous measures. To create the dichotomous measures to be used in the bivariate analysis, first the frequency for each variable was checked, such as available slots, number of services and generosity scores. The data were strongly skewed to the left and therefore, dichotomous variables were created based on median values.

Covariates. Choice of covariates were informed by prior research on predictors of lower quality of end of life among older adults and their availability within the dataset. Individual-level covariates were as follows: Sociodemographic characteristics were age, grouped into 65-74, 75-79, 80-84, 85-89 and 90+; gender (Lee et al., 2020); and race/ethnicity (Sharma et al., 2017), grouped into White/Non-Hispanic, Black/Non-Hispanic, Hispanic/Other. Severity of illness and impairment was measured with dementia status and number of chronic diseases (including heart disease, arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer). Chronic diseases were commonly associated with increased symptom severity (Smith et al., 2010; Chaudhry et al., 2013; Singer et al., 2016). Also, dementia has been found to increase functioning and symptom challenges at the end of life (Pinzon et al., 2013; Hendriks et al., 2014). I also included several end-of-life indicators namely hospice use and place of death (home, hospital, nursing facility/hospice/other).

Statistical Analysis

This paper utilized 1-year lagged effect approach to examine the association between state level HCBS policy characteristics and quality of end-of-life indicators, due to an expected lag effect of any policy on the target population. Analytical model of lagged effect of HCBS availability and generosity on quality of end of life can be seen on Figure 4.1. This analytical model was based on a time order between the lagged association between quality of end of life and HCBS availability and generosity. To explore the lagged association between the two indicators, I used the policy environment of states from year t and quality of end of life from year t + 1.

Descriptive summary tables were prepared estimating frequencies of outcome variables by state level policy variables and by individual level variables. Then I analyzed the weighted bivariate associations with the independent t-test for continuous variables and the chi-square test for binary and categorical variables to compare sample characteristics and quality of end-of-life accounting for NHATS complex survey design (Montaquila et al., 2012). I set the weights using *pweight* commend and run the analysis using the *svy subpopulation* code.

All analyses considered the sample weights and sample design variables available in NHATS to generate weighted, nationally representative estimates, and 95% confidence intervals (CIs). Although NHATS provides sample weights and design variables at each round for each cohort (Freedman and Kasper, 2019), state weights are not available since NHATS is not designed to be representative at the state level (Freedman et al., 2020). Use of survey weights for multilevel analysis nested under states required complex survey data analysis, which means scaling design weights and fitting the multilevel models using scaled-weighted data (Carle, 2009). Following the guidance of Carle (2009), I scaled the weights based on the entire sample of individuals with weights, which achieves nearly identical weighted results across the fixed and random effects (Asparouhov, 2006). To scale the weighted data, I created new weights that sums to the effective cluster size.

The final step of the analysis was to construct hierarchical multivariate logistic regression models for the dependent variable of quality of end of life as a function of state-level policy domains and individual level variables. The models accounted for the two-level hierarchical structure of the data, with individuals (level 1) nested within states (level 2). This approach allowed for the decomposition of the variance in the dependent variable into individual level (t+1) and state level variance (t) in policy domains. All variables were entered simultaneously in the hierarchical multivariate logistic regression models. Figure 4.1 shows the analytical model of lagged effect of HCBS availability and generosity on quality of end of life. Here is the equation:

Level 1:

$QEOL_{ij(t+1)} = p_{0j} + p_{1j}$ Individual level covariates$_{ijt} + e_{ij}$

Level 2:

$p_{0j} = g_{00} + g_{01}$ State level covariates$_{ijt} + r_{0j}$

$p_{1j} = g_{10} + g_{11}$ State level covariates$_{ijt} + r_{1j}$

Where,

$QEOL_{ij}$ = Dependent quality of end of life outcome variable for older adult i in state j.

Individual level covariates $_{ij}$ = Individual level socio-demographic and health indicators

State level covariates $_{ij}$ = State level policy indicators for availability and generosity for state 1915(c) waivers

p_{0j} = The slope of the intercepts varying across states

p_{1j} = The slope for each covariate across states

t = Time in terms of the year

g_{j0} = Group mean

g_{j1} = Between-group regression coefficient

r_{0j} and r_{1j} = Residual error

All the analyses were conducted using the STATA 16 software program.

Sensitivity Analysis

As a part of this paper's analysis, two sensitivity analyses were also conducted to account for the decisions about the measures. As a part of the first sensitivity analysis, I controlled for the alternative cut points for the state policy measures to create dichotomous variables. As alternative cut points, I tried mean scores as the cut point to create the dichotomous policy measures instead of medians and reran the bivariate analysis using these new variables. None of the results have changed with this sensitivity analysis, therefore I continued using the median values as threshold values in all analysis.

With the second sensitivity analysis, I conducted further analysis using the sample without excluding the states that do not have any 1915(c) waivers to control for selection bias. I conducted sensitivity analysis by repeating all analyses without excluding participants who died in the states without any 1915(c) waivers to compare the findings with the sample that excluded the states without 1915(c) waivers. In this analysis, I defined all state level policy variables as zero for the states without any

1915(c) waivers. Results stayed very similar; therefore, I continued to use the sample as the older adults died in a state with 1915(c) waivers.

Post Hoc Analysis

After completing all analysis, I reexamined the multilevel models for functioning and symptom severity separately as a part of the post hoc analysis. The aim of this analysis was to examine whether any one of these indicators can be associated with HCBS policies that were not identified using the summary measure of quality of end of life.

Results

Table 4.1 presents the weighted prevalence of the sample for full demographic characteristics by patterns in high and low quality of end of life. The total sample description showed that the majority of the sample is female (58.98%), living alone (73.37%), and non-Hispanic whites (52.26%). Their age at death varied between 65 and above 90, with the majority group being in the 80-84 age category group (21.03%); 17.51% of the sample had dementia and 77.34% had more than 2 chronic diseases. Most of them were not on hospice when they died (61.12%). The place of death was mostly hospital (40.55%) which was followed by home (39.93%) and nursing facility/hospice (19.52%) (Table 4.1).

< Insert Table 4.1 >

Quality of End of Life in Total Sample and by States

In this sample, 43.93% had a high quality of end of life, with a mean score of 2.25 between the ranges of 0 and 5. When the indicators of quality of end of life were examined separately, the sample had medium functioning levels with a mean score of

1.02 between the range of 0 and 2, where 58.42% of the sample were alert and 43.47% were able to get out of the bed during the last month of their lives. On the other hand, the mean score for symptom control was 1.23 between the range of 0 and 3, where 30.16% of the sample had no pain, 49.3% had no sadness/anxiety and 43.35% had no breathing difficulties (Table 4.2).

< Insert Table 4.2 >

Quality of End of Life by Sociodemographic, Health and End-of-Life Indicators

Results of the bivariate analysis between the high and low quality of end-of-life and sociodemographic characteristics, severity of illness and impairment, and end of life indicators can be seen in Table 4.1. Bivariate analysis showed that the quality of end of life was significantly associated with marital status (p-value = 0.027), race/ethnicity (p-value = 0.016), and hospice use (p-value = 0.004). In terms of hospice use, 27.23% of older adults who had a high quality of end of life were using hospice compared to 48.01% of older adults with a low quality of end of life were on hospice.

Quality of End of Life by Generosity and Availability of State HCBS

Table 4.3 indicates the availability and generosity of HCBS in state states in which the sample participant resided. Less than a quarter of the sample lived in a state with a waiver targeting only older adults (23.29%), and more than three quarters lived in a state with participant direction (77.87%). The sample mean for the available number of waivers in a state was 3.39, with a range of 0 and 8. The mean number of available services for the current sample was high (9.59), within the range of 0 and 13. The generosity of the HCBS showed a variation by type of service. 51.17% of the sample lived in a state where spending for homemaker services was more than the national median; 58.16% of the sample lived in a state with a spending for home health more than national median; and 60.93% of the sample lived in a state with spending for adult day services was higher than national median.

< Insert Table 4.3 >

Weighted bivariate analysis of quality of end-of-life measures by state-level factors can be seen in Table 4.4. Overall quality of end-of-life measures did not differ significantly by state-level policy options.

< Insert Table 4.4 >

Regression Results

The results of the multilevel models of quality of end-of-life measure can be seen in Table 4.5. The multilevel model for the dichotomous high quality of end-of-life outcome showed that higher numbers of available slots for the 1915(c) waivers were also found to be linked to more older adults died with high quality of end of life (β= 0.57, p-value=0.037). The results also showed that race/ethnicity was associated with quality of end of life such that older adults with Hispanic or other ethnicities (β= 0.98, p-value=0.016) had higher qualities of end of life compared to non-Hispanic white older adults. Receiving hospice during the last month of life was associated with worse quality of end of life compared to older adults who did not receive hospice (β= -1.02, p-value=0.017). Also, marital status was found to be associated with quality of end of life, where the older adults who were married/living together had higher quality of end of life compared to the older adults who were living alone (β= 0.79, p-value=0.007).

< Insert Table 4.5 >

The results of the multilevel models for the quality of end-of-life indicators as a part of our post hoc analysis, namely functioning and being symptom-free also showed similar patterns for age groups and hospice (Appendix C - Table 1). Being symptom free during the last month of life was associated with receiving hospice (β= -1.27, p-value=0.001) and number of waivers (β= 0.62, p-value=0.045). Functioning was associated with being in age group of 80-84 (β= -1.08, p-value=0.014), being in Hispanic/Other race/ethnicity group (β= 0.91, p-value=0.044), having dementia (β= -1.07, p-value=0.020), dying in hospital (β= 0.85, p-value=0.042), and home health spending (β= -0.85, p-value=0.011).

Discussion

This study aimed to examine the patterns of quality of end of life which was measured as functioning and being symptom-free during the last month of life among economically vulnerable community-dwelling older adults and to explore whether there is any association between state variation in the availability and generosity of HCBS waivers and quality of end of life. In this sample, more than half of the sample had low quality of end of life, while only 43.93% had a high quality of end of life. Quality of end of life was found to be associated with certain sociodemographic and severity of illness and impairment categories, such as age status, marital status, number of chronic diseases, end of life indicators, such as place of death, hospice use as well as slots available in HCBS waivers and generosity for homemaker services.

This analysis found evidence that 43.93% of Medicare-Medicaid receiving community-dwelling older adults had a high quality of end of life during last month of their lives, with a mean score of 2.25 between the ranges of 0 and 5. A previous study conducted on the same topic among community dwelling older adults with a range of incomes found that the mean score for quality of end of life was 2.78 between the ranges 0-5 (Lee et al., 2020). A similar pattern of results was obtained in indicators of quality of life, such that this study found that the mean score for symptom control was 1.23 between the range of 0-3 compared to the previous research found the mean score for symptomatic domain was 1.13 between 0-3 (Lee et al., 2020). This sample had lower functioning levels with a mean score of 1.02 between the range of 0 and 2, while it was 1.59 between 0-2 in the previous study for community dwelling older adults (Lee et al., 2020).

These results suggest that the sample of Medicaid-Medicare dual eligible older adults may have a lower quality of end of life compared to the only Medicare eligible older adults during the last month of their lives. This result can be mostly attributed to the relatively lower functioning scores in the dual eligible sample, because this sample had a relatively higher symptom score. In the previous study 9% of the Medicare-only sample were not alert and 29% were not able to get out of bed (Lee et al., 2020), compared to 41.58% of dual eligible sample was not alert and 56.53% of them were not able to get out of the bed during the last month of life. On the other hand, 30.16% of the sample had no pain, 43.35% had no breathing difficulty and 49.3% had no sadness/anxiety in Medicaid-Medicare dual eligible sample, compared to 29% of older adults had no pain, 45% had no trouble breathing and 43% had no anxiety/sadness during the last month of life in the sample of Medicare-only older adults (Lee et al., 2020). Medicaid-Medicare dual-eligible sample had lower functioning, but similar symptoms the end of their lives.

The results on state policy characteristics demonstrated a link between availability of higher numbers of slots in the 1915(c) waivers and higher quality of end of life among Medicaid-Medicare receiving community dwelling older adults. States have flexibility to decide the maximum number of unduplicated participants who are served each year that the waiver is in effect, so states vary substantially in available slots (Miller & Kirk, 2016). By adjusting the total number of available slots in each state by the average number of Medicaid/Medicare dual eligible in that state allows for a more accurate state-to-state comparison. More slots available through the 1915(c) waivers for dual eligible older adults lead to better quality of end of life. This result indicates that when there are more spots available dual eligible older adults may benefit from the services provided by 1915(c) waivers during the end of their lives which may improve the quality at end of life.

Informed by previous research in the field, this study also explored various factors that may be associated with the quality of end of life, such as sociodemographic characteristics, severity of illness and impairment, end of life indicators and HCBS policy options. Similar to the previous findings, I also found that among sociodemographic characteristics, marital status was associated with quality of end of life, where older adults who were married or living together had significantly higher quality at the end of life compared to older adults who were single or widowed. The quality of end of life was found to be related to certain end of life indicators, such as receiving hospice. The findings indicated that receiving hospice during the last month of life was associated with lower quality of end of life. These results need to be interpreted with caution. Despite being surprising, overall, these findings may reflect previous reports on underutilization of hospice (Alexandria, 2018; NHPCO, 2013; Diamond et al., 2016; Rickerson et al., 2005). Referral to and being on hospice can be an indicator of worse quality of end of life during the last month of life. When comparing our results to those of older studies, it must be pointed out that in this sample we did not find any evidence for dementia status as a risk factor for lower quality of end of life. However, the findings from earlier research have shown that people with dementia were more likely to have lower quality of life at the end of life (Pinzon, Claus, Perrar, et al., 2013; Hendriks, Smalbrugge, Hertogh et al., 2014; Amjad, Snyder, Wolff, et al., 2019).

Implications for Policy and Practice

The findings of this paper suggest that the end of life is a critical time that requires higher level of care that is more complex and medicalized. This level of care may be too burdensome for family caregivers, hence older adults without the resources to cover the expenses to receive assistance at home during the end of life may move to nursing facilities or be hospitalized. Nursing facilities and hospitals are being used to receive care for symptom management and support with low functioning during the end of life, however older adults prefer staying home as long as their care needs are met, and quality of life is supported. Therefore, our findings suggest several policy and practice implications to support quality of end of life of economically vulnerable community-dwelling older adults.

First, this study indicates that quality of end of life may be lower among community-dwelling dual eligible older adults compared to Medicare-only community-dwelling older adults, so specialized services may be necessary for this population. Functioning in this sample was significantly lower, including being less alert and unable to get out of bed. It is important to note that Medicaid nursing home level of care is being used as a measure that must be met for HCBS. However, there is not any federal level definition of nursing home level of care and therefore this definition changes from state to state. Our finding suggests that functioning should be a critical part of this definition to target this high-need population at the end of life.

Another issue that emerged from these findings was that slots available in the 1915(c) waivers may have a strong association with quality of end of life among economically vulnerable older adults. Economically vulnerable older adults with care needs may have difficulty in accessing these services if the states they live in do not have sufficient slots. Lower numbers of available slots lead to longer waiting lists. More than three-quarters of the states reported an HCBS waiver waiting list with an average wait time of 39 months (Musumeci et al., 2020). Our findings suggest that states should increase the number of unduplicated participants in their 1915(c) waivers as high as possible to provide as much coverage as possible to dual eligible populations to meet the care needs of impoverished older adults.

Last but not least, our findings on hospice use raised intriguing questions regarding when and by whom hospice is being utilized. We found that there is a strong association between hospice use and lower quality of end of life, higher symptom burden and lower functioning. This result may be due to strict eligibility criteria of the Medicare hospice program, the stigma associated with the end-of-life care or late referrals to hospice - only when symptom burden and functioning become unbearable for the older adult and family. However, hospice care is designed to support individuals with symptoms and functioning for longer than the last 30 days of life. Our results suggest the need to change eligibility criteria that result in late referrals to Medicare hospice programs. These findings also imply that economically vulnerable community dwelling older adults may benefit from home or community-based palliative programs for their symptoms and functioning troubles. Recent studies on home-based palliative care programs show promising results that shows improving end of life experiences (Brian et al., 2016; Morrison et al., 2011), but outpatient or home-based palliative care is limited. However, 1915(c) waivers could potentially be a resource to expand provision of palliative care in community and in-home settings. States can consider including palliative care services as a part of their HCBS waiver requests to better serve the high need older adult population until the very end of their lives.

Limitations

There are several limitations of this study. First, we utilized the lagged data approach where the HCBS policies that we analyzed were limited to the years between 2011 and 2015, and the data that we analyzed for the outcome measures were the years between 2012 and 2017. However there remains a question whether some of the policies put in effect had adequate time to impact the quality of end of life. For instance, some HCBS policies which began in 2015 may have required more implementation time to measure the impact. Similarly, some of the policies that were cancelled immediately after 2015 may also be out of scope of this study yet had important implications for quality of end of life among our sample.

Another major source of limitation was due to the use of aggregated data. This study collected HCBS policies at the state level but was unable to measure HCBS use at the individual level. This limitation became clearer in our findings of generosity for homemaker services, where we could not identify who was currently utilizing homemaker services and who was not during the last month of life. As a result of this, the findings of our study about generosity of 1915(c) services remain limited. However, if the data on state policies was not aggregated, this study would not be able to investigate the HCBS policy factors that may be influencing quality of end-of-life experiences at the individual level. In future research, individual level data with detailed information on service use would help identify the direct impact of these services. Provision of detailed information about who uses which services would ensure better measurement of how much of care is needed to reach high quality of end of life.

A limitation in this paper was due to our combination of the dual eligible older adults who aged into disability and acquired disability at older ages. This study focused on a sample who were economically vulnerable, older, at the end of life and had limitations with self-care and mobility activities. However, this sample includes older adults who had disability with self-care and mobility activities before their older ages and aged with these disabilities, and older adults who acquired disability with self-care and mobility activities in their older ages. These two groups might show substantial differences in their needs, priorities and service using patterns. Yet, this study grouped them in the same sample and treated the same.

Although widely accepted as a measurement procedure for end-of-life issues, this study also suffered from limitations due to the use of proxy responses to measure quality of end of life. I utilized the last month of life dataset composed of responses by a proxy respondent, typically a family member describing the decedent’s end-of-life experience. Functioning of the older adults, like being able to get out of bed and being alert can be easier to observe by proxies compared to symptoms like pain, sadness and anxiety. Another limitation about the outcome measures was the lack of analysis of severity of symptoms. This study addressed the prevalence of three end of life symptoms -- pain, breathing difficulties and sadness/anxiety -- but no information was available on the severity of these symptoms.

Conclusion

In this study, I examined the patterns of quality of end of life experienced by economically vulnerable community-dwelling older adults at the end of life and explored whether there is any association between state variation in the availability and generosity of HCBS waivers and quality of end of life experienced by older adults during the last month of their lives. Results demonstrated that having lower quality of end of life was common experience for Medicare-Medicaid dual eligible community dwelling older adults at the end of life. This sample had low levels of functioning and high symptom burden. Quality of end of life was found to be associated with certain sociodemographic and severity of illness and impairment categories, such as age status, marital status, number of chronic diseases, end of life indicators, such as place of death, hospice use as well as slots available in HCBS waivers and generosity for homemaker services.

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Table 4.1.

Weighted Description of and the Bivariate Analysis Between the High and Low Quality of End of Life and Sociodemographic Characteristics, Severity of Illness and Impairment and End of Life Indicators

	Total sample	**High QEOL[b]**	**Low QEOL[b]**	**p-value [a]**
	N = 309	N = 146	N = 163	
Sociodemographic characteristics				
Age groups (%)				0.331
65-74	34.79	37.29	32.83	
75-79	12.95	14.91	11.41	
80-84	21.03	15.00	15.74	
85-89	16.17	18.58	14.28	
90+	15.07	14.22	15.74	
Gender (%)				0.935
Female	58.98	59.31	58.72	
Male	41.02	40.69	41.28	
Marital Status (%)				0.027
Living together	26.63	35.15	19.96	
Living alone	73.37	64.85	80.04	
Race/Ethnicity (%)				0.016
White, Non-Hispanic	52.26	40.93	61.05	
Black, Non-Hispanic	24.28	29.95	19.65	
Hispanic/Other	23.46	29.12	18.85	
Severity of illness and impairment				
Dementia status (%)				0.089
No dementia	82.49	87.02	78.96	
Dementia	17.51	12.98	21.04	
Chronic diseases				0.085
0/1 chronic diseases	22.66	28.67	17.95	
2+ chronic diseases	77.34	71.33	82.05	
End of life indicators				
Hospice use (%)				0.004
No hospice	61.12	72.77	51.99	
Hospice	38.88	27.23	48.01	
Place of death				0.137
Home	39.93	36.98	42.24	
Hospital	40.55	48.22	34.56	
Nursing Facility/Hospice	19.52	14.80	23.20	

Notes: All the results are weighted using the appropriate year weights. [a] P values represent the results of the chi-squared test for the null hypothesis of no difference in the high quality of end of life by sociodemographic characteristics, severity of illness and impairment characteristics and end of life indictors. [b] High and low quality of end of life was defined as those had 3 and more symptoms or functioning difficulties with scores 0-2 (low quality of end of life) and those had less than 2 symptoms or difficulties with scores 3-5 (high quality of end of life).

Table 4.2.

Weighted Prevalence of Quality of End-of-Life Indicators

	Prevalence
Functioning during the Last Month of Life	
Alert (%)	58.42
Getting out of bed (%)	43.47
Functioning score (mean, range)	1.02 [0-2]
Symptom Control during the Last Month of Life	
Pain controlled (%)	30.16
Sadness/Anxiety controlled (%)	49.30
Breathing difficulty controlled (%)	43.35
Symptom Control Score (mean, range)	1.23 [0-3]
Summary measures	
Quality of End-of-Life Score (mean, range)	2.25 [0-5]
High Quality of End of Life (%)	43.93

Notes: All the results are weighted using the appropriate year weights.

Table 4.3.

Weighted Sample Characteristics for State-Level Factors of Generosity and Availability of the Home and Community-Based Services

State-level factors	**Prevalence**
Generosity	
Homemaker - More than median (%)	51.17
Home Health - More than median (%)	58.16
Adult Day - More than median (%)	60.93
Availability	
Only older adult waivers (%)	23.29
Participant direction (%)	77.87
More than median in available slots (%)	44.77
Number of waivers (mean, range)	3.39 [0 - 8]
Number of services (mean, range)	9.59 [0 - 13]

Table 4.4

Weighted Bivariate Analysis Between State Level Factors and Quality of End-of-Life Measures

	Quality of End of life	
State-level factors	**High QEOL**	**p-value [a]**
Only older adult waivers		
Available	46.96	0.622
Not available	43.00	
Participant direction		
Available	45.84	0.313
Not available	37.18	
Available slots		
% slots more than median	50.97	0.078
% slots less than median	38.21	
Number of waivers		
# of waivers more than median	46.26	0.644
# of waivers less than median	42.71	
Number of services		
# of services more than median	40.23	0.453
# of services less than median	45.84	
Generosity for Homemaker		
More than Median	47.57	0.305
Less than Median	40.11	
Generosity for Home Health		
More than Median	37.92	0.075
Less than Median	50.84	
Generosity for Adult Day		
More than Median	38.45	0.056
Less than Median	52.47	

Notes: All the results are weighted using the appropriate year weights. [a] P values represent the results of the chi-squared test for the null hypothesis of no difference in the percentages of high quality of end of life by state level policies on HCBS.

Table 4.5

Weighted Multilevel Models of Quality of End-of-Life Measure

	High Quality of Life		
	Coef.	[95% C.I.]	p-value
Sociodemographic characteristics			
Age groups [a]			
75-79	0.64	[-0.52 – 1.79]	0.279
80-84	-0.24	[-1.41 – 0.93]	0.687
85-89	0.35	[-0.46 – 1.17]	0.392
90+	0.26	[-0.84 – 1.37]	0.641
Female [b]	0.37	[-0.36 – 1.11]	0.320
Married/Living together [c]	0.79	[0.22 – 1.36]	0.007
Race/Ethnicity [d]			
Black, Non-Hispanic	0.61	[-0.11 – 1.34]	0.099
Hispanic/Other	0.98	[0.18 – 1.78]	0.016
Severity of illness and impairment			
Dementia [e]	-0.46	[-1.15 – 0.24]	0.200
Has more than 2 chronic diseases [f]	-0.61	[-1.33 – 0.11]	0.097
End of life indicators			
Received Hospice [g]	-1.02	[-1.85 - -0.18]	0.017
Place of death [h]			
Hospital	-0.02	[-0.69 – 0.64]	0.948
Nursing Facility/Hospice	-0.13	[-0.85 – 0.58]	0.715
State-level factors			
Availability			
Has waiver for only older adults [i]	-0.25	[-1.53 – 1.04]	0.706
Has participant direction [j]	0.52	[-0.19 – 1.23]	0.148
Available slots [k]	0.57	[0.03 – 1.12]	0.037
# of services more than median [l]	-0.23	[-1.33 – 0.86]	0.675
# of waivers more than median [m]	0.21	[-0.46 – 0.88]	0.538
Generosity			
Homemaker spending > median [n]	0.03	[-0.47 – 0.54]	0.894
Home health spending > median [n]	-0.45	[-0.99 – 0.08]	0.097
Adult Day spending > median [n]	-0.58	[-1.25 – 0.08]	0.086
Constant	-0.23	[-1.32 – 0.86]	0.680

Notes: [a] Reference age group is age group 65-74. [b] Referent category is male. [c] Married/Living together includes married and living with a partner. The referent category is not living together and includes separated, divorced, widowed and never married. [d] Referent category is non-Hispanic White. [e] Referent category is not having dementia diagnosis. [f] Referent category is having 0 or 1 chronic diseases. [g] Referent category is those who did not received hospice during the last month of life. [h] Referent category is home death. [I] Referent category is living in a state without any waivers designed for only older adults. [j] Referent category is living in a state without participant direction policy option. [k] Referent category is living in a state with less than median slots. [l] Referent category is states with available services less than median. [m] Referent category is states with available number of waivers less than median. [n] Referent category for all expenditure variables is living in a state with spending less than median.

Figure 4.1. Analytical Model of Lagged Effect of HCBS Availability and Generosity on Quality of End of Life

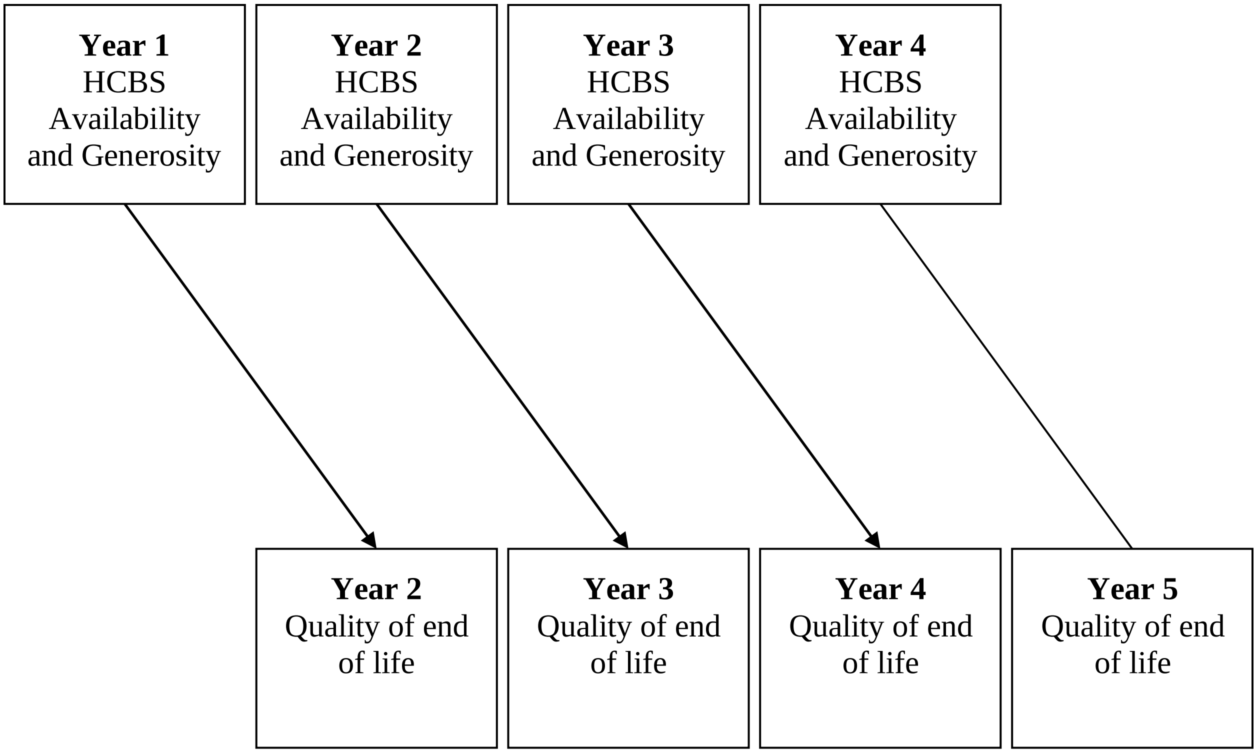
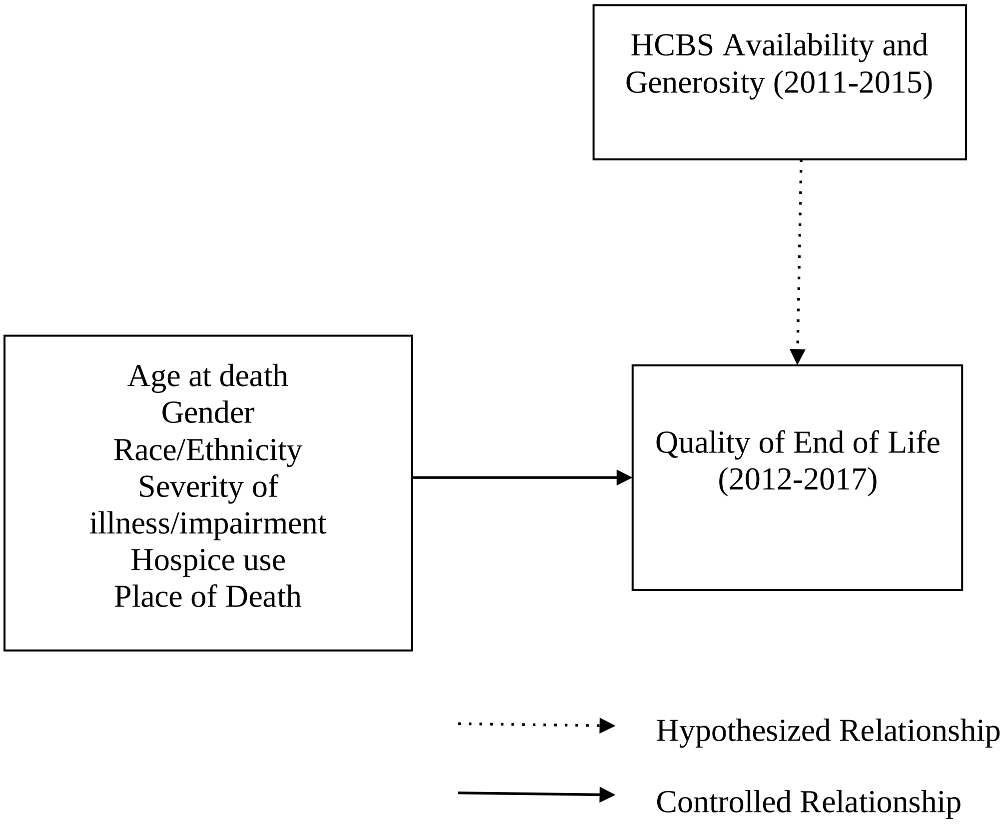


Figure 4. 2. Conceptual Model



Appendix C

Appendix C - Table 1

Post Hoc Analysis of Weighted Multilevel Models of Indicators of Quality of End of Life

	Being Symptom-free			**Functioning**		
	Coef.	[95% C.I.]	p-value	Coef.	[95% C.I.]	p-value
Sociodemographic characteristics						
Age groups [a]						
75-79	0.24	[-0.69 – 1.18]	0.612	-0.65	[-1.69 – 0.38]	0.216
80-84	0.17	[-0.94 – 1.28]	0.760	-1.08	[-1.93 - -0.22]	0.014
85-89	0.27	[-0.52 – 1.06]	0.507	-0.45	[-1.45 – 0.55]	0.374
90+	0.49	[-0.48 -1.47]	0.318	-0.64	[-1.79 – 0.52]	0.283
Female [b]	0.23	[-0.29 – 0.76]	0.383	-0.48	[-1.22 – 0.25]	0.198
Married/Living together [c]	0.33	[-0.34 – 1.01]	0.333	0.33	[-0.41 – 1.07]	0.384
Race/Ethnicity [d]						
Black, Non-Hispanic	0.44	[-0.32 -1.20]	0.254	0.32	[-0.23 – 0.88]	0.256
Hispanic/Other	0.61	[-0.22 – 1.43]	0.149	0.91	[0.03 – 1.79]	0.044
Severity of illness and impairment						
Dementia [e]	0.16	[0.51 – 0.83]	0.648	-1.07	[-1.97 - -0.17]	0.020
Having 2+ chronic diseases [f]	-0.71	[-1.50 – 0.07]	0.076	-0.31	[-0.87 – 0.24]	0.266
End of life indicators						
Received Hospice [g]	-1.27	[-2.04 - -0.49]	0.001	-0.31	[-1.00 – 0.38]	0.381
Place of death [h]						
Hospital	-0.27	[-0.93 – 0.39]	0.425	0.85	[0.03 – 1.66]	0.042
Nursing Facility/Hospice	0.41	[-0.47 – 1.29]	0.361	0.19	[-0.35 – 0.73]	0.492
State-level factors						
Availability						
Has waiver for only older adults [I]	-0.57	[-1.95 – 0.80]	0.414	0.01	[-1.39 – 1.39]	0.995
Has participant direction [j]	0.48	[-0.24 – 1.21]	0.194	0.11	[-0.49 – 0.72]	0.715
Available slots [k]	0.06	[-0.52 – 0.64]	0.834	-0.22	[-0.75 – 0.32]	0.426
# of services more than median [l]	-0.44	[-1.86 – 0.98]	0.545	0.10	[-1.33 – 1.53]	0.888
# of waivers more than median [m]	0.62	[0.01 – 1.23]	0.045	-0.09	[-0.96 – 0.78]	0.843
Generosity						
Homemaker spending > median [n]	-0.07	[-0.64 – 0.51]	0.818	-0.27	[-0.84 – 0.31]	0.364
Home health spending > median [n]	-0.33	[-1.08 – 0.42]	0.391	-0.85	[-1.51 - -0.19]	0.011
Adult Day spending > median [n]	-0.24	[-0.81 – 0.32]	0.400	-0.22	[-0.95 – 0.51]	0.560
Constant	-0.17	[-1.35 – 0.99]	0.770	2.10	[0.99 – 3.22]	0.000

Notes: [a] Reference age group is age group 65-74. [b] Referent category is male. [c] Married/Living together includes married and living with a partner. The referent category is not living together and includes separated, divorced, widowed and never married. [d] Referent category is non-Hispanic White. [e] Referent category is not having dementia diagnosis. [f] Referent category is having 0 or 1 chronic diseases. [g] Referent category is those who did not received hospice during the last month of life. [h] Referent category is home death. [I] Referent category is living in a state without any waivers designed for only older adults. [j] Referent category is living in a state without participant direction policy option. [k] Referent category is living in a state with less than median slots. [l] Referent category is states with available services less than median. [m] Referent category is states with available number of waivers less than median. [n] Referent category for all expenditure variables is living in a state with spending less than median.

CHAPTER 5

CONCLUSION

In this dissertation, I sought to better understand Medicaid HCBS waivers and the role they play in experiences for older adults at the end of life. Building on current research, I began by conducting a systematic policy analysis on 1915(c) waivers that examined the availability and generosity of the waivers that could be used by the older adults at the end of their lives. Following this, I analyzed nationally representative data of deceased community-dwelling Medicaid-Medicare recipient dual-eligible older adults to explore whether there is an association between HCBS availability and generosity and end-of-life experiences in this population.

Synthesis and Summary of Arguments

Before starting the project, I expected to find state variation in availability and generosity of 1915(c) waivers for economically vulnerable older adults and that this variation would mean that economically vulnerable older adults living in states with more availability and generosity would have less unmet needs and higher quality of end of life. The findings of the papers mostly aligned with these expectations.

Main Findings of Paper 1. Paper 1 focused on examining Medicaid 1915(c) waivers that can provide home and community-based services to economically vulnerable older adults and explored state variation in availability and generosity of services provided through these waivers. I found that states have a great deal of flexibility in their waivers that can cause substantial between state variation in terms of availability and generosity. Frequency of available types of services showed a variation between the states, with equipment, technology, and modifications services being the most, family training being the least frequent service provided. Participant direction was not available in 10 states and this option showed difference by the target population.

Main Findings of Paper 2. Paper 2 examined the patterns of unmet care needs experienced by economically vulnerable community-dwelling older adults at the end of life and whether there is any association between state variation in the availability and generosity of HCBS waivers and unmet care needs experienced by older adults during the last month of their lives. Results demonstrated that having unmet needs with self-care and mobility activities were a common experience for older adults at the end of life. More specifically, 40.26% of the sample had any unmet need at the end of life with 22.39% had any unmet need with self-care activities, and 28.98% had any unmet need with mobility activities. Dementia diagnosis was associated with higher levels of unmet need for assistance for self-care and mobility activities, while having a participant direction option available, higher numbers of waivers available and generosity for HCBS were significantly associated with a decrease in the risk for unmet needs during the last month of life.

Main Findings of Paper 3. Paper 3 explored quality of life at the end of life as experienced by economically vulnerable community-dwelling older adults whether there was any association between state variation in the availability and generosity of HCBS waivers and quality of end of life experienced by older adults during the last month of their lives. Findings showed that having lower quality of end of life was a common experience for Medicare-Medicaid dual eligible community dwelling older adults during the last month of their lives whose proxies reported low levels of functioning and high symptom burden; 43.93% had a high quality of end of life, with a mean score of 2.25

between the ranges of 0 and 5. Functioning score was 1.02 between the range of 0 and 2, and symptom control was 1.23 between the range of 0 and 3. Quality of end of life was found to be associated with certain sociodemographic and severity of illness and impairment categories, such as age status, marital status, number of chronic diseases, end of life indicators, such as place of death, hospice use as well as slots available in HCBS waivers and generosity for homemaker services.

Implications and Future Directions

Social Justice Implications

The findings of the dissertation highlight how Medicaid-Medicare receiving dual-eligible community-dwelling older adults at the very end of their lives are a highly marginalized group that could benefit from Medicaid 1915(c) waiver services to have better end of life experiences. Currently, there are 12.2 million individuals simultaneously enrolled in Medicare and Medicaid (CMS, 2019) and this group is expected to grow (Feng, 2018). The dual-eligible population has a high prevalence of disproportionately high Medicaid and Medicare expenditures (Young et al., 2015). Most dually eligible older adults are female, low-income, disabled, and non-white (Feng, 2018).

This dissertation demonstrated important social justice implications for this population. The findings showed that almost half of the dual-eligible older adults at the end of life had unmet needs with ADL activities. Among them, older adults with dementia and the ones without hospice care found to be at higher risk for unmet needs at the end of life. Given the longer timeline that an older adult with dementia would need care and underutilization and limited use of hospice, our findings highlighted an important disparity at the end of life, especially experienced by dually eligible older adults. Tailored HCBS for dual eligible older adults with dementia or integrating hospice services into HCBS could be helpful to support care needs of this population with their self-care and mobility activities and would decrease disparities experienced at the end of life. Gender and age were also found to be associated with unmet needs at the end of life. Findings showed that dual eligible older adults who are married and male have fewer unmet needs at the end of life compared to dual eligible older adults who lived alone and were female.

Another important social justice implication of the findings was about the quality of end-of-life outcomes seen in dual eligible older adults' sample. Findings demonstrated that Medicare-Medicaid receiving community-dwelling older adults had a lower quality of end of life during last month of their lives compared to Medicare-only community dwelling older adults (Lee et al., 2020). This finding showed again that dual eligible older adults are a marginalized group who experience worse quality at the end of life. I also found that being single and having higher numbers of chronic diseases decreased the quality of end of life and increased symptom burden at the end of life.

Policy implications

The findings of this dissertation have several important policy implications. First, it was demonstrated that participant direction is an approach that HCBS waivers could use more often to better meet the needs of economically vulnerable older adults at the end of life. Participant direction is an option that states can choose to allow Medicaid beneficiaries to hire, train, and fire their own providers, with state oversight of provider qualifications and monitoring of service delivery (Department of Health and Human

Services, 1997) with the ultimate purpose of giving service recipients greater control over the services they receive (Thompson et al., 2016). Momentum for participant direction begun to build in the late 1990s, and in recent years the use of participant direction increased significantly in Medicaid programs (Thompson et al., 2016). Results of this dissertation showed that older adults living in a state with a participant direction option available had fewer unmet needs and higher quality of end-of-life rates. Therefore, states should make participant direction more available within its 1915(c) waivers to target end of life needs of dual eligible older adults.

The second policy implication of the findings of this dissertation was on the generosity of Medicaid 1915(c) services. I found that generosity of services in the forms of expenditures and available slots were associated with the end-of-life experiences of dual-eligible older adults. The accessibility of these services was strongly shaped by the available number of slots in these waivers and expenditures of the states. Having limited generosity in these services works as a form of gatekeeping in which long waiting lists prevent service access (Meyer & Abdul-Malak, 2020). As a result of the limited provision of HCBS services, long waiting lists are seen in many states (Cooper, 2017). To minimize waiting lists that can last several years before receiving services and to maximize the number of Medicaid HCBS recipients that can benefit from the services, states should consider expanding the funding of HCBS to increase the number of slots and expenditures for the services.

Another policy implication of this dissertation was about the great variation of HCBS waivers between the states. The findings of paper 1 showed that HCBS waivers are largely driven by state decisions which creates inconsistency and complexity between the states. The current patchwork of programs is complex and difficult to navigate which inevitably creates barriers to obtaining timely and effective care (Yang, 2019), to accessing appropriate services that allow this population to stay in their homes until the very end of their lives and to avoiding unmet needs and low quality of end of life. Setting national expectations for service provision would decrease the disparities between the states and provide comprehensive and standardized services to community-dwelling economically vulnerable older adults with care needs at the end of life.

Fourth, the findings inform Medicaid policymakers about the need for universal HCBS. Social welfare programs in the US, like Medicaid, are primarily poverty-based rather than universal (Igel & Szydlik, 2011). Medicaid is only available for individuals who meet income and other eligibility requirements. Older adults at the end of life can benefit from Medicaid HCBS waivers, yet the financial requirements hinder older adults who are not poor enough to benefit from these services but are still not able to afford in-home care. Therefore, HCBS policymakers should consider expanding these services beyond the severely impoverished population to improve end-of-life experiences among older adults regardless of their income status.

The last implication of my findings is about the medicalization of end-of-life care. End-of-life care is highly fragmented and uncoordinated in the US and focuses on medical care that encourages a combative focus on diagnosing and treating disease (Livne, 2019). Extreme interventions have become routine and standard practice (Livne, 2019), and this creates problems particularly near the end of life. However, end-of-life care should include day-to-day, long-term services and supports that are needed by older adults (Feder et al., 2000) which is a major cost driver that is typically overlooked and unaddressed in traditional medical care (Reuben & Tinetti, 2012). Therefore, the findings suggest that the link between HCBS and hospice/palliative care should be strengthened. This can be either HCBS's integration of hospice and palliative care into their services or hospice and palliative care's being more available in the community and home-based services being more available for economically vulnerable older adults.

Limitations

This dissertation had several limitations. The first limitation was due to the use of aggregated data for the state-level measures. Although I took advantage of nationally representative individual-level data for the measurement of outcome variables, I measured state policies based on aggregated data of Medicaid HCBS waivers at the state level. To do this, first, I analyzed and aggregated the policies and expenditures of each state and then examined the association between states characteristics where the older adult resided and their end-of-life experiences.

I recognize that the use of aggregated state data influenced the interpretation of the results of this dissertation. With the use of state-level aggregated data, my analysis was more vulnerable to misinterpretation due to the lack of knowledge of waiver use on the individual level. Use of more detailed data on the actual usage of the Medicaid 1915(c) waivers, such as state-level administrative data, may be valuable to explore as an avenue to identify individual-level information such as who uses the services when and how often the services were being utilized, and the type of services that are being used. This information could provide results that link HCBS use to individual outcomes, thereby providing more detailed evidence to inform policies. For instance, this type of analysis would potentially better inform policymakers about how to tailor these services to better meet the high need, high-cost, dual-eligible older adults ability to stay at home in their own community until the very end of their lives.

One other limitation of the use of aggregated data was the lack of ability to examine the potential influence of other Medicaid authorities that provide HCBS to older adults. In addition to 1915(c) waivers, Medicaid also uses optional state plan amendments (i.e., 1915(i), (j), (k) HCBS state plans), and optional 1115 waivers for community-dwelling older adults. Some states that do not have any 1915(c) waivers are currently utilizing these other mechanisms to provide HCBS. For instance, 1115 waivers are commonly used to provide services that are similar to those provided by 1915(c) waivers. Arizona (1115 Demonstration Project waiver), Rhode Island (Global Waiver), Delaware (Elderly and Disabled (E&D) Waiver and AIDS/HIV Related Diseases 1115 waiver) and Vermont (Global Commitment to Health and Choices for Care waivers) provide HCBS to Medicaid participants through 1115 waivers and not 1915(c) HCBS waivers[16]. Therefore, it must be acknowledged that not all states that are not high in availability and generosity of 1915(c) waiver ranking are providing lower quality or less HCBS in reality. To avoid any bias that may be rooted in this limitation, I excluded the states that do not have any 1915(c) waivers from the analysis and then run the additional sensitivity analysis including the states without 1915(c) waivers to see whether there were any significant differences. The results did not change dramatically between these two analyses.

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[16] The approved application documents of 1115 waivers are not standardized like the 1915(c) waivers. Therefore, it would not be possible to add the 1115 waivers to be included in this study, because it is not always clear which services are provided and which ones are available as participant-directed, or participant numbers. Also, MAX OT data does not have information about 1115 waivers for the state generosity. Therefore, this study mainly focused on 1915(c) waivers as the unit of analysis, and did not include 1115 waivers.

And the last limitation of this dissertation was the use of proxy reports to measure end-of-life experiences of older adults. In Paper 2 and Paper 3, I utilized the NHATS last month of life interview to operationalize the care received with limitations of self-care and mobility activities and quality of end-of-life indicators like functioning and symptom management. The last month of life interview was conducted with someone who was familiar with the older adult's daily routine during their last month of life. Proxy reports have been commonly used in research and have been helpful to provide information when data cannot be obtained directly from the target person (Gerlach, et al 2017). The validity and utility of proxy reports have been repeatedly demonstrated in the aging studies (Boyer et al., 2004; Snow et al., 2005; Perkins, 2007).

I used proxy reports about end-of-life experiences of older adults to be able to understand the end of their lives (last month of life). The last month of life interview was conducted with a proxy after the older adult was deceased and focused on learning more about the care that the older adult received. The use of proxy response was required to explore the last month of life experiences of older adults because otherwise, the only information to be used would be from the last interview that the older adult could attend in person when they were living, which could be almost a year earlier than the date of their death. Therefore, despite potential limitations, proxy reports are a valuable source of information to explore the end-of-life experiences of older adults.

Future Directions for Research

This dissertation provides a general framework for understanding HCBS waivers for older adults and starts exploring the potential end-of-life implications of Medicaid 1915(c) HCBS waivers for economically vulnerable older adults. However, there were some limitations in this dissertation due to data and measurement that can be improved in future research. First, future research is needed at the individual-level analysis of HCBS use, such as linking administrative data on service use to end of life outcomes, to have a better understanding of the real-life implications of these services. This dissertation is based on aggregated data of HCBS policies at state levels which does not illustrate the actual utilization of services. Therefore, future research could consider conducting this research utilizing more detailed data on HCBS waiver policies.

Second, this dissertation is based on only 1915(c) waivers, however, HCBS sources for older adults vary. States are using various authorities to provide HCBS to Medicaid recipients. For instance, most of the states that do not have 1915(c) waivers available for older adults currently have 1115 waivers. This dissertation remains limited in HCBS availability and generosity analysis. Future research that includes different Medicaid HCBS authorities would provide knowledge of HCBS that can inform potential actionable gaps in HCBS policies that need to be improved.

Conclusion

The purpose of this dissertation was to describe the variation of 1915(c) waiver for dual eligible older adults among states and explore whether there is any association between this variation and end of life experiences of older adults using data from the National Health and Aging Trends Study (NHATS). Drawing on unmet need and quality of end-of-life measures from NHATS, I examined variation by socioeconomic characteristics, severity of illness and impairment factors, end of life indicators and waiver availability and generosity variables. The findings of this dissertation showed that there is a variation between the states in available services, coverage for target groups, service slots available, ability to direct participants' own care and generosity.

The findings of end-of-life experiences of dual eligible older adults provides evidence for the high prevalence of unmet needs with self-care and mobility activities and low quality at the end of life. These findings may inform Medicaid policies for 1915(c) waivers. Generosity for the services and slots available for dual eligible older adults were also associated with end-of-life experiences of this sample, therefore Medicaid waivers should increase their generosity and slots to better meet the needs of economically vulnerable older adults at the end of life.

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Appendix D

Appendix D - Table 1.

Table of Measure and the Codebook Details for Unmet Need for Self-Care and Mobility Activities

Difficulty with Self-Care Activities			
Dressing			
	Difficulty with Dressing	sc#ddressfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with Dressing	sc#ddreshelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with dressing	Difficulty with dressing and Care Received with dressing	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Bathing			
	Difficulty with Bathing	sc#dbathsfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty	

		7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with Bathing	sc#dbathhelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with Bathing	Difficulty with bathing and Care Received with bathing	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Toilet use			
	Difficulty with using toilet	sc#dtoilsfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with using toilet	sc#dtoilhelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with using the toilet	Difficulty with using toilet and Care Received with using toilet	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Eating			
	Difficulty with eating	sc#deatsfdf	[1] =1 [2] =0 [3] = 1 [4] = 0
		1 - Did not do by self in last month 2 - No difficulty by self	

		3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	[5] = 1 [6] = 0
	Care Received with eating	sc#deathelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with eating	Difficulty with eating and Care Received with eating	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Difficulty with Mobility Activities			
Getting in/out of bed			
	Difficulty with getting in/out of bed	mo#dbedsfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with getting in/out of bed	mo#dbedhelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with getting in/out of bed	Difficulty with getting in/out of bed and Care Received with getting in/out of bed	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	

Moving inside home			
	Difficulty with moving inside home	mo#dinssfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with moving inside home	mo#dinshelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	
	Unmet need with moving inside home	Difficulty with moving inside home and Care Received with moving inside home	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Going outside			
	Difficulty with going outside	mo#doutsfdf	[1] =1 [2] =0 [3] = 1 [4] = 0 [5] = 1 [6] = 0
		1 - Did not do by self in last month 2 - No difficulty by self 3 - Difficulty by self 4 - DKRF did by self in last month/no difficulty 5 - DKRF did by self in last month/difficulty 6 - Did by self in last month/DKRF difficulty 7 - DKRF did by self in last month/DKRF difficulty 8 - Not done in last month	
	Care Received with going outside	mo#douthelp	[1] =1 [2] = 0 [3/9] =.
		1 - No help in last month 2 - Had help in last month 3 - DKRF if had help in last month	

	Unmet need with going outside	Difficulty with going outside and Care Received with going outside	[Care received = 1] = 0 [Care received = 0 & Difficulty = 0] = 0 [Care received = 0 & Difficulty = 1] = 1
		[Derived]	
Summary measures			
	Unmet need with Self-care activities	Unmet need with dressing + bathing + using toilet + eating	[0] = 0 [1/4] = 1
	Unmet need with mobility activities	Unmet need with getting in/out of bed + moving inside + going outside	[0] =0 [1/3] =1
	Unmet need with self-care and mobility activities	Unmet need with dressing + bathing + using toilet + eating + getting in/out of bed + moving inside + going outside	[0] =0 [1/7] =1

Appendix D - Table 2.

Table of Measures and the Codebook Details for Quality of End of Life

Quality of end of life			
Functioning			[0] = 0 [1-2] = 1
	Being alert	pd#alert	[Everyday] = 1 [Less than everyday] = 0
		“For how much of the last month of {SP}’s life was {he/she} alert, that is, awake and able to communicate? Would you say every day, most days, some days, rarely, or not at all?” 1 - Everyday 2 - Most Days 3 - Some Days 4 - Rarely 5 - Not at all	
	Being able to get out of the bed	pd#outbed	[Everyday] = 1 [Less than everyday] = 0
		“For how much of the last month of {SP}’s life was {he/she} able to get out of bed? Would you say every day, most days, some days, rarely, or not at all?” 1 - Everyday 2 - Most Days 3 - Some Days 4 - Rarely 5 - Not at all	
Being symptom-free			[0/1] = 0 [2/3] = 1
	Being pain-free	lm#pain	[YES] = 0 [NO] = 1
		“During the last month of {SP}’s life, were there times when {he/she} experienced pain?” 1 - Yes 2 - No	
	Being sadness / anxiety-free	lm#sad	[YES] = 0 [NO] = 1
		“During the last month of {SP}’s life, did {he/she} have any feelings of anxiety or sadness?” 1 - Yes	

		2 - No	
	Having no breathing troubles	lm#bre	[YES] = 0 [NO] = 1
		"During the last month of {SP}'s life, were there times when {he/she} had trouble breathing?" 1 - Yes 2 - No	
Quality of end-of-life summary measure			
	Dichotomized quality of end of life	Being alert + Being able to get out of bed + being pain-free + being sadness/anxiety-free + Having no breathing troubles	[0-2] = 0 [2.01-5] = 1