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Addressing the Gap: Occupational Therapy in Hospice Care

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Abstract

Patients receiving hospice care have a host of occupational challenges, though few are being seen in occupational therapy for treatment. Occupational therapy can help those receiving hospice care live with dignity before death. Data retrieved from the National Home and Hospice Care Survey were analyzed using independent t-tests, Wilcoxon rank-sum tests, Chi-square tests and logistic regressions. Only 10.6% of the participants received occupational therapy. Patients who received occupational therapy were significantly older and had shorter lengths of hospice care service compared to their counterparts. Over 85% of the patients needed assistance with at least one task of activity of daily living (ADL). Findings suggested a need to increase occupational therapy

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workforce in hospice care and advocate the value of occupational therapy services in hospice settings.

Keywords

occupational therapy; hospice; palliative; quality of life

Hospice care is a benefit for individuals certified to be terminally ill with a medical prognosis including a life expectancy of six months or less, should the illness run its traditional course (Centers for Medicare & Medicaid Services [CMS], 2018). Occupational

therapy is one of the hospice care services that can assist the patients to maintain independence in meaningful activities of daily living and functional skills (CMS, 2018,

section 40.1.8). CMS indicates that occupational therapy, along with other services such as physical therapy and speech-language therapy, must be provided in hospice settings, either directly or arranged, to address and meet the patient or family's needs (CMS, 2018, section

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Research ethics:

This study was approved by the University of Texas Medical Branch Institutional Review Board as an exempt study. A copy of IRB approval is attached.

Declaration of interest statement:

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Mueller et al. Page 2

40.5). To date, the number of individuals needing hospice care services has grown to nearly

20 million worldwide. However, only 14% of those individuals actually receive the end of life care they need (Von Post & Wagman, 2019).

Rehabilitation professionals can provide unique care services for the hospice population (Benthall & Holmes, 2011), though this concept of providing rehabilitation services for the dying has been challenged and is often considered controversial (Barawid, Covarrubias, Tribuzio, & Liao, 2015). Historically, research has shown that an interdisciplinary approach across all rehabilitation services is crucial to improving quality of life, dignity, function, autonomy, and independence for patients receiving hospice care (Javier & Montagnini, 2001; Russell & Bahle-Lampe, 2016; Trump, Zahoransky, & Siebert, 2005). Research has also shown positive outcomes for patients receiving end of life care that utilize both palliative care and physical medicine and rehabilitation (PM&R), a medical discipline that

addresses prevention, diagnosis, and treatment of disease or injury that results in functional limitations. These types of care share commonalities to include an emphasis on quality of life during the disease process, a focus on mind, body, and spirit, and the consideration of relationships in the family system (Wu & Quill, 2011).

At the end of life, individuals often have difficulty maintain their routines, occupational roles, occupations, and performance abilities (American Occupational Therapy Association [AOTA], 2011, p. S67). Occupational therapy helps patients participate in desired and meaningful activities, roles, and routines, with a goal to facilitate patients' overall function, well-being, autonomy, dignity, and social participation in all stages of life (World Federation of Occupational Therapists, 2016). For patients receiving hospice care in particular, engaging their participation in meaningful occupations in the last stage of life is highly

valuable (AOTA, 2016; Jacques & Hasselkus, 2004; Trump et al., 2005).

To meet the changing occupational needs for persons nearing the end of life, occupational therapy can modify personal or contextual environments to maximize occupational performance and improve quality of life. Occupational therapy can provide services such as

energy conservation counselling, caregiver education, and orthotic device evaluation (Hsin Hsiu Yeh & McColl, 2019; Javier & Montagnini, 2001; Russell & Bahle-Lampe, 2016; Trump et al., 2005). Moreover, occupational therapy can address the common concerns in hospice care, including pain and symptom management, stress management, enhance mental functions, coping, relationship or social participation, support life reflection or spiritual engagement, and provide strategies for relaxation and death planning (Benthall & Holmes, 2011; Jacques & Hasselkus, 2004; Javier & Montagnini, 2001; Lyons, Orozovic, Davis, & Newman, 2002; Pizzi & Briggs, 2004; Russell & Bahle-Lampe, 2016; Von Post & Wagman,

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2019). Occupational therapists are well equipped to address psychosocial enhancement (Benthall & Holmes, 2011). This involves helping patients continue to find meaning in life, while also preparing for death (Jacques & Hasselkus, 2004; Marcil, 2006; Russell & Bahle Lampe, 2016). Within the balance of living life and preparing for death comes the pain of loneliness, isolation, abandonment, detachment from the world, fear, and loss of control (Marcil, 2006; Pizzi & Briggs, 2004). After a client dies, there is grieving experienced by the family and other loved ones. Occupational therapy practitioners are trained to instil hope

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 3

and provide care for both the patients and their caregivers through therapeutic use of self and

Author Manuscript

utilizing the healing power of occupations (Marcil, 2006; Pickens, Chow, & McKay, 2016).

Occupational therapists provide client- and family-centered care to positively influence the lives of patients during the hospice care process (Pizzi & Briggs, 2004), though the role of occupational therapy in hospice care remains largely unexplored. It is important to identify the types of rehabilitation services the hospice population receives and benefits from. Further, it is important to identify the value of occupational therapy in hospice care. This study aims to address gaps in knowledge by comparing client demographics, needs for ADL assistance, and service use between patients with and without occupational therapy services while receiving hospice care.

Methods

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Data Source

The National Home and Hospice Care Survey (NHHCS) is a population-based database managed by the Centers for Disease Control and Prevention since 1992. The NHHCS used a stratified two-stage probability sampling to collect data nationally (Dwyer, Harris-Kojetin, Branden, & Shimizu, 2010). Collected information includes hospice agencies, staff, patients and the services provided at each home health agency. The NHHCS represents national sample as the data were collected from all types of hospice care agencies regardless of their certification or licensing status. Based on the agency census sheets, a computer algorithm was used to randomly select patients discharged from the included agencies. In-person interviews were only conducted with agency directors and their designated staffs to collect the data. The NHHCS used additional agency administrative records to supplement agency

data and medical records to supplement patient data. We used the 2007 NHHCS, the latest de-identified data in a series of the surveys. The 2007 NHHCS data are publicly available and can be downloaded from the Inter-University Consortium for Political and Social Research (ICPSR) website (<https://www.icpsr.umich.edu/icpsrweb/NACDA/studies/28961>). We obtained Institutional Review Board approval from our institution prior to conduct this study. It was approved as an exempt study and therefore, a formal IRB number was not required.

Variables

The primary variable is whether the patients used occupational therapy services while receiving home health hospice care (yes/no) during the study period. We classified our study sample into two groups: individuals who received occupational therapy services versus those

who did not receive occupational therapy services in the context of home health hospice care.

We included the following variables of interest: demographics, needs for ADL assistance, service utilization, patient characteristics associated with occupational therapy utilization, and diagnostic information at and after admission to hospice care. Demographics included age, sex, race and ethnicity, primary source of payment, and life expectancy post hospice admission. Needs for ADL assistance included the total number of ADL tasks that a client

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 4

needed help with, and six types of ADL (dressing, bathing, toileting, transferring, walking,

and eating). Other used services in addition to occupational therapy, included physical therapy, respiratory therapy, speech therapy, skilled nursing, counselling and/or psychosocial, mental health, physician, pharmacy, podiatry, wound care, dietary/nutritional, telemedicine, pastoral/spiritual services and emergent care. Types of emergent care used included hospital emergency room and doctor's office emergency visit or house call. Emergent care included medication problem/complication, injury due to fall, wound infection/new lesion/ulcer, diabetes control issues/hypoglycemia/ hyperglycemia, and other health issues that can be treated in emergent care. To identify patient characteristics associated with occupational therapy utilization for the hospice population, we analyzed variables of age, sex, race and ethnicity, marital status, primary source of payment, living status prior to admission, and type of primary caregiver. Those variables were selected based on current literature finding (Hsin-Hsiu Yeh & McColl, 2019; Javier & Montagnini, 2001;

Russell & Bahle-Lampe, 2016; Trump et al., 2005), clinical observations and data availability in the NHHCS survey. Diagnostic information included primary diagnosis at admission and after admission primary and secondary diagnoses while receiving hospice care.

Statistical Analysis

We used descriptive statistics to examine differences among demographics, needs for ADL assistance, healthcare utilization, and diagnostic information between patients receiving occupational therapy and those who did not receive occupational therapy in the context of hospice care. We conducted independent t-tests or Wilcoxon rank-sum tests based on the normality distributions for continuous variables and Chi-square tests for categorical variables. We applied the Bonferroni corrections to adjust critical p-values for multiple

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comparisons on the dependent variables of ADL needs assistance and service utilization. We used odds ratios (OR) from logistic regression to identify characteristics of patients receiving hospice care associated with probability of using occupational therapy. We also compared rates of frequency in primary admission diagnoses, and after admission primary and secondary diagnoses for patients receiving occupational therapy versus those who did not. We used SAS 9.4 (SAS, n.d.) to perform all analyses.

Results

Demographics

Table 1 illustrates the demographics between individuals who received (n=497) and those who did not receive occupational therapy services (n=4,179).

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Needs for ADL Assistance

Table 2 shows statistical significance between groups (without vs. with occupational therapy) for the total number of ADLs a patient needed help with (p<.0001). 520 individuals in the without OT group and 32 individuals in the with OT group had missing data (did not know, inapplicable or not ascertained).

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 5

Service Utilization

Author Manuscript_t

Table 3 displays other services in addition to occupational therapy used by the patients receiving hospice care between groups (without vs. with occupational therapy).

Patients Characteristics Associated with Occupational Therapy Utilization

Table 4 showed patients characteristics associated with probability of occupational therapy utilization, with higher odds ratio representing higher probability of using occupational therapy services in hospice care. REF used in the table is the reference group for each corresponding variable. "Others" in marital status included 'separated' or 'living with partner'. The variable of 'receive inpatient care prior to hospice care' included individuals who were inpatient in a hospital and who received nursing home or other health/hospice care prior to current hospice care at home.

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Occupational Therapy Visits per Diagnosis

Based on the International Classification of Diseases, Clinical Modification (ICD9) codes (Centers for Disease Control and Prevention, 2015), Table 5 showed the most common diagnoses at and after admission. We only included diagnoses that had at least 10 individuals with that respective diagnosis. Missing diagnoses data may have been due to coding or processing errors at collection, or other reasons from the reporting agency that we are not aware of. We do not have additional data sources to validate whether missing data were due to missing at random or not at random.

Discussion

The purpose of this study was to address a gap in knowledge about occupational therapy use

in hospice care. We compared demographics, needs for ADL assistance, and service use between individuals who did and did not receive occupational therapy in home health hospice care settings. Aside from patients who received occupational therapy being significantly older and having shorter lengths of hospice care services, the most important finding was that a large number of patients required assistance with at least one ADL (87.3%) but only 9.9% received ADLs assistance. Both groups of patients (without vs. with occupational therapy) needed the least assistance with eating, which may be due to the generally low difficulty/strain required for the activity (Li et al., 2016; Li et al., 2017). Additionally, the majority of the sample had a life expectancy of six months or greater. This is atypical according to the design of the hospice benefit, which is intended for individuals with a prognosis of six months or less to live. Previous reports have suggested that patients receiving hospice on average live only 2.5 months once being enrolled in the services (Teoli

& Bhardwaj, 2019). However, the illness may not always run its normal course and many factors can potentially impact actual life expectancy. Each individual deserves living their lives with dignity regardless of the length of life expectancy after being prescribed hospice care. Teoli and Bhardwaj (2019) reported that individuals receiving hospice care had multiple diagnoses that may affect their life expectancy. In our study, we found abnormality of gait, later effects of cerebrovascular disease, and diabetes mellitus were common diagnoses occupational therapy served in home health hospice care settings. Occupational

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 6

therapy can delay developmental process of multiple or worsening comorbidities in the

context of hospice care to enhance patients' quality of life.

Reasons for emergent care use were also an important finding of our study. According to the Occupational Therapy Practice Framework, reasons for emergent care fall under the occupations of health management/maintenance and functional mobility (AOTA, 2020), including injury due to fall, other type of injury, wound infection or new lesion/ulcer and diabetes control. These are conditions that occupational therapy practitioners are skilled in addressing such as providing strategies in self-management in patients' pain or their diseases symptoms and help patients perform some levels of self-care activities such as bathing and

dressing (AOTA, 2020). Among 12% of the sample utilized emergent care, only 1.7% received occupational therapy. If an occupational therapist was able to intervene with these individuals, emergent care use may be significantly reduced.

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To explore the above-mentioned gap further, we analyzed patient characteristics associated with occupational therapy utilization and also admission primary, after admission primary, and after admission secondary diagnoses per visit. It is expected that patients enrolled in Medicare used more occupational therapy service compared to their counterparts because Medicare covers hospice benefit (CMS, 2018). In addition, being in a hospital, nursing home, or other institutional care setting prior to hospice care may make for easier access to other services such as occupational therapy compared to those living at home on their own or in the community. However, being in institutional settings also implies an already compromised health status of the patients. It is essential to advocate and educate the role and value of occupational therapists to other professions in hospice care regardless of working at the institutional or community-based care settings. Interestingly, we found patients with a

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primary caregiver (outside of the agency they received services from) used more occupational therapy services. This finding implies primary caregivers may seek for advices or more services and advocate for their loved-one or care recipients to receive supports and use more resources.

Occupational therapy has traditionally been an indirect consultation service for hospice agencies with a role that has not been clearly defined (Russell & Bahle-Lampe, 2016). Primary caregivers may have more direct knowledge of the benefit of occupational therapy than agencies as caregivers work closely with the patients. We suggest occupational therapists working in hospice care can collaborate and advocate the role of occupational therapists to the associations ran or supported by the caregivers. Agencies may also need additional training and resources to expand their understanding of positive influences occupational therapy can bring to patients' life in hospice settings. Saeed et al. (2018) found

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women were more likely than men to prefer comfort care at the end of life. However, our results did not find significant difference in occupational therapy use by sex. We suggest future studies examining sex differences in hospice care and occupational therapy use as there is little research on effectiveness of hospice care by males and females.

Study Limitations

This study had several limitations. First, the group that did receive occupational therapy services was much smaller than their counterparts. Thus, the power of our study finding

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 7

could be limited. We also had a similar issue (not enough power) for detecting a meaningful

difference between groups with small sample size (e.g. respiratory therapy). Second, the available data were collected more than a decade ago and interventions may have changed over the past years, though the data are the latest available and the primary eligibility or

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structure of many care programs have not changed since that time. Many studies to date still use this data as a source of detailed hospice care because this data provides rich information that cannot be obtained elsewhere. Third, this was a retrospective study that was not designed to answer our study questions nor allow for obtaining additional variables such as psychosocial information (e.g. stress, anxiety) for our study cohort. Psychosocial information in the dataset did include a depression rating, however, “inapplicable/not ascertained” was reported for all participants. Lastly, our finding can only apply to the home health hospice patients, which does not make it generalizable to the individuals receiving different types of hospice care.

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Conclusion

This study found only 10.6% of the patients received occupational therapy in a national sample while utilizing home health and hospice care but a high percent of this population required ADL assistance. Even at the end of life, individuals should have the right to participate in ADLs and other desired occupations to maintain their dignity and quality of life. More than 80% of our national sample had life expectancy greater than six months; this makes it important for patients and their family members to maintain their well-being during this period. Occupational therapy is a profession that can make unique contribution to help patients receiving hospice care live their life to the fullest by managing their symptoms, participate in their desired occupations, and improve their abilities to perform basic self-care

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activities. Our findings provide a glimpse of our current professional role and value in home based hospice care. It also shows a gap between current occupational therapy workforce and the needs to advocate the role of occupational therapy practitioner to serve the hospice population.

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Table 1.

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Sample Demographics Comparison (N=4,676)

Variables Without OT (n=4,179)		With OT (n=497)		p value
Age at interview (year)	67.8 (SD=22.2)	72.4 (SD=18.1)	Age Group (year) (n, %)	<0.0001* ^a
1–18	207 (5.0)	12 (2.4)	19–45	344 (8.3)
19–45	344 (8.3)	23 (4.6)	46–65	827 (19.9)
46–65	827 (19.9)	76 (15.3)	66–75	782 (18.8)
66–75	782 (18.8)	103 (20.7)	76–85	1147 (27.6)
76–85	1147 (27.6)	176 (35.4)	85–99	819 (19.7)
85–99	819 (19.7)	105 (21.1)	Length of current episode of care from admission to interview (day)	273.4 (SD=349.7)
91.5 (SD=187.8)	<0.0001* ^b	Sex	0.4001	
Female	2,627 (62.9)	322 (64.8)	Male	1,552 (37.1)
Male	1,552 (37.1)	175 (35.2)	Race/Ethnicity	0.0070* ^c
Non-Hispanic White	3,200 (76.6)	412 (82.9)	Non-Hispanic Black	452 (10.8)
Non-Hispanic Black	452 (10.8)	42 (8.5)	Hispanic or Latino	275 (6.6)
Hispanic or Latino	275 (6.6)	16 (3.2)	Others	102 (2.4)
Others	102 (2.4)	8 (1.6)	Did not know	150 (3.6)
Did not know	150 (3.6)	19 (3.8)	Primary Source of Payment	<0.0001* ^d
Medicare	2,236 (53.5)	398 (80.1)	Private insurance	435 (10.4)
Private insurance	435 (10.4)	42 (8.5)	Self-pay (patient/family)	139 (3.3)
Self-pay (patient/family)	139 (3.3)	1 (0.2)	Other	349 (8.4)
Other	349 (8.4)	22 (4.4)	Life Expectancy	0.0112* ^e
Greater than 6 months	3,423 (82.0)	407 (81.9)	6 months or less	562 (13.4)
6 months or less	562 (13.4)	83 (16.7)	Not indicated but receiving palliative care/end of life care	13 (0.3)
Not indicated but receiving palliative care/end of life care	13 (0.3)	0 (0.0)	Not indicated and not receiving palliative/end of life care	87 (2.1)
Not indicated and not receiving palliative/end of life care	87 (2.1)	2 (0.4)		

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*p < 0.05: Significant difference between groups (without OT vs. with OT)

^a:Age was missing for 18 individuals in the without OT group.

^b:Length of current episode of care was missing for six individuals in the without OT group.

^c:Life expectancy was missing for 94 individuals in the without OT group and five individuals in the with OT group.

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 10

Table 2.

Needs for ADL Assistance (N=4,676)

	Variables Without OT (n=4,179)		With OT (n=497)		p value
Total # of ADLs Client Needs Help With (dress, bath, toilet, transfer, walk, or eat)	<0.0001*				
	0	43 (1.0)	1	(0.2)	
	1	712 (17.0)	35	(7.0)	
	2	625 (15.0)	57	(11.5)	
	3	732 (17.5)	115	(23.1)	
	4	1,072 (25.7)	193	(38.8)	
	5	475 (11.4)	64	(12.9)	
ADL Client Needs Help With[^]	<0.0001*	Dressing 2,492 (59.6)	363	(73.0)	<0.0001*
		Bathing 3,035 (72.6)	419	(84.3)	<0.0001*
		Toileting 1,584 (37.9)	246	(49.5)	<0.0001*
		Transferring 2,078 (49.7)	340	(68.4)	<0.0001*
		Walking 2,221 (53.1)	345	(69.4)	0.0457
		Eating 781 (18.7)	114	(22.9)	

*p < .008 (Bonferroni correction): Significant difference between groups (without OT vs. with OT);

[^]:the same person can be counted for more than one ADL task(s).

Table 3.

Service Utilization in Hospice Care (in addition to OT) (N=4,676)

Variables Without OT (n=4,179)		With OT (n=497)		p value
Other Services Used				
Physical Therapy	1,072 (25.7)	427 (85.9)	<0.0001*	Respiratory Therapy 42 (1.0)
	34 (0.8)	38 (7.6)	<0.0001*	8 (1.6) 0.2154 Speech Therapy
	(22.6)	176 (35.4)	<0.0001*	Skilled nursing 3,525 (84.4)
				449 (90.3) 0.0003* Counselling and/or psychosocial 943
				0.0840 Physician 285 (6.8)
				38 (7.6) 0.1533 Pharmacy
				156 (3.7) 22 (4.4) 0.1451 Podiatry 26 (0.6)
				1 (2.1) 0.0988 Wounds 699 (16.7)
				100 (20.1) 0.0311 Dietary/nutritional 297 (7.1)
				32 (6.4) 0.1689 Telemedicine 69 (1.7)
				12 (2.4) 0.0908 Pastoral/spiritual 28 (0.7)
				5 (1.0) 0.3976 Emergent care 479 (11.5)
				81 (1.7) 0.0038
Reason for Emergent Care Use				
Medication problem/complication	19 (0.5)	5 (1.0)		Injury due to fall 37 (0.9)
				4 (0.8)
Other health issues	11 (0.3)	2 (0.4)		Wound infection/new lesion/ulcer 42 (1.0)
				7 (1.4)
Diabetes control problem/hypoglycemia/hyperglycemia	2 (0.3)	6 (1.2)		

Table 4.

Patients Characteristics Associated with Utilization of Occupational Therapy Services in Hospice Care (n=497)

	Variable Odds Ratio 95% Wald Confidence Limits
Age <65 years old REF	≥65 years old 1.06 0.67 1.67
Sex Female REF	Male 1.08 0.78 1.9
Race White REF	Black 0.68 0.40 1.14 Hispanic 0.53 0.26 1.05
Marital Status Married REF	Single 1.22 0.74 2.00 Divorced 1.24 0.70 2.19 Widowed 1.25 0.87 1.78 Others 1.30 0.44 3.8
Medicare* No REF	Yes 2.31 1.29 4.13
Medicaid No REF	Yes 0.60 0.30 1.22
Dual (both Medicare and Medicaid enrolment) No REF	Yes 0.50 0.22 1.15
Veterans No REF	Yes 0.83 0.46 1.48
Receive inpatient care prior to hospice care* No REF	Yes 2.21 1.65 2.97

Live alone No REF	Yes 0.84 0.59 1.18
Receive primary care prior to hospice care No REF	Yes 1.41 0.94 2.10

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*Significant association between the corresponding variable and the outcome (use of OT services in home health hospice

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care).

Occup Ther Health Care. Author manuscript; available in PMC 2021 June 11.

Mueller et al. Page 13

Table 5.

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Occupational Therapy Visits per Primary Diagnoses at Admission, after Admission Primary and Secondary Diagnoses of Home Health Care (n=497)

ICD-9 Diagnosis	Admission primary		After Admission	
	Primary	Secondary	Primary	Secondary
	Number (%)	496 (99.8)	496 (99.8)	452 (90.9)

25002 Diabetes mellitus without mention of complication,

type II or unspecified type, uncontrolled 19 (3.8) 22 (4.4) 34 (7.5) 340 Drug dependence 11 (2.2) 10 (2.0) - 42731 Atrial fibrillation 10 (2.0) - - 4280 Congestive heart failure, unspecified 19 (3.8) 19 (3.8) 18 (4.0) 43889 Other late effects of cerebrovascular disease 34 (6.9) 34 (6.9)

496 Chronic Obstructive Pulmonary Disease, unspecified 14 (2.8) 14 (2.8) 12 (2.7) 72887 Muscle weakness, generalized - 11 (2.2) - 7289 Unspecified disorder of muscle, ligament, and fascia 10 (2.0) 11 (2.2) 15 (3.3) 78079 Other malaise and fatigue 10 (2.0) 11 (2.2) 22 (4.9)

7812 Abnormality of gait 53 (10.7) 49 (9.9) 38 (8.4) V5413 Aftercare for healing traumatic fracture of hip 23 (4.6) 20 (4.0) - V5419 Aftercare for healing traumatic fracture of other bone 13 (2.6) 12 (2.4) - V5849 Other specified aftercare following surgery 15 (3.0) 12 (2.4) -

4019 Unspecified essential hypertension - - 51 (11.3) 71590 Osteoarthritis, unspecified whether generalized or

localized, site unspecified - - 14 (3.1)

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