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Unique Service-Related Characteristics among Home Health Care Patients with Cognitive Impairment in the United States

Kaplan DB*

Adelphi University School of Social Work, USA

*Corresponding author: Daniel B Kaplan, Adelphi University School of Social Work, Garden City, NY, USA

Abstract

National home health survey data are examined to compare service-related psychosocial and clinical characteristics in patients with and without advanced cognitive impairment. Knowing such differences will allow providers to assess patient needs in areas where groups differ. Cognitive status and psychosocial and clinical characteristics are examined through bivariate analyses of 2007 National Home and Hospice Care Survey data, the most recent nationally representative sample survey in this series of cross-section sample surveys of U.S. home health and hospice agencies. Significantly more patients with cognitive impairment have greater medical daily care needs, medical emergencies, incontinence, and difficult behaviors. Unique service-related needs among patients with cognitive impairment warrants tailored approaches to care, including more direct care and behavioral interventions.

Keywords: Dementia; Neurocognitive disorder; Cognitive impairment; Homecare; Home health services

Abbreviations

ADL: Activities of Daily Living; ICD-9: International Statistical Classification of Diseases and Related Health Problems; MICE: Multiple Imputation by Chained Equations; NCHS: National Center for Health Statistics; NHHCS: National Home and Hospice Care Survey; OASIS: Outcome and Assessment Information Set

Introduction

A basic understanding of patient characteristics, illness levels, and care needs is required for designing appropriate interventions to assist individuals confronting disorders resulting in complex and multidimensional disabilities. Yet, such characteristics and needs, while routinely documented for all home health care patients, have not been appropriately assessed among people with cognitive impairment nor reported in the research literature. To assist practitioners and policy makers in identifying appropriate home health care strategies based on valid data, this study examines nationally-representative home health care survey data to identify illness-levels and service-related needs among patients with moderate-to-severe cognitive impairment.

Background

A continuum of health, mental health, and aging services programs provides formal care services for older adults and those living with disabilities [1]. Formal, paid care services are a vital resource in the dementia care arena because some people with dementia do not have opportunities for informal care and even those with informal providers benefit from formal services when burdens of care surpass the ability or availability of informal providers. The location of formal care for older adults has been shifting out of institutions and into private homes since the passage of Medicare and Medicaid legislation in the Social Security Act of 1965 [2]. Home health care agencies offer health-oriented services, such as skilled nursing, wound care, medication administration and social services. They provide short-term, post-acute care as well as ongoing support for people with functional disabilities. These services allow people to remain living at home after they acquire a disability or chronic illness as well as during brief periods of rehabilitation after hospital procedures [3].

Dementia is a broadly defined clinical term used to describe a syndrome that is common to many diseases, and cognitive impairment is characteristic of these heterogeneous disorders [4]. The most current conceptualization of dementia names the syndrome Neurocognitive Disorder [5]. Neurocognitive disorder causes dysfunction and disability, dependence upon assistance from others for Activities of Daily Living (ADL), depression, and premature institutionalization and death [6-9]. Neurocognitive disorder is known to complicate the treatment of co-occurring illnesses such as cancer, diabetes, congestive heart failure, and chronic obstructive pulmonary disease- all of which are common among older adults [10]. People with neurodegenerative diseases not only need an extraordinary level of care and supervision, but are also known to have hospital and nursing home stays that are twice as long as their peers and suffer from repeated health care crises related to malnutrition and accidental injury [10]. These medical complications lead to significantly elevated costs to health insurance programs, such as Medicare and Medicaid, and higher out-of-pocket healthcare expenses incurred by older adults with neurodegenerative diseases and their families [11,12].

It is reasonable to expect that home health care patients with cognitive impairment differ from patients without cognitive impairment in meaningful ways, with particular distinctions in their severity of disability and particular needs that could be addressed

by home health care providers. To date, there have been no studies describing differences between these groups of patients. Instead, limited studies on the relationships between neurocognitive disorder and community-based services have focused primarily on individual determinants of the use of different kinds of community-based services, caregiver correlates of formal help-seeking, or influences on community tenure [13-18]. A systematic review of services used by community-dwelling individuals with dementia found that home health care is the community resource most often used among people with dementia [19].

An important step toward assessing the effectiveness of home-based care is to understand the unique service-related characteristics of home health care patients with cognitive impairment, such as the availability of informal supports, levels of functional impairment and needs for specific types of care, the presence of behavioral disturbances, and which insurance programs will pay for and structure the scope of services. This study is the first to compare these characteristics for home health care patients with and without documented advanced cognitive impairment.

Materials and Methods

This study makes use of data from a nationally representative sample survey conducted by the Long-term Care Statistics Branch of the Division of Health Care Statistics of the National Center for Health Statistics (NCHS), specifically the 2007 National Home and Hospice Care Survey. The National Home and Hospice Care Survey (NHHCS) is part of a continuing series of cross-section sample surveys of U.S. home health and hospice agencies which began in 1992. It was designed to gather information that describes home health and hospice agencies, staff members, services, and patients. These data are essential in answering the research questions driving this inquiry, and the 2007 survey was the seventh and most recent survey from this series. It was a redesigned and expanded version of its predecessors, with many new data items, larger sample sizes, and the use of a computer-assisted personal interviewing system. Participating agencies were either certified by Medicare and/or Medicaid or were licensed by a state, and all provided home health and/or hospice services. This study focuses exclusively on home health care agencies and patients.

More than one million older adults received home health care each day in the U.S in 2007 [20]. The 2007 wave of the National Home and Hospice Care Survey used a stratified two-stage probability sample design to gather information about a nationally-representative sample of these patients. The first sampling stage involved the selection of home health and hospice agencies from the total sample frame of more than 15,000 agencies. The primary sampling strata of agencies were defined by metropolitan statistical area and agency type. Within these strata, agencies were sorted by several characteristics, including census region, state, county, ZIP code, size (number of employees), ownership type, and certification status.

Interviewers completed the second stage of sample selection during the agency interviews. Up to 10 current home health patients and/or hospice discharges were randomly selected from each agency by a computer algorithm based on a census list provided by each agency. Interviewers guided agency representatives through data collection interviews for each of the 10 randomly selected patients or discharges. Data were collected by the National Center for Health Statistics between August 2007 and February 2008 through in-person interviews with agency directors and their designated staffs who used agency records to answer survey questions. Agency records include information obtained through nurse evaluations and interviews at the time of intake assessment, as well as some information from referral sources, medical records, and subsequent evaluations by nurses and other clinicians. For the NHHCS survey, no interviews were conducted directly with patients or their families. Interviews of agency personnel were facilitated by NCHS surveyors with the aid of a computer-assisted personal interviewing instrument available on each interviewer's laptop.

For the 2007 wave of NHHCS, a total of 1,461 agencies were systematically and randomly sampled with probability proportional to size and considered in the scope of the study. A total of 1,036 home health and hospice care agencies chose to participate in the survey (a weighted response rate of 59%), and data are available on 9,416 current home health patients and hospice discharges from these agencies (a weighted response rate of 96%). This study examines a smaller subsample consisting of 3,309 home health care patients nested within 595 agencies. Inclusion criteria for this study include: 1) patients received home health care services, not hospice; 2) patients received at least one service visit; and 3) data on patient cognitive functioning assessment were available.

Measures

Cognitive impairment status is the primary patient characteristic being evaluated to determine if the sampled patients differ significantly in service-related needs. The National Home and Hospice Care Survey uses case records as documented sources of information for describing patients' current health status, including levels of cognitive functioning. Agency administrators reported information from these case records to categorize patient cognitive impairment status as either: 0) No cognitive impairment; 1) Requires only occasional reminders (in new situations); 2) Requires some assistance/direction in certain situations (is easily distracted); 3) Requires a great deal of assistance/ direction in routine situations; and 4) Severe cognitive impairment (constantly disoriented, comatose, delirium). This 5-point scale is identical to the cognitive functioning measure (item M0560) used in the Outcome and Assessment Information Set (OASIS), which is the uniform data collection instrument use by certified home care providers at the time of service initiation, change, and discharge for all benefits-funded skilled-care patients. Agency administrators completing NHHCS questionnaires used these readily-available OASIS data to inform their answers regarding patient cognitive impairment status. OASIS reporting is based on clinical assessments conducted by trained home health nurses. A recent study of the validity of OASIS measures found the OASIS item for cognitive function to significantly correlate with a valid and reliable measure of cognitive impairment, the Short Portable Mental Status Questionnaire ($r=.62$, significant at $p=.01$) [21]. For this study, patients are considered to have moderate-to-severe cognitive impairment if they were scored as 2, 3, or 4 on the scale and little-to-no cognitive impairment if scored 0 or 1. This approach fits with most conceptualizations for the degree and type of cognitive impairment associated with neurocognitive disorder [4,21,22]. When operationally defining the construct in this

way, 32% of the home health care sample in the 2007 NHHCS dataset is found to have moderate-to-severe cognitive impairment. This rate of impairment is consistent with the expected range for this type of sample.

The selection of service-related variables for this analysis is built upon a conceptual framework modeled by the behavioral model of health services utilization created by Andersen and Newman in 1973. The original behavioral model of health services utilization details the interrelation of societal factors, health service system factors, and individual attributes in determining utilization of health services [23]. This conceptual model has been used widely in its original and modified forms in recent decades to structure studies demonstrating the association of such factors with the utilization of many types of health services [24-26]. In the Andersen-Newman conceptual framework, individual determinants include predisposing factors (e.g., demographics and beliefs about health care), enabling factors, (e.g., family and community resources), and levels of illness (e.g., perceived and evaluated levels of illness and need for care).

Predisposing components of the service utilization framework are individual characteristics which exist before the onset of illness but contribute to a person's propensity to use services [23]. Demographic factors such as gender, age, and marital status have been critical to health service utilization in prior studies [23,27]. Race and ethnicity have also demonstrated strong associations with variation in supportive services and health outcomes at the time of discharge from home care and differences in overall costs of care among people with Alzheimer's disease who have Medicaid insurance [15,28].

Demographic and social-structural characteristics may predispose individuals to use health services, but there must also be some means available for them to do so. Enabling factors include the purchasing power of health insurance and availability and relationships of informal supports [27,29]. These factors are suggested in the studies cited above to play a role in identifying the need for service and in facilitating access to service. However, health insurance programs also structure the services provided by dictating reimbursement approval for only select types of care. Medicare, Medicaid, and private insurance programs each have unique target populations and eligibility requirements. As such, the profiles of service use among health care consumers vary significantly based on the insurance program being billed, and even more so when compared to people who self-pay for home care services and are therefore free to choose the packages of care that best meet their needs and budgets.

In more recent iterations of the health service utilization framework, illness level has been described more accurately as need for service [24]. This may be the most important level of influence on utilization as health services are typically designed to respond to illness-based needs. Several illness level factors have previously been shown to predict health service use for older adults, including physical frailty, ADL limitations and functional disabilities, incontinence, co-occurring chronic illnesses, and severity of cognitive impairment and/or dementia [10,13,30,31]. Patient characteristics relevant for this study include age, gender, marital status, and race/ethnicity, caregiver status (Does the patient have an informal caregiver?), the relation of informal caregivers to patients, co-habitation status (With whom does the patient live?), and both primary and secondary sources of

payment for services. The options for primary and secondary source of payment for services include Medicare, Medicaid, private insurance, and self-pay by the patient or family. Indicators of illness level were also evaluated in this study, including incontinence status for both bladder and bowels, need for assistance with activities of daily living and with taking medications, any episodes of emergency medical care during the current service period, the presence of difficult behaviors, number of medical diagnoses and categories of diagnoses, use of assistive devices and medical devices, and where patients received in-patient care prior to admission into the home health care service. Primary diagnosis is classified using the International Statistical Classification of Diseases and Related Health Problems (ICD-9) and grouped by the 19 ICD-9 diagnostic groups. All of these data were derived from agency health records and therefore rely upon nurse or clinician assessments and validation of information from electronic or printed medical records, and referral sources.

Analyses

Bivariate analyses of cognitive impairment status and multiple psychosocial and clinical characteristics were used in this study to answer the following research question: Is there a significant difference between moderately-to-severely cognitively impaired patients and patients with mild or no cognitive impairment in terms of service-related patient characteristics (listed above). NHHCS is a stratified two-stage probability sample survey designed to produce national estimates for agencies and current home health care patients. Data analyses must therefore include survey weights to inflate the sample numbers to represent accurate national estimates. This study used Stata 12 software, which allows the user to designate variables that contain information about the survey design and specify the default method for variance estimation, in this case using Taylor linearization and a finite population correction, and then apply that weighting structure to any analysis.

Analysis of the variables used in this study revealed that data were missing on one or more variables for nearly half of all home care patients, but no variables were missing data in more than 10% of cases. Additionally, 29% of home care cases were missing data for just one study variable, 13% were missing data for two study variables, and only 7% were missing data for three or more of these variables. Multiple model-based imputation procedures were used in this study as they offer a satisfactory solution to this problem [32,33]. The data used in this study were determined to be "Missing at Random" and the patterns of "missingness" were generally ignorable. Therefore, conducting multiple imputation procedures to address the missing data in this dataset was fully appropriate [32]. Missing data were addressed through the use of Multiple Imputation by Chained

Table 1: Distribution of Home Health Care Patient Cognitive Status from 2007 National Home and Hospice Care Survey.

Cognitive Status (n=3309)	Percentage
No cognitive impairment	45
Requires occasional reminders	23
Requires some direction in certain situations	17
Requires a great deal of direction in routine situations	12
Severe cognitive impairment	3

Note: All values calculated using imputed data and represent weighted estimates.

Table 2: Demographics of Home Health Care Patients with and without Advanced Cognitive Impairment from 2007 National Home and Hospice Care Survey.

Demographics			
	All Patients (n=3309)	**Mild-to-No Cognitive Impairment (n=2248)**	**Moderate-to-Severe Cognitive Impairment (n=1061)**
	Mean	*Mean*	*Mean*
Age	68.28	69.78	65.12
	Percentage	*Percentage*	*Percentage*
Gender			
Female	65	64	67
Male	35	36	33
Marital Status			
Married	32	36	**23***
Widowed	35	34	39
Divorced	9	10	7
Separated	1	2	1
Never married	21	17	**30***
Living with a partner	1	2	0
Race/Ethnicity			
Caucasian	73	74	72
African American	16	16	18
Latino/Hispanic	8	8	9
Other	2	2	1

Note: All values calculated using imputed data and represent weighted estimates within patient categories (table columns).
* = Statistically significant difference (p < 0.05) by cognitive impairment.

Table 3: Informal Supports and Insurance among Home Health Care Patients with and without Advanced Cognitive Impairment from 2007 National Home and Hospice Care Survey.

Informal Supports and Insurance Programs			
	All Patients (n=3309)	**Mild-to-No Cognitive Impairment (n=2248)**	**Moderate-to-Severe Cognitive Impairment (n=1061)**
	Percentage	*Percentage*	*Percentage*
Habitation Status			
Alone	31	32	27
With family members	62	61	63
With non-family members	8	6	10
Has a caregiver	82	82	83
Informal Caregiver Status			
Spouse/Significant Other	27	32	**17***
Child	23	19	**30***
Other family member	50	49	53
Service Primary Payment Source			
Medicare	63	64	58
Medicaid	26	22	**34***
Private insurance	10	12	**6***
Self-pay	2	2	2
Any Secondary Payment Source	10	10	9
Secondary Payment Source			
Medicare	17	17	19
Medicaid	43	39	52
Private insurance	27	29	22
Self-pay	14	16	8

Note: All values calculated using imputed data and represent weighted estimates within patient categories (table columns).
* = Statistically significant difference (p < 0.05) by cognitive impairment.

Equations (MICE). Ten complete imputed datasets were generated using the MICE approach, and pooled analyses of these imputed datasets were used in this study. Since multiple imputation procedures are designed to give point estimates only, certain statistics that require nonlinear operations, such as calculating standard deviations from the mean and precise frequencies that are represented by sample proportions, are not available in this report.

Results and Discussion

Cognitive impairment findings

The cognitive impairment status of patients in the NHHCS sample is summarized in Table 1. Those patients with scores ranging from 2 to 4 on this scale, considered to have moderate-to-severe cognitive impairment, represent 32% of the sample. The other 68% of patients have mild-to-no cognitive impairment. These two groups are compared in this study with regard to predisposing, enabling, and illness-level factors.

Demographics findings

The average age of home health care patients is 68.28 (Table 2). Approximately one-third of patients are married, one-third are widowed, and the remaining one-third are either divorced, separated, living with a partner, or were never married. With regard to race/ethnicity, 73% of the sample is comprised of Caucasians, 16% are

African American, 8% are Latino, and a very small number are classified in the "other" category (2%).

The only significant demographic difference among patients with moderate-to-severe cognitive impairment as compared to those with mild-to-no cognitive impairment is in marital status. A smaller proportion of patients with moderate-to-severe cognitive impairment were married (23%, compared to 36% for those with mild-to-no cognitive impairment) and a larger proportion of patients with moderate-to-severe cognitive impairment were never married (30%, compared to 17% for those with mild-to-no cognitive impairment).

Informal supports and insurance programs findings

Patient informal supports and insurance programs are presented in Table 3. Sixty-two percent of patients live with family members, while only 8% live with people who are not family. Another 31% live alone. Overall, 82% of patients have an informal caregiver, which includes those living alone as well as those living with family members or other people. The relationship of the informal caregiver to the patient includes spouse or significant other (27%), child (23%), and other family member (50%).

The leading primary source of payment for home care services among patients in the NHHCS sample is Medicare (63%). Medicaid is the second leading source of payments (26%), followed by private

Table 4: Illness-Level Indicators among Home Health Care Patients with and without Advanced Cognitive Impairment from 2007 National Home and Hospice Care Survey.

Illness-Level Indicators			
	All Patients (n=3309)	**Mild-to-No Cognitive Impairment (n=2248)**	**Moderate-to-Severe Cognitive Impairment (n=1061)**
	Mean	*Mean*	*Mean*
Number of ADLs requiring assistance	2.78	2.61	**3.14***
Number of ADLs for which staff provides assistance	1.5	1.33	**1.84***
Number of diagnoses	4.24	4.09	**4.54***
	Percentage	*Percentage*	*Percentage*
Difficult Behaviors	8	5	**14***
Use of Assistive Devices	58	55	**64***
Use of Medical Devices	45	43	**51***
Incontinence Status			
Bladder incontinence	48	39	**67***
Bowels incontinence	20	12	**37***
Needs Help Taking Medications	38	30	**53***
Used Any Emergency Care	14	12	**18***
Inpatient Care Prior to Home Health Care	51	55	**42***
Place Staying Prior to Home Health Care			
Hospital	76	75	79
Nursing Facility	11	11	10
Rehabilitation Center	11	12	8
Assisted Living Facility	2	2	3
Other	0	0	0
Any Surgical, Diagnostic or Therapeutic Procedures Related to Admission to Home Health Care	23	27	**16***

Note: All values calculated using imputed data and represent weighted estimates within patient categories (table columns).
* = Statistically significant difference ($p < 0.05$) by cognitive impairment.

Table 5: Primary Diagnosis Categories of Home Health Care Patients with and without Advanced Cognitive Impairment from 2007 National Home and Hospice Care Survey.

Primary Diagnosis Category			
	All Patients (n=3309)	Mild-to-No Cognitive Impairment (n=2248)	Moderate-to-Severe Cognitive Impairment (n=1061)
	Percentage	*Percentage*	*Percentage*
Primary Diagnosis Category (ICD9 Codes)			
Infectious and Parasitic Diseases (001-139)	1	1	0
Neoplasms (140-239)	4	5	**2***
Endocrine, Nutritional and Metabolic Diseases, and Immunity Disorders (240-279)	14	13	15
Diseases of the Blood and Blood-Forming Organs (280-289)	2	2	**1***
Mental Disorders (290-319)	5	2	**10***
Diseases of the Nervous System (320-359)	7	5	**12***
Diseases of the Sense Organs (350-389)	0	0	0
Diseases of the Circulatory System (390-459)	19	20	17
Diseases of the Respiratory System (460-519)	5	7	**3***
Diseases of the Digestive System (520-579)	2	2	1
Diseases of the Genitourinary System (580-629)	3	3	2
Complications of Pregnancy, Childbirth, and the Puerperium (630-679)	0	0	0
Diseases of the Skin and Subcutaneous Tissue (680-709)	5	5	4
Diseases of the Musculoskeletal System and Connective Tissue (710-739)	9	10	**6***
Congenital Anomalies (740-759)	1	0	**2***
Certain Conditions Originating in the Perinatal Period (760-779)	1	0	3
Symptoms, Signs, and Ill-Defined Conditions (780-799)	9	7	**13***
Injury and Poisoning (800-999)	4	5	**3***
Supplementary Classification of Factors Influencing Health Status and Contact with Health Services (V01-V82)	9	11	**5***

Note: All values calculated using imputed data and represent weighted estimates within patient categories (table columns).
* = Statistically significant difference ($p < 0.05$) by cognitive impairment.

health insurance programs (10%). The primary payment source is listed as "patient and/or family" for only 2% of the sample. Only 10% of patients have a secondary source of payment listed in agency files, and among these patients the leading source of supplemental payments is Medicaid (43%), followed by private insurance programs (27%), Medicare (17%), and self-pay (14%).

While there were no significant differences in the overall proportions of patients with informal caregivers based on cognitive status, compared to other patients, patients with moderate-to-severe cognitive impairment were less likely to be cared for by spouses (17%, compared to 32%) and more likely to be cared for by adult children (30%, compared to 19%). A larger proportion of patients with moderate-to-severe cognitive impairment paid for services with Medicaid (34%, compared to 22% of other patients) and a smaller proportion of patients with moderate-to-severe cognitive impairment paid for services with private insurance (6%, compared to 12% of other patients).

Illness-Level indicators findings

On average, sampled patients require assistance with 2.78 activities of daily living, and receive help from home care personnel with 1.5 activities of daily living (Table 4). Nearly three-fifths of patients (58%) used assistive devices of some kind, and 45% used

medical devices. Almost half of the sample (48%) was incontinent of bladder, and one-fifth of patients (20%) were incontinent of bowels. About two-fifths of patients (38%) needed routine help with taking their medications. Half of the patients in the sample (51%) were receiving inpatient care prior to their admission to home health care, three-quarters of whom (76%) were in the hospital, and around one-quarter of the sample (23%) had some sort of medical procedure that was related to their admission to home health care. While receiving home health care services, 14% of patients experienced some acute medical need that required emergency care on at least one occasion. Only 8% of the sample was described in agency records as having difficult behaviors.

Patients with moderate-to-severe cognitive impairment were generally more ill than their peers, and these findings are comparable when analyzed by patient subpopulations defined by primary source of payment for service. Compared to other patients, those with moderate-to-severe cognitive impairment required assistance with more activities of daily living (3.14, as compared to 2.61), received assistance for more activities of daily living (1.84, as compared to 1.33), and had higher numbers of co-occurring medical diagnoses (4.54, as compared to 4.09). In addition, a larger percentage of patients with moderate-to-severe cognitive impairment exhibited difficult behaviors (14%, as compared to 5% for other patients), used

assistive devices (64%, as compared to 55%), used medical devices (51%, as compared to 43%), experienced bladder incontinence (67%, as compared to 39%), experienced bowels incontinence (37%, as compared to 12%), required help with taking medications (53%, as compared to 30%), and required emergency medical care during the current service period (18%, as compared to 12%). However, a smaller proportion of patients with moderate-to-severe cognitive impairment had received care on an in-patient basis prior to the current service period (42%, as compared to 55% for other patients) and a smaller percentage had a medical procedure that was related to their enrollment in home care services (16%, as compared to 27%).

Medical diagnoses are another important illness-level factor, and the sampled patients had an average 4.24 diagnoses. Table 5 displays the differences between cognitively impaired patients and their peers in terms of the ICD-9 categories containing primary medical diagnosis listed in agency records. The categories featuring primary diagnoses afflicting at least 5% of sampled patients included: Diseases of the Circulatory System (19%); Endocrine, Nutritional and Metabolic Disorders, and Immunity Disorders (14%); Diseases of the Musculoskeletal System and Connective Tissue (9%); Symptoms, Signs, and Ill-Defined Conditions (9%); Supplementary Classification of Factors Influencing Health Status and Contact with Health Services (9%); Diseases of the Nervous System (7%); Diseases of the Respiratory System (5%); Diseases of the Skin and Subcutaneous Tissue (5%); and Mental Disorders (5%).

Two disease categories with significantly larger proportions of patients with moderate-to-severe cognitive impairment included Mental Disorders (10%, as compared to 2% for other patients) and Diseases of the Nervous System (12%, as compared to 5%). While other significant differences were found among categories of primary diagnosis, these two categories are the most pertinent to this study as they include the leading causes of neurodegenerative disorder, including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal lobar degeneration, Pick's disease, Parkinson's disease, normal-pressure hydrocephalus, and alcohol-related dementia [34,35].

Discussion

The major findings of this study are that compared to other patients receiving home health services, patients with moderate-to-severe cognitive impairment had more needs for care and co-occurring illnesses, and greater medical needs and disability. They had more complex needs for assistance with medical compliance and routine tasks, as well as more behavioral challenges. In addition, they were less likely to have a spouse and more likely to pay for service with Medicaid. These findings may point to the need for specialized packages of care, including behavioral and direct care services. While such findings may fit with anecdotal information or experiential knowledge about home health care patient needs, never before have such comparisons been assessed and documented based on a nationally-representative sample nor with particular attention to cognitive impairment.

Home health care patients sampled in the NHHCS are representative of the population of patients in the United States. Although age and gender do not vary by cognitive impairment,

patients with moderate to severe cognitive impairment were less likely to have a spousal caregiver and their informal caregivers were more likely to be other family members such as adult children. These differences in caregiver relations are likely associated with the duration, frequency, and quality of informal family care for this patient population, and this has implications for assuring appropriate formal care services in home health.

Payment also varied by cognitive status, with cognitively impaired patients being less likely than other patients to pay with private insurance and more likely to pay by Medicaid. If the ability to purchase private insurance and the need or desire to enroll in the means-based Medicaid program are indicators of high and low socio-economic status, respectively, it appears that significantly more home health care patients with moderate-to-severe cognitive impairment are poor or have spent down their assets as compared to other home health patients.

The illness-level factors which determine service utilization have been found to vary significantly between patients with moderate-to-severe cognitive impairment and those with mild-to-no cognitive impairment. This includes: ADL needs; number of diagnoses; the presence of difficult behaviors; the use of assistive and medical devices; incontinence of bladder and bowels; the need for help with medications; the recent need for emergency medical attention; and the receipt of inpatient care and medical procedures prior to home care admission. The only illness-level factor that does not significantly vary by cognitive impairment status is the type of inpatient care location used prior to home care.

Home health care patients need help with an average 2.78 activities of daily living, yet the aides who provide formal care are addressing only an average 1.5 ADLs. The remaining needs are likely addressed by informal care providers, and, indeed, 82% of patients are found to have informal caregivers. Home health care patients with moderate-to-severe cognitive impairment are found to have greater needs, as well as statistically significant differences in the severity of need as compared to their less impaired peers. Patients with moderate-to-severe cognitive impairment need assistance, on average, with 3.14 activities of daily living (as compared to 2.61 ADLs for those with mild-to-no cognitive impairment) and receive assistance from formal providers for an average 1.84 ADLs (as compared to 1.33 ADLs for their less impaired peers).

The medical needs of home health care patients are extensive, with large proportions of the sample needing assistive devices (58%) or medical devices (45%), experiencing urinary incontinence (48%), and receiving in-patient care prior to enrolment in home health care (51%). More than 75% of patients who received in-patient care before home health care came out of the hospital, and another 22% came out of nursing or rehabilitation facilities. When examining differences between patients with and without advanced cognitive impairment, it is clear that home health care patients with moderate-to-severe cognitive impairment have significantly greater medical needs than their peers, with larger proportions needing help with medications, needing assistive and medical devices, and experiencing situations requiring emergency medical care. More than three times as many patients with moderate-to-severe cognitive impairment are incontinent of bowels, far more are incontinent of bladder, and nearly

three times as many exhibit difficult behaviors. The only two illness-level factors effecting significantly smaller proportions of patients with moderate-to-severe cognitive impairment are the receipt of inpatient care prior to home health care and the experience of some sort of medical procedure that was related to admission to home health care.

Limitations

The National Home and Hospice Care Survey uses a 5-point cognitive impairment scale score equivalent to the standardized OASIS measure found in nearly all case records. Since neurocognitive disorder should be operationally defined for research based on high quality diagnostic information, and such information is not available in the NHHCS dataset, the OASIS scale is used as a proxy measure for cognitive impairment and is significantly correlated with a "gold standard" measure of cognitive impairment, the Short Portable Mental Status Questionnaire [21]. However, this proxy measure should not be considered an indicator of neurocognitive disorder, and it does not allow for distinctions to be made between acute conditions like delirium and long-term conditions like coma. In addition, a small proportion of patients considered moderately-to-severely cognitively impaired are not middle-aged or elderly and are therefore likely suffering from some form of pervasive developmental disorder as opposed to an acquired neurodegenerative disease.

Importantly, while this report does not include multivariate analyses which control for covariates, such analyses were done as part of a larger study and will be reported. The larger study tests if these differences hold true after adjusting for covariates, are unique within patient populations defined by insurance payor, have an effect on service utilization and cost, and are influenced by provider agency characteristics. In this report, patient population characteristics are reported alone to provide the necessary foundational knowledge upon which future reports will be built and which offer novel insights about a major healthcare consumer population with unique and previously unreported service needs.

Conclusion

The findings reported here suggest a more complex profile of care-related needs among patients with advanced cognitive impairment, as well as service initiation more typically associated with these intense needs as opposed to patients who receive home care for rehabilitation after a hospital stay or major medical procedure. Thus, this subpopulation of patients should ideally receive tailored approaches to home health care which respond to these unique needs, including higher volumes of direct care services as well as appropriate behavioral health interventions.

Routine assessment of behavioral issues and ADLs are required in the home health care industry, but often do not trigger care plan components which appropriately respond to these needs or capitalize on the opportunities for cognitive impairment related interventions. This research demonstrates significant relationships between cognitive impairment and unique service needs among home health patients. These findings suggest that unique packages of care for home health care patients with dementia are warranted, particularly in terms of the specific behavioral and direct care services provided as well as the frequency and duration of service visits in general. The

number of older adults with neurocognitive disorder will effectively double by the year 2030 and then double again by 2050 [36]. It is critical to identify and promote the adoption of models of home health care service delivery that effectively respond to the unique needs of these impaired patients.

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