The Influence of Engaging in Medical and Nursing Tasks on Caregiver Burden among Caregivers of Individuals with Cognitive Impairment

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Abstract

Background: Almost half of caregivers perform medical/nursing tasks (MNT) such as managing multiple medication and providing wound care. However, little is known about the involvement of providing MNT to caregiver burden, particularly, among caregivers of individuals with cognitive impairment (ICI).

Objective: (1) To examine differences in caregivers' background characteristics and caregiving context between the group performing MNT versus the group *not* performing the tasks, and (2) to investigate the effect of caregivers' appraisal of performing MNT on caregiver burden.

Methods: Secondary data analyses were conducted using data from the 2015 National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP). Independent *t*-tests, bivariate correlation, and hierarchical multiple regression were used. Missing data were examined and a single-stage weighting was applied.

Results: More caregivers who performed MNT lived with care recipients and provided longer hours of care than caregivers who did not perform MNT. Caregivers' feeling difficulty in MNT was the most influential factor followed by caregivers' physical health, income, and level of the care coordination.

Discussion: This is the first study that comprehensively examined the relationship of performing MNT to caregiver burden. Healthcare providers should be cognizant of caregiver burden related to MNT and researchers should develop interventions and community services to decrease caregivers' difficulty in performing their roles.

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Dedication

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Taste and see that the LORD is good; blessed is the one who takes refuge in him.

-Psalm 34:8-

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CHAPTER 1: Introduction

Cognitive impairment is defined as a noticeable decline in one of the intellectual domains, such as memory, language, or executive functioning (American Psychiatric Association, 2013). Up to 42% of adults, aged 65 years or older, have cognitive impairment and need assistance in their day-to-day functions such as balancing a checkbook, driving a car, or finding housing (Geda, 2012; U.S. Preventive Services Task Force, 2016). Caregivers such as family members, friends, and neighbors provide 83% of the care needed by older adults in the United States (Alzheimer's Association, 2018). More than 16 million people provide care for older adults with cognitive impairment, and their unpaid care has valued at $232 billion to the nation (Alzheimer's Association, 2018). Without rewards or payments, caregivers considerably sacrifice or suffer their physical, emotional, and financial well-being to take care of their loved ones, and this has been conceptualized as caregiver burden (van der Lee et al., 2014).

It is clear from the literature that the level of a person's functional impairments usually determines the amount and frequency of the caregiver's support for the person's daily living activities that increases the caregiver burden (Mohamed, Rosenbeck, Lyketsos, & Schneider, 2010; Razani et al 2014). What is less clear is the caregiver burden experienced when caregivers engage in more specific roles such as performing medical/nursing tasks. Medical/nursing tasks are skilled activities such as dealing with wound and ostomy care, incontinence care, assistive mobility devices and medical equipment, and complex medication regimen including injections (Reinhard, Levine, & Samis, 2012). Recent evidence suggests that almost half of family caregivers perform medical/nursing tasks and the caregivers "felt stressed and worried about making mistakes" while performing their role (Reinhard & Levine, 2012, p.3). However, current literature does not address the association between caregivers’ medical/nursing assistance for individuals with cognitive impairment (ICI) and caregiver burden.

The **purpose of the current study** is to examine whether performing medical/nursing tasks for ICI affects caregiver burden, to better understand the caregiving environment and to help caregivers recognize often hidden caregiving responsibilities. In this proposed study, cognitive impairment will refer to a decline in memory, which is one of the main intellectual domains, because memory loss is the most common symptom in cognitive impairment diseases (Alzheimer's Association, 2017). Research Questions are (1) What is the current evidence regarding prevalence, types, challenges, and the impact of medical/nursing tasks on caregivers for older adults with cognitive impairment, (2) Are there differences in caregivers’ background characteristics and caregiving context between the group performing medical/nursing tasks versus the group not performing the tasks, and (3) What is the effect of caregivers’ appraisal of performing medical/nursing tasks on caregiver burden.

CHAPTER 2: Dissertation Proposal

BACKGROUND

Individuals with Cognitive Impairment

Because of the rapidly growing numbers of older adults, especially the dramatic increase in adults aged 80 and older, cognitive impairment will increase dramatically, resulting in a public health crisis (Wimo, Jönsson, Bond, Prince, & Winblad, 2013). When decline in one or more cognitive domains (e.g. memory, language, executive functioning) is severe enough to affect every day activities, dementia is often diagnosed, the most common type being Alzheimer’s disease (American Psychiatric Association, 2013; Alzheimer's Association, 2017). Globally, 47 million people have dementia and the number of people with dementia is expected to double in 20 years; and to exceed 74.7 million by 2030 and 131.5 million by 2050 (The Global Voice on Dementia, n.d.; WHO, 2017).

In the U. S., the population older than 65 years old will double to 72 million in the next 25 years; approximately 20% of the U.S. population will be older adults by 2030 (CDC, 2013). Among all Americans today, 5.5 million are estimated to have Alzheimer’s disease. Every 66 seconds, another American is diagnosed with Alzheimer’s disease; 16 million are expected to have Alzheimer’s disease by 2050 (Alzheimer’s Association, 2017). The health care costs of Alzheimer’s and other types of dementia in the U.S. is estimated to be $259 billion in 2017. This figure will increase to over $1.1 trillion in 2050 based on the current trajectory (Alzheimer’s Association, 2017).

Caregivers

Currently, more than 15 million family members or friends provide care to an ICI without any financial compensation (Alzheimer’s Association, 2017). It is estimated that 18.2 billion hours of care were provided in 2016, at a value of $230 billion (Alzheimer's Association, 2017). Because of the rapidly growing number of ICIICI, far more care provided by family and friends will be required in the near future (CDC, 2011).

Caregivers provide a broad spectrum of assistance for ICI. Caregivers assist not only with activities of daily living (ADL), such as feeding and dressing; but also with instrumental activities of daily living (IADL), such as managing finances and shopping. Moreover, caregivers coordinate with a wide variety of healthcare providers, giving crucial information regarding healthcare history and changes in symptoms and complications (Institute of Medicine, 2008). Caregivers are essential to successful treatment, reduced home health care use, and delayed nursing home placement (Van Houtven & Norton, 2004).

Caregiver Burden

Caregiver burden is the physical, emotional, and financial suffering of caregivers' health, social life, job, and other family relations, when caring for a person with a disability or some type of deterioration (George & Gwyther, 1986; Zarit, Todd, & Zarit, 1986; Pearlin, Mullan, Semple, & Skaff, 1990; Gaugler et al., 2010). Caregiving effects on caregivers' health are various and complex, and the effects on an individual level are diverse. However, there have been consistent reports on a great deal of negative physical, psychological, and financial consequences on caregivers (Brodaty, 2009).

Caregivers of ICI (i.e., dementia and Alzheimer's disease) are at an increased risk of numerous physical health problems such as decreased immunity, cardiovascular disease, and higher rates of chronic conditions (e.g., hypertension and diabetes) (Schulz & Martire, 2004; Mausbach, Harvey, Goldman, Jeste, & Patterson, 2007). It is reported that caregivers visit the emergency room twice as often as non-caregivers and three times the number of visits to a physician compared to non-caregivers (National Alliance for Caregiving, Schulz, & Cook, 2011). Moreover, caregivers experience depressive symptoms, anxiety, and sleeplessness as a consequence of caregiving and they tend to have decreased self-esteem and self-efficacy (Pinquart & Sorensen, 2003; Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014; Liu et al., 2017). Lastly, caregivers are twice as likely to suffer financial difficulty, five times as likely to withdraw from social activities, and three times more likely to experience a loss in job productivity than individuals who did not provide care to their loved ones (JAMA Network, 2016).

Medical/nursing tasks

The *Home Alone* (Reinhard et al., 2012) national survey raised an alarm about caregiver burden, reporting that 47% of caregivers provide a range of medical/nursing tasks. The *types of medical/nursing tasks* have become complicated due to the advancement of medicine, care recipients' complexity of chronic diseases, and earlier discharge after acute episodes of a disease (Donelan et al., 2002; Schulz & Martire, 2004). More than one-third of caregivers help administer five to nine medications, including giving intravenous fluids and injections, and approximately 14% of caregivers operate mechanical ventilators and tube feeding systems (Donelan et al., 2002; Reinhard et al., 2012).

Caregivers may be poorly prepared to perform medical/nursing tasks compared to professional healthcare providers because they have not been trained to perform those tasks. Registered nurses are trained to provide this type of care after approximately two to four years of education that combines didactic lecture and clinical learning hours (on average 900-1200 hours in Bachelor of Science in Nursing program) (Commission on Collegiate Nursing Education, 2013; American Nurses Association, 2016). In contrast, caregivers may get limited training on how to perform medical/nursing tasks when an older adult is being discharged from an inpatient setting or at a routine doctor's appointment. Only 14% of caregivers report receiving some preparation or training; about 61% of caregivers learned how to perform at least some of these tasks *on their own* (Reinhard et al., 2012; National Alliance for Caregiving and the American Association of Retired Persons [NAC/AARP], 2015). Nearly 12% of the caregivers reported that they made errors in the administration of medication (Donelan et al., 2002) and 66% of them responded in a survey that they felt providing wound care was hard; they were anxious about harming the care recipients and making a mistake (Reinhard et al., 2012).

Recently, two qualitative studies were published on caregivers of ICI and caregiver experience with medical/nursing tasks (Ball et al., 2015; Smith, Grijseels, Ryan, & Tobiansky, 2015). Ball et al (2015) found that family caregivers had a lack of information and support specific to feeding strategies. In addition, the caregivers had no training on assessing nutritional needs for the care recipients or on methods for ensuring adequate food intake. Smith and colleagues (2015) investigated caregiver needs regarding medication regimens and found that caregivers urgently need education on what or how much medication to give and potential side-effects.

In summary, current literature offers some descriptive findings about general caregivers and caregivers of ICI challenges who perform medical/nursing tasks. The relationship between medical/nursing tasks and caregiver burden has not been clearly understood. To better understand caregiver burden among caregivers of ICI, there is a critical need to examine whether the caregivers' sociodemographic profile (e.g., gender, age, income, education) and functional status of the ICI is related to that burden of medical/nursing tasks (Moorman & Macdonald, 2012).

SPECIFIC AIMS

This dissertation study comprises three manuscripts based on each specific aim. First, a review of the current literature regarding prevalence, types, challenges, and the impact of medical/nursing tasks on caregivers for older adults with cognitive impairment was conducted, second, an examination of the caregivers' background characteristics and caregiving context between the group performing medical/nursing tasks versus the group not performing the tasks was done, and finally, an investigation of the effect of caregivers' appraisal of performing medical/nursing tasks on caregiver burden was examined.

CONCEPTUAL FRAMEWORK

The stress process model is designed to understand the caregiving phenomenon particularly among caregivers of persons with dementia (Pearlin, Mullan, Semple, & Skaff, 1990). Pearlin and colleagues (1981) viewed stress as occurring over time within social and psychological conditions and these components are interconnected to form a process. The stress process model explains how and what multidimensional domains affect caregivers' psychological outcomes within the four *domains*: (1) contexts, (2) stressors, (3) intervening variables in the relationship with stress (the mediators of stress), and (4) its outcomes. First, the background contextual variables that include caregivers' sociodemographic characteristics affect the degree of caregiver burden. For example, female caregivers tend to report increased caregiver burden compared to male caregivers and caregivers who are of an older age or a lower educational level experience greater burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Springate & Tremont, 2014). Given that those contextual factors link with the caregivers' social and economic aspects of their role, they shape the caregivers' personal and social resources available to deal with the stressors associated with caregiving. Second, the stressors are care recipient-related factors that compose the primary and secondary stressors. Primary stressors are patient symptomatology and secondary stressors are consequences of the primary stressors. As patients' symptoms worsen, they are more dependent on caregivers with higher levels of ADL/IADLs. Research shows that the patient's dependency on ADL/IADL was associated with higher caregiver burden (Kang et al., 2014). In addition, spending more hours of caregiving or living with the care recipients was associated with higher levels of caregiver burden (Kim, Chang, Rose, & Kim, 2012). Third, the intervening or mediating variables that may decrease the degree of caregiver burden are social support and other resources. Social support includes education, emotional support, and family associations. Social resources contain domiciliary, community, and institutional support. Lastly, some identified caregiver-related *outcomes* are depression, anxiety, irascibility, cognitive disturbances, physical health, and yielding of the caretaking role (Pearlin et al., 1990). Although Pearlin and colleagues did not articulate caregiver burden in their outcomes, caregiver burden is an interchangeable terminology for caregiver stress. The caregiver burden is the most common and major psychological outcome related to caregiving (Llanque, Savage, Rosenburg, & Caserta, 2016).

In this study, the current framework was used to understand burden associated with performing medical/nursing tasks. The variables were selected based on the availability on the 2015 NAC/AARP data set. First, the contextual variables were socio-demographic factors of caregivers: Age, gender, education, and income level. Second, the stressors were care recipients' functional status: ADL and IADL scores, the number of hours of caregiving, co-habitus status, and caregiver's physical health. To examine whether performing medical/nursing tasks contributes to the caregiver burden, 1) delivery of the tasks (Yes or No) and 2) the perceptions of the difficulty of the tasks were examined. Fourth, caregiver burden was chosen as the outcome in the study. Based on the demands of contextual variables and the stressors, caregiver emotional, physical, and financial burden were investigated.

METHODS

A. Research Design

The proposed dissertation study used a cross-sectional, descriptive, and correlational design using secondary data collected by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) released in 2015.

B. Subjects and Setting

The sample of this study was drawn from the NAC/AARP data (NAC/AARP, 2015) that was consisted of 1,248 caregivers regardless of care-recipients' disease status. For the purposes of the current study, the sample who reported that their care recipients need care because of a memory problem were selected. Two subgroups of caregivers were of interest: Those who performed medical/nursing tasks and those who did not.

The sampling recruitment of NAC/AARP (2015) data was nation-wide simple random sampling. The NAC/AARP (2015) recruited family caregivers by utilizing Growth from Knowledge (GfK) online KnowledgePanel® from September 18th to November 5th in 2014. The GfK selected the possible participants by a random selection of telephone numbers and residential addresses. The selection criteria were the following: (1) informal caregivers (who provide unpaid care); (2) adult (age equal to and older than 18); (3) have provided care at any time in the last 12 months; and (4) caring for household members in the community. Persons in those selected households were invited as part of a KnowledgePanel® through telephone or mail. The people who agreed to participate in the online interview received unique log-in information for accessing the questionnaires. In short, only the respondents randomly-selected by GfK were eligible to complete the full interview. The sample in the data set are nationally representative of family caregivers with respect to a large random sample (N=1,248) and a low margin of error (2.8%). The response rate of the study was low (16.3%, 1,248 were obtained out of 7,660 attempts) because the invitation attempts to the survey included a screening for eligibility for the survey, hence, the compromising response rate was inevitable (National Alliance for Caregiving, 2015).

C. Instruments

The details of operationalization of study constructs are presented (see **Table 1**) including the variables, levels of measurement, instruments to measure each, and methods to capture each construct.

1) Socio-Demographic Questionnaire (SDQ). The NAC/AARP developed 33 questions of socio-demographic characteristics of care-recipients and caregivers for *Caregiving in the U.S. 2015* research. For this study, 9 questions out of 33 questions were pulled out and used to capture care-recipients' and caregivers' socio-demographic characteristics: Care-recipients' backgrounds (age and gender) and caregivers' contextual information (age, gender, race, education level, geographical region [rural or not]), employment status, and income level).

2) Caregiving Questionnaire (CQ). The NAC/AARP developed 25 questions regarding caregiving characteristics. For this study, 6 questions out of 25 questions were used: Number of helpers, number of hours for caregiving (weekly), caregiver status (primary or secondary),

caregiver heath status (self-rated, single item, 5-point Likert-scale), caregivers' relationship with care-recipients (spouse, adult-child, relatives, friends, others), and caregivers' co-habitus status with care-recipients.

3) Performing Medical/Nursing Tasks Questionnaire (PMNTQ). The NAC/AARP developed a 7-item questions of performing medical/nursing tasks questionnaire. For this study, 2 questions out of 7 questions were used: performing medical/nursing tasks (Yes = 1; No = 2, and Not sure = 3) and the degree of feeling difficulty in performing medical/nursing tasks (1-5 Likert scale; 1 is not at all difficult, 5 is very difficult).

4) Activities of Daily Living (ADL). Katz and colleagues (1963) developed the ADL scale to measure the basic functional status of patients, particularly for the chronically ill and aging population (Katz, Ford, Moskowitz, Jackson, & Jaff, 1963). The ADL is a 6-item dichotomous-type (1 = dependent, 0 = independent) scale that evaluates care-recipients' basic functional abilities (such as getting in and out of beds, getting dressed, toileting, bathing, and feeding). The total ADL score were used which sums individual responses of the six items (range: 0-6). The higher the score, the more dependent and the lower functional status of care-recipients. The Katz ADL showed high internal consistency (Cronbach's $\alpha = 0.838$) and strong convergent validity with Barthel Index (BI) ($rs = 0.988$, $p<0.001$) and with the 36 item short-form physical functioning (SF-36 PF) scale ($rs = 0.674$, $p<0.001$) in a previous study (Arik et al., 2015).

5) Instrumental Activities of Daily Living (IADL). The IADL developed by Lawton and Brody (1969) assesses the more complex activities of daily living skills that are necessary for independent living in the community (Lawton & Brody, 1969). The IADL is a 7-item dichotomous-type (1 = dependent, 0 = independent) scale that evaluates care-recipients' complex

functional ability (such as shopping, preparing food, housekeeping, doing laundry, using transportation, handling medications, and handling finances). The total IADL score was used in this study which sums individual responses of the seven items (range: 0-7). The higher the score, the more dependent status of care-recipients. The IADL showed high interrater reliability (.85) and strong convergent validity with Physical Self-Maintenance Scale (Pearson r =. 61) and with the Physical Classification Scale (Pearson r = .40) (Lawton & Brody, 1969).

6) Caregiver Burden Questionnaire (CBQ). The NAC/AARP developed 3 items for a caregiver burden questionnaire to measure three domains (emotional, physical, and financial burden). The individual item and the combined (total CBQ) scores were used in this study. The CBQ asks the respondents to consider "How emotionally stressful would you say that caring for your family member is for you?" and offers five ordinal Likert-type responses that range from 1 to 5 (not a strain at all = 1; very much of a strain = 5). The total CBQ score is a combination of individual responses of the three items (range: 3-15) and the higher score means more caregiver burden.

The CBQ questionnaire has been used by NAC/AARP since 2004, but the organization did not report the reliability and the validity of the questionnaire. One study (Kim et al., 2012) used the CBQ and the Cronbach's alpha was .76 when they analyzed the 2004 NAC/AARP data for investigating predictors of caregiver burden. In this study, Cronbach's α was checked for assessing the reliability of the CBQ for the current study sample.

D. Procedure

The proposed study was a cross-sectional, descriptive, and correlational design using secondary data analysis. The NAC/AARP collected data in 2014 and they released the deidentified data and made it publically available in 2015. This study was approved as exempt (IRB# 2017-0488-00) by the University's Institutional Review Board for the Social and Behavioral Sciences. Permission for usage of the data set was obtained from the NAC/AARP and the data management/analysis were conducted.

E. Plan for Data Analysis/Management

Data Analysis

The analytical methods by specific aims are presented in **Table 2**. First, to describe characteristics of caregivers who perform medical/nursing tasks, descriptive statistics were used (Specific Aim 1). Second, to examine the impact of performing medical/nursing tasks on caregivers' burden (Specific Aim 2), Independent t-test or χ^2 were conducted. The level of significance (α) of .05 and the two-tailed test were used. Third, to examine if the perceived level of difficulty in medical/nursing tasks can predict caregiver burden (Specific Aim 3), hierarchical multiple regression was performed. Hierarchical multiple regression is to identify predictive factors on caregiver burden considering interrelationships among variables. Data were checked for violations of the assumptions including normality, multicollinearity, and homoscedasticity. The Statistical Package for Social Science (SPSS) version 24 (IBM Corp, 2016) was used.

In addition to these analytical methods, a **weighting technique** was applied to reflect the national population. The samples of the 2015 NAC/AARP data set (1,248 sample size) were randomly-selected and weighted using a single-stage weighting approach by age, sex, and race/ethnicity for population estimates. The population estimates were based on the public-use data file of the Current Population Survey performed by the U.S. Census Bureau in 2014. The

2015 NAC/AARP data set included the population weighting variable in their SPSS data file and the weighting was implemented in this study to reflect the U.S. population of caregivers of ICI.

Data Management

Data screening/coding and missing data management were considered. Four steps of data screening/coding management were considered: (1) *Descriptive statistics* and *Univariate normality* were performed to check that all the variables are entered correctly. Out-of-range and impossible values were checked by utilizing minimum/maximum and means/standard deviations statistics. (2) *Multivariate outliers* in the data set were further examined using several diagnostic indices such as Centered Leverage (2k/n) for leverage, studentized residual (±3.0) for discrepancy, and Cook's distance ($D_i > 1.0$) for influence. Careful consideration on whether or not to change the outliers or exclude from the data analysis was given. If the outliers result from an unanticipated extraneous process, the outliers were excluded (Van den Broeck et al., 2005). (3) *Multicollinearity* (the correlation between two independent variables) were checked using variance inflation factor (VIF), tolerance, condition number (kappa), and/or condition indices. If nonessential multicollinearity was found, the mean was set to zero or the variable was centered (Kellar & Kelvin, 2013). (4) *Multivariate normality* was checked. Each variable was paired up and the pair's linear relationship was tested; homoscedasticity was tested for the residuals (Kellar & Kelvin, 2013).

F. Limitations

There were four potential limitations in the study. First, psychometric properties (reliability and validity) of the caregiver burden scale were not clearly delineated for the primary data set (NAC/AARP 2015). To address this issue, testing Cronbach's α for assessing the reliability of the scale was conducted. Second, this study could not draw causal inference to mediation effect, given that the nature of the primary data set is cross-sectional. The data set provided a snapshot at a specific point in time, hence, information from what occurred before and after the snapshot were missing (Levin, 2006). To make the causal inference, a randomized controlled trial is needed in the future study to meet three conditions for causal relations such as isolation, association, and direction of causality (Bollen, 1989). Third, care recipients' memory problem was not specified into particular disease type such as mild cognitive impairment, Alzheimer's disease, or other types of dementia. It was based on caregivers' self-reported response whether their care recipients have memory problems or not. It was thus, be difficult to ascertain whether the type of memory loss was influential in understanding caregiver burden and performing medical/medical/nursing tasks. Fourth, the 2015 NAC/AARP data set did not provide subpopulation weights for the caregivers of ICI, although the data set contains a population weight. To address this limitation, in this study, finite population statistics was applied to the population weight in our analysis, but the results might have not been fully representative with respect to caregivers of older adults with cognitive impairment (Lavallée & Beaumont, 2015).

G. Human Subjects

This study was submitted to the University's Institutional Review Board for the Social and Behavioral Sciences and it has been classified as exempt (IRB#: 2017-0488-00). This study was under the exempt review categories that involve a publicly available and de-identified existing data set (U.S. Department of Health & Human Services, 2009). Minimal risk existed because the applicant was using an existing data set and subjects could not be identified directly or through identifiers linked to them. The benefits outweighed the risks in the study. This study contributed to a better understanding of caregiver burden related to medical/nursing tasks performed by the caregivers in the community setting.

Table 1

Operationalization of Study Constructs

Construct	Variables/Coding	Level of Measurement	Instrument & Source	Method
Socio-demographic Properties	Care-recipients’		Socio-demographic Questionnaire Form (developed by National Caregiving Alliance, 2015)	Self-report
	1) Age (in years)	Ratio		
	2) Gender 1=Male, 0=Female	Nominal*		
	Caregivers’			
	1) Age (in years)	Ratio		
	2) Gender 1=Male, 0=Female	Nominal*		
	3) Race/Ethnicity 0=White 1=Black 2=Hispanic 3=Asian/Pacific Islander 4=Other	Nominal		
	4) Education 1=high school or less 2=some college of higher	Ordinal		
	5) Residence Area 1=Rural 2=Not Rural	Ordinal		
	6) Employment Status 1=Full time 2=Part time 3=Unemployed	Ordinal		
	7) Income level 1=Less than 50,000 2=$50,000 or greater	Ordinal		

Caregiving Status	1) Number of helpers	Ratio	Caregiving Questionnaire Form (developed by National Caregiving Alliance, 2015)	Self-report
	2) Number of hours for caregiving (weekly)	Ratio		
	3) Caregiver status 1=Primary 0=Secondary	Nominal*		
	4) Caregiver health status 1=Poor 2=Fair 3=Good 4=Very good 5=Excellent	Ordinal		
	5) Caregivers’ relationship with patient 1=Spouse 2=Adult-child 3=Relatives 4=Friends 5=Other	Nominal		
	6) Residential status 1=Living together 2=Living separately	Nominal		
Performing Medical/ Nursing Tasks	1) Performing medical/nursing tasks 1=Yes 0=No	Nominal*	Performing Medical/Nursing Tasks Questionnaire Form (developed by National Caregiving Alliance, 2015)	Self-report
	2) The degree of feeling the difficulty of performing medical/nursing tasks 1=Not at all difficult 5=Very Difficult	Ordinal		
Care Recipients’ Functional Status I	1) Getting in and out of beds and chairs 1=Yes 0=No	Nominal	Katz Activities of Daily Living Scale (Katz, Ford, Moskowitz, Jackson, & Jaff, 1963) Independence in *basic* daily activities of living (sum of	Self-report
	2) Getting dressed 1=Yes 0=No			
	3) Getting to and from the toilet 1=Yes 0=No			
	4) Bathing or showering			

	1=Yes 0=No 5) By dealing with incontinence or diapers 1=Yes 0=No 6) By feeding him or her 1=Yes 0=No		the each item of ADL score)	
Care Recipients' Functional Status II	1) Managing finances, such as paying bills or filling out insurance claims 1=Yes 0=No 2) Grocery or other shopping 1=Yes 0=No 3) Housework, such as doing dishes, laundry, or straightening up 1=Yes 0=No 4) Preparing meals 1=Yes 0=No 5) Transportation, either by driving him/her, or helping him/her get transportation 1=Yes 0=No 6) Arranging outside services, such as nurses, home care aides, or meals-on-wheels 1=Yes 0=No 7) By giving medicines, like pills, eye drops, or injections for his/her condition 1=Yes 0=No	Nominal	Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) Independence in *complex* daily activities of living (sum of the each item of IADL score)	Self-report

Caregiver Burden	1) Physical Strain 1=Not a strain at all 5=Very much of a strain	Ordinal	Caregiver Burden Questionnaire Form (Developed by National Caregiving Alliance, year)	Self-report (5 min)
	2) Emotional Strain 1=Not a strain at all 5=Very much of a strain	Ordinal		
	3) Financial Strain 1=Not a strain at all 5=Very much of a strain	Ordinal		

* Nominal treated as interval by dummy coding.

Table 2

Analytic Methods by Study Aims

Specific Aims	Analytic Methods
1. To describe caregivers' socio-demographic and caregiving characteristics among caregivers of persons with cognitive impairment who perform medical/nursing tasks	Descriptive statistics to describe the characteristics of caregivers of people with dementia who perform medical/nursing tasks. Variables -Caregivers' sociodemographic characteristics (age, gender, race, education, residence area, employment status, income level) -Care-recipients' status (age, gender, ADL/ IADL scores) -Caregiving characteristics (number of hours for caregiving, primary caregiver status, health status, caregivers' relationship with care-recipients, co-residential status) -Caregivers' burden (emotional, physical, financial, and the total burden score)
2. To examine if performing medical/nursing tasks have an impact on caregiver burden among caregivers of persons with cognitive impairment, compared to those caregivers who do not perform these tasks	Independent *t*-test and χ^2 to examine caregivers' burden mean difference between two groups Independent variable: a group category based on the status of performing medical/nursing tasks (Yes or No) Dependent variables: Caregivers' burden scores (emotional, physical, financial, and the total burden score), caregivers' sociodemographic characteristics, and caregiving context characteristics
3. To examine if the perceived level of difficulty of the medical/nursing tasks can predict caregivers' burden among caregivers of persons with cognitive impairment	Hierarchical Multiple Regression to predict caregivers' burden (emotional, physical, financial, and the total burden) Variables: -Caregivers' sociodemographic characteristics (age, gender, education, income), care-recipients' status (ADL/IADL scores) -Caregivers' self-rated health -Level of difficulty of performing medical/nursing tasks -The total caregiver burden score

CHAPTER 2: Manuscript One

Exploring the Challenges of Medical/Nursing Tasks Experienced by Caregivers of Individuals with Dementia: An Integrative Review

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Abstract

Aims: To examine prevalence, types, challenges, and the impact of medical/nursing tasks (MNT) on caregivers for older adults with dementia.

Background: MNT have been perceived as a professional healthcare role; however, research shows that dementia caregivers perform those tasks, such as giving injections, tube feedings, or operation of medical equipment at home. Little is known about the challenges of engaging in these MNT experienced by the caregivers.

Design: An integrative review.

Methods: Ovid Medline, CINAHL, PsychINFO, and Web of Science databases were searched exploring MNT in caregivers among older adults with dementia living in a community setting. Four quantitative and nine qualitative studies published between 1980 and 2018 were included. Overall process of the review was guided by PRISMA.

Results: About 67% of dementia caregivers perform MNT in the U.S, such as managing multiple medications, wound care, and nutritional management. Care recipients' cognitive impairment complicated the provision of those tasks due to limited cognitive functioning, behavioral problems, comorbidities, and complex medication regimen. Insufficient information and training from healthcare professionals as well as caregivers' advanced age and their own health problems made those tasks even more challenging. As a result, the caregivers frequently suffered from emotional distress such as worrying, anxiety, feeling difficulty of doing MNT, and sleep disturbance.

Conclusions: MNT have become one of the daily tasks of dementia caregivers within the home. However, the tasks are difficult and complicated, and inadequate support from healthcare professionals may threaten the caregivers' well-being.

Relevance to clinical practice: Increased awareness and education from healthcare professionals are critical needs of the caregivers. Structured-medical information, skill-based instructions, and hands-on training may be beneficial to decrease the caregivers' distress from MNT.

Keywords: Dementia Care, Carers, Literature Review, Caregiver Burden

WHAT DOES THIS PAPER CONTRIBUTE TO THE WIDER GLOBAL CLINICAL COMMUNITY?

- Two-thirds of caregivers of older adults with dementia perform medical/nursing tasks, such as multiple medication management, skin wounds/sores care, nutritional management, and/or handling care recipient's symptoms that needed acute care.
- Performing medical/nursing tasks by caregivers can be influenced by the care recipients' dementia symptoms, comorbidities, caregivers' advanced age and their own health problems, and information and training from healthcare professionals related to needed medical/nursing tasks.
- Nurses can assess the caregivers' knowledge and skills of medical/nursing tasks that they are involved in and provide structured information, demonstration, and/or hands-on skills as well as support by encouragement, according to the caregivers' needs and preference.

1. INTRODUCTION

Approximately, one in 10 older adults (≥ 65 years) have dementia in the U.S., and the number of people having dementia (5.7 million people in 2018) will be exponentially increased as the Baby Boomer Generation gets older (Alzheimer's Association, 2018). Dementia is a syndrome that entails difficulties in cognitive functions such as memory, language, and/or problem-solving skills. Because of these difficulties, older adults with dementia often need assistance for their daily living from others. Mostly, family members, friends, or neighbors provide unpaid care for home-dwelling older adults with dementia, and they are the caregivers of individuals living with dementia (hereafter, called dementia caregivers). More than 16 million of dementia caregivers are the major source of helping older adults with dementia who live independently in community settings, whereby decreasing the social burden of institutional care costs in the U.S. (Alzheimer’s Association, 2018).

Traditionally, caregivers provide assistance with both basic activities of daily living, such as feeding and bathing, and complex activities of daily living, such as managing finances and shopping (Reinhard, Levine, & Samis, 2012). In addition to this type of assistance, a recent U.S. national report, *Home Alone: Family Caregivers Providing Complex Chronic Care*, spotlighted the unnoticed caregivers’ role of performing medical/nursing tasks. Medical/nursing tasks are typically thought of as healthcare professionals’ jobs which require nursing care along with medical judgment (Spillman, Wolff, Freedman, & Kasper, 2014). However, it was found that almost half of the caregivers (47%) provide medical/nursing tasks, such as managing multiple medications, providing wound care, and operating medical equipment (Reinhard et al., 2012).

The national report on the caregivers’ involvement in medical/nursing tasks has already had an impact on health policy and research. Within five years of the *Home Alone* report, the

Caregiver Advise, Record, Enable (CARE) Act was enacted in 39 states and territories in the U.S. The CARE Act required the provision of education and instruction of medical/nursing tasks to caregivers at hospital discharge (Anthony, 2018; Glazer & Ali, 2017). Researchers also have investigated how medical/nursing tasks were linked to a burdensome caregiving experience among spousal caregivers and cancer caregivers (Mollica, Litzelman, Rowland, & Kent, 2017; Polenick, Leggett, & Kales, 2017). Lastly, the American Journal of Nursing (2017) published a special issue, *Supporting Family Caregivers: No Longer Home Alone*. This issue included ten articles that may help nurses provide caregivers with structured information and education for how to provide medical/nursing tasks, specifically, ostomy care, wound care, and administration of subcutaneous injections.

Dementia caregivers may be in high demand for medical/nursing tasks compared to older adults without dementia; this is because older adults with dementia have more comorbid conditions (6.5 vs. 8.1) respectively, including mental health problems, neurologic disorders, cerebrovascular disease, diabetes, and injuries (Kuo, Zhao, Weir, Kramer, & Ash, 2008). Increased comorbid conditions can lead to multiple medications, frequent healthcare service use, and numerous procedures and treatments. Additionally, a recent national report from a primary authoritative body points out that dementia caregivers arrange more outside services (46% vs. 27%) and communicate more frequently with health care professionals (80% vs. 59%) in order to meet their older adults' care needs (National Alliance for Caregiving [NAC] in Partnership with the Alzheimer's Association [AA], 2017).

The current literature does not specifically address the nature of involvement of dementia caregivers in performing medical/nursing tasks. Specifically, it is unknown what types of medical/nursing tasks they perform at home, how many of them perform those tasks, what are the unique challenges they face, and what the impact is on caregivers' physical and mental health. Building a shared understanding is the first step in helping dementia caregivers manage medical/nursing tasks and in discovering relevant areas to apply interventions.

2. AIMS

This integrative review aimed 1) to examine the prevalence and range of medical/nursing tasks, and 2) to synthesize the challenges and impacts of medical/nursing tasks on dementia caregivers. In addition, the quality appraisal of each study provides content of the quality for the synthesis as a whole.

3. METHODS

3.1 Search Strategy

An integrative review aims at delineating the processes and subject components of particular phenomenon by allowing the examination of various methodologies, such as experimental and non-experimental studies (Whittemore & Knafl, 2005). Whereas, systematic reviews are the method of choice for establishing best practices based on available experimental-studies and typically use meta-analysis or quasi-statistical techniques (Whittemore & Knafl, 2005). To provide a comprehensive understanding of caregivers' experience with medical/nursing tasks, including the context and the subjective appraisal by the caregivers, an integrative review was chosen to include both quantitative and qualitative studies. This integrative review was guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) because there was no widely accepted integrative review guidelines (See Supplementary File 1).

A resource librarian was consulted and recommended using major health science related databases including Ovid Medline, CINAHL, PsycINFO, and Web of Science to search relevant articles. Two MeSH terms ‘caregiver' and ‘dementia' and the following terms of ‘task or duty or responsibility' were combined to search the database literature. As the caregivers’ role in medical/nursing tasks were not commonly considered in the literature, citations that dealt with any kind of task, duty, or responsibility delivered by caregivers were included in the search. To capture all relevant primary articles, there was no limitation on publication year. A manual search of the reference lists of included articles was also used to locate additional material because the included articles were likely to have the relevant citations.

3.2 Inclusion and Exclusion Criteria

Articles were included in this review (a) if a study included caregivers who provided unpaid help; (b) if the care recipients had any type of dementia or memory loss including Alzheimer’s dementia, vascular dementia, Lewy body dementia, or mixed dementia; (c) if the care recipients were dwelling in the community; and (d) if a study dealt with any types of medical/nursing tasks, including medication, wound care, catheter care, nutritional care, or handling of medical equipment.

Articles were excluded (a) if a study only included professional caregivers who received payment such as general practitioners, pharmacists, or home health aides; (b) if the care recipients had other types of significant disability rather than dementia, such as cancer, cardiovascular disease, or muscular disabilities; (c) if the care recipients were in institutional care facilities, such as nursing home, hospitals, or assisted living facilities; (d) if a study dealt with only activities of daily living or instrumental activities of daily living provided by caregivers; (e) if a study was a secondary data analysis, such as reviews, meta-analyses, or concept analysis; (f) if a study was considered as grey literature, such as editorials, theses, or conference proceedings; or (g) if a study was written in non-English language. Although review articles were not included in this study, the bibliographies were examined. If there was a citation that met this study criteria, it was included.

3.3 Quality Appraisal

The study quality of the included articles was assessed using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011). The MMAT tool provides guidance for researchers to assess the risk of bias for both quantitative and qualitative articles. The MMAT has two screening criteria and four methodological quality criteria for both quantitative and qualitative studies. Two screening criteria include (1) having clear research questions, and (2) addressing the research questions based on the collected data. The screening questions were used to determine that further appraisal would be feasible or appropriate.

Regarding quantitative studies, the MMAT provides four methodological quality criteria: using relevant method of sampling strategy (e.g., random or convenience sampling), having representative sample of the population under study (e.g., inclusion and/or exclusion criteria are explained), using appropriate measurements (e.g., clear origin, or validity known, or standard instrument), implementing appropriate data analysis strategy (e.g., containing a table that lists key demographic information), and having acceptable response rate (e.g., 60% or above).

For qualitative studies, the MMAT also suggests four methodological quality criteria: examining relevant sources of qualitative data (e.g., in-depth interviews, group interviews, observations, and/or documentary sources), analyzing qualitative data pertinent to the research questions (e.g., thematic analysis and content analysis), appropriate consideration given to how findings related to the context (e.g., the setting), and proper attention given to how findings relate to researchers' influence (e.g., researchers critically explain how findings relate to their perspective, role, and interactions with participants). From each study, all relevant data were identified and coded according to the MMAT criteria.

3.4 Data Extraction and Synthesis

Data analyses, including data extraction and synthesis, were directed by the framework of integrative review by Whittemore & Knafl (2005). Data were extracted from each primary source, including sample characteristics both caregivers’ and care recipients’ as well as information related to medical/nursing tasks. Specifically, the components of extracted data included: the year of publication, where the study was conducted (country), aims of the study, design of the study, number of participants, characteristics of caregivers (mean age, percentage of female caregivers, caregiver relationship with care recipients), and characteristics of care recipients (types of disability that care recipients had and mean age). The extracted data also covered the following predetermined information: caregivers’ percentage of performing medical/nursing tasks (prevalence), types of medical/nursing tasks which caregivers perform at home, issues of involving medical/nursing tasks, and the impact of these tasks on the caregivers. If a study did not report these findings, they were stated as not reported.

All the extracted data were compiled into a excel spreadsheet and the first author (ML) rechecked their accuracy for inclusion. After that, to formulate into a manageable framework, the data were categorized into separated tables under categorization including sample, methods, characteristics, and the prevalence, types, issues, and impacts of medical/nursing tasks. Finally, the findings were synthesized based on each research question by iteratively comparing the data in the separated tables. To enhance the rigor of the study, a second reviewer (CC) independently checked those included and excluded primary sources and the rationale. When there was conflicts between the two authors, a third reviewer (IW) was involved and resolved the disagreements. There was no funding sources for this integrative review.

4. RESULTS

This integrative review was conducted to explore the nature and challenges of medical/nursing tasks among dementia caregivers. Utilizing four databases, 1,661 potentially relevant articles were retrieved and a total of 13 relevant articles were included for this integrative review as shown in a PRISMA flow chart of the full search (Figure 1). Out of the 13 articles, four articles were quantitative studies that used a cross-sectional study design (n=4), and nine articles were qualitative studies that utilized a descriptive qualitative design (n=7) or a grounded theory (n=2). The studies included in this review were conducted in developed countries, such as the United States (n=5), the United Kingdom (n=4), Australia (n=3), and Canada (n=1).

4.1 Participants

Table 1 describes the summary of the 13 included articles. Five articles featured caregivers only and eight articles addressed both caregivers and care recipients as participants. The total sample size of dementia caregivers and care recipients were 731 (range: 9-372) and 262 (range: 4-104), respectively.

The average age of dementia caregivers was 64 (range: 54-76), and the average proportion of female caregivers was 74% (range: 55-90). The average age of care recipients was 75 (range: 66-80). Five articles reported the caregiver relationship with care recipients and the proportion of spousal caregivers was 80% (range: 45-100). The rest of the eight articles described the caregiver relationship with care recipients without exact proportion, but in general, family caregivers or caregivers are relatives, friends, or neighbors.

4.2 Prevalence and Types of Medical/Nursing Tasks

Table 2 reports on the prevalence and types of medical/nursing tasks of the 13 included articles. Approximately, 67% of dementia caregivers were found to perform medical/nursing tasks (NAC in partnership with the AA, 2017). A higher prevalence rate of medical/nursing tasks was reported among spousal dementia caregivers, ranging from 82% to 92% (NAC in partnership with the AA, 2017; Polenick, Leggett, Maust, & Kales, 2018). The prevalence rates of specific medical/nursing tasks were rarely reported, with only two studies specifically reported data (Cotrell, Wild, & Bader, 2006; Polenick et al., 2018). Approximately, 82-85% of dementia caregivers performed medication administration (Cotrell et al., 2006; Polenick et al., 2018). About 47% of spousal dementia caregivers cared for skin wounds/sores, 22% managed ostomy care/IV/blood testing, and 15% gave shots/injections (Polenick et al., 2018)

Regarding types of medical/nursing tasks, medication management was found to be the most prominent type of medical/nursing task that was reported in this integrative review of the literature. Among the included studies, nine out of 13 studies dealt with medication management by dementia caregivers; one study explored nutrition support (Ball et al., 2015); one study examined monitoring/handling acute symptoms of care recipients (Sadak, Zdon, Ishado, Zaslavsky, & Borson, 2017); two studies examined various types of medical/nursing tasks performed by dementia caregivers (NAC in partnership with the AA, 2017; Polenick et al., 2018).

4.3 Challenges of Medical/Nursing Tasks Faced by Dementia Caregivers

Table 3 describes the challenges faced by dementia caregivers while providing medical/nursing tasks. Dementia caregivers confronted six challenging issues in performing medical/nursing tasks. First, dementia caregivers reported that care recipients' cognitive impairment required hypervigilance and constant involvement in medication management (Gillespie, Harrison, & Mullan, 2015). These dementia caregivers often checked-up on their care recipients' understanding of medication instructions from doctors. As changes occurred with the progression of dementia over time, medication management expanded from medication reminders to checking pillboxes, and, actually, dispensing medications and monitoring side effects (Cotrell et al., 2006; While, Duane, Beanland, & Koch, 2013).

Second, it was reported that dementia caregivers regularly deal with the care recipients' behavioral changes and the refusal of the caregivers' care (Ball et al., 2015). In addition, care recipients may lose insight about their disease status and the need to take foods or medication. Consequently, one study reported that nutritional management could be difficult because care recipients stockpiled food or showed aggression during the meal time. Similarly, care recipients did not appreciate help from caregivers or resisted their support in medication management (Gillespie et al., 2015; Kaasalainen et al 2011; Maidment, Aston, Moutela, Fox, & Hilton, 2017; While et al., 2013). Two studies reported that care recipients were suspicious or paranoid about taking medications, and they sometimes even thought medicines were poisonous (Gillespie et al., 2015; Kaasalainen et al., 2011).

Third, data showed dementia caregivers often dealt with a complicated medication regimen. One study reported that care recipients had an average of nine comorbidities and took more than 10 medications (Erlen et al., 2013). The medication regimen were from multiple prescriptions and multiple sites, such as hospitals and primary care practices. Furthermore, the dosing specifications were of varying lengths and different times during the day (Gillespie et al., 2015; Maidment et al., 2017; Smith, Grijseels, Ryan, & Tobiansky, 2015). Even harder situations, such as using puffers, injections, or suppositories as well as adjusting medication doses (e.g., Warfarin and Insulin injections) added to the complexity of the caregivers' roles (Gillespie et al., 2015).

Fourth, evidence showed that dementia caregivers received limited information and training for medical/nursing tasks. About 53% of dementia caregivers performed medical/nursing tasks without training, based on a U.S. national report on caregiving (NAC in partnership with AA, 2017). Four studies reported receiving information and advice from healthcare providers was limited due to clinicians' lack of time and constrained access to them. The limitations were not having enough time with primary care providers during clinic visits and not being able to ask questions during night time or weekends (Ball et al., 2015; Gillespie et al., 2015; Maidment et al., 2017; Smith et al., 2015). About 92.3% of patient-caregiver dyads found themselves with at least one deficiency in medication knowledge, in proper methods of taking medications, and in the appropriate procurement of drugs (Erlen et al., 2013). In addition, dementia caregivers also reported that it was difficult to interpret prescriptions, especially, when the descriptions included medical jargon, such as “PRN” medication (Poland et al., 2014).

Fifth, studies reported that dementia caregivers had to engage in clinical decision-making situations. When care recipients were in the early stages of dementia, the dementia caregivers had to determine when to take over the responsibility of medical/nursing tasks from care recipients (Kaasalainen et al., 2011; Poland et al., 2014). In addition, caregivers were often being asked to consider the changing health status of care recipients, the ratio of risks and benefits in medication, and management of care recipients' acute exacerbation of their chronic diseases

(Poland et al., 2014; Sadak et al., 2017). One study also reported that the decision-making situations sometimes involved ethical issues, such as administering sleep medication depended on caregivers' judgment. For example, the caregivers could be tempted to provide sleep for the care recipients in order to ensure sleep for themselves, but the necessity for the drug for the recipient’s sleep was hard to determine (Poland et al., 2014).

Sixth, dementia caregivers had to take care of themselves as well. Dementia caregivers tended to be at an advanced age and had their own health problems (Maidment et al., 2017). Having their own prescriptions increased the difficulty in managing the care recipients’ medications (Erlen et al., 2013; While et al., 2013).

4.4 Impacts of Medical/Nursing Tasks on Dementia Caregivers

Performing medical/nursing tasks affected dementia caregivers both positively and negatively. Table 2 summarizes the impacts of medical/nursing tasks of the 13 included studies. Only one out of 13 studies (8%) identified a positive impact of performing medical/nursing tasks, in which dementia caregivers reported feeling assurance, given that they put their efforts for the loved one’s care (Hutchings et al., 2010).

In contrast to only one study that identified a positive impact, negative impacts on mental health of medical/nursing tasks were well documented (Ball et al., 2015; Maidment et al., 2017; NAC partnership with AA, 2017; Poland et al., 2014; While et al., 2013). Dementia caregivers are twice as likely (22% vs. 11%) to report difficulty in performing medical/nursing tasks than caregivers with other chronic diseases (NAC partnership with AA, 2017). Moreover, dementia caregivers felt a burden because they were obligated to perform medical/nursing tasks. In spite of the care, the care recipients' cognitive and behavioral problems were not always improved, rather they sometimes experienced worsening physical symptoms, such as sudden weight loss (Ball et al., 2015; Maidment et al., 2017). Furthermore, noticing an overdose in care recipients' medication (e.g., being sleepy) or an inadequate dose of medication (e.g., pain breakthrough) made dementia caregivers worry about the care recipients' safety (While et al., 2013). Not having confidence in performing the medical/nursing tasks or finding that their decision caused harm for the care recipients resulted in anxiety, worry, stress, and guilt (Poland et al., 2014; Ball et al., 2015).

In addition, three separated studies showed negative physical and social consequences of performing medical/nursing tasks. Dementia caregivers usually put the care recipients' needs above their own health problems; thus, the caregivers' health needs were not fulfilled (Maidment et al., 2017). The caregivers' sleep also was disturbed, particularly when they provided care of care recipients' wounds/sores, due to flashbacks of the skin lesions' images (Polenick et al., 2018). Lastly, dementia caregivers restricted their own activities, such as traveling for the weekend, because they needed to perform the medical/nursing tasks for their care recipients (Hutchings et al., 2010).

4.5 Study Quality

A summary of the quality appraisal conducted for this review is shown in Appendix 1. All included studies met the screening criteria (1) having clear research questions, and (2) addressing the research questions based on the collected data. Among the 13 studies, four studies were quantitative descriptive studies in which all used cross-sectional design (Cotrell et al., 2006; Erlen et al., 2013; NAC partnership with AA, 2017; Polenick et al., 2018). Nine studies were qualitative studies, including seven descriptive (Ball et al., 2015; Gillespie et al., 2015; Hutchings et al., 2010; Maidment et al., 2017; Poland et al., 2014; Sadak et al., 2017; Smith et al., 2015) and two grounded theory-based studies (Kaasalainen et al., 2011; While et al, 2013). In regards to the sampling strategy of the quantitative studies, only one study (NAC partnership with AA, 2017) used a random sampling technique, and the rest of the studies were based on a convenience sampling strategy. All of the four quantitative studies implemented inclusion/exclusion criteria to have a representative sample. Two studies (Cotrell et al., 2006; Erlen et al., 2013) used measures that had published the results of validity; but the other two studies used an investigator-developed questionnaire whose psychometric properties were not reported (NAC partnership with AA, 2017; Polenick et al., 2018). Only one out of four quantitative studies reported an acceptable response rate of ≥ 60% (Polenick et al., 2018).

Most of the qualitative studies used semi-structured interviews (6 out of 9, 66.7%) (Ball et al., 2015; Kaasalainen et al., 2011; Maidment et al., 2017; Sadak et al., 2017; Smith et al., 2015; While et al, 2013). The remaining three studies used focus group interviews (Poland et al., 2014) or applied mixed methods of semi-structured and focus group interviews (Gillespie et al., 2015; Hutchings et al., 2010). Thematic analysis (7 out of 9, 77.8%) was the most widely used qualitative analysis method (Ball et al., 2015; Gillespie et al., 2015; Hutchings et al., 2010; Poland et al., 2014; Sadak et al., 2017; Smith et al., 2015; While et al, 2013). The last two studies used a systematic cross-comparison analysis (Maidment et al., 2017) or axial coding (Kaasalainen et al., 2011). Five out of nine studies (55.6%) presented contextual influences on research findings (Ball et al., 2015; Kaasalainen et al., 2011; Maidment et al., 2017; Poland et al., 2014; Sadak et al., 2017); but, none of the nine qualitative studies addressed the researchers' influence or bias in reporting the research findings.

5. DISCUSSION

Although the involvement of medical/nursing tasks by dementia caregivers is a growing field of research, there has been no integrative review that has reviewed existing literature to date. This review presents the descriptions, issues, and impacts of medical/nursing tasks among dementia caregivers. In providing an in-depth understanding of medical/nursing tasks by dementia caregivers, this report may initiate research development to deal with the hidden care challenges as well as promote health policy changes. This is in line with a social disability model which is in contradiction with the biomedical model (Guleria & Curtice, 2016). Within the biomedical model, dementia has been viewed as a disease with irreversible decline and the person is perceived as a passive agent. However, the social disability model asserts that people with dementia also have rights, and they should be valued equally as non-disabled people (Guleria & Curtice, 2016). Providing better caregiver support may allow people with dementia to live with more autonomously and to remain more engaged within their own lives.

Overall, a higher number of dementia caregivers perform medical/nursing tasks compared to caregivers of people with disabilities in general. Compared to statistics from the *Home Alone* U.S. national report, approximately 67% of dementia caregivers and 92% of *spousal* dementia caregivers perform medical/nursing tasks, whereas less than half of caregivers (46%) perform medical/nursing tasks among those who take care of people with any other disability (Reinhard et al., 2012). In addition, considering specific types of medical/nursing tasks, dementia caregivers perform nearly two times greater than caregivers do in general. Specifically, about 82.4% of dementia caregivers keep track of medications, while 48% of caregivers of people with any other disability keep track of medications (Donelan et al., 2002). Similarly, 46.6% of dementia caregivers care for wounds/sores compared to 26% of caregivers of people with any other disability (Donelan et al., 2002).

There are alarming findings related to dementia caregivers' demographic characteristics. Dementia caregivers are older (63.7 years vs. 54.0 years) and a higher number of them are female (74% vs. 62%) than caregivers of people without any cognitive disabilities. Moreover, a higher percentage (80% vs. 28%) of dementia caregivers were spouses in comparison to caregivers of people with any disabilities (Reinhard et al., 2012). Having a higher percentage of spousal caregivers is worrisome because spousal caregivers are typically vulnerable groups with lower educational levels, less income, and less employed than non-spousal caregivers (Reinhard, Levine, & Samis, 2014). In being older and having their own health problems, dementia spousal caregivers may be the most vulnerable groups that need support and resources in performing medical/nursing tasks.

This integrative review identifies that care recipients' dementia process and comorbidities made the medical/nursing tasks extremely difficult for the caregivers. Although Reinhard et al., (2012) indicated that cognitive conditions might make the medical/nursing tasks difficult, detailed explanations were not addressed. This review reveals that the care recipients' unappreciation, refusal of care, aggression, and forgetfulness increase the burden of medical/nursing tasks. Furthermore, this review points out how care recipients' complex medical conditions and regimen add to substantial challenges to medical/nursing tasks, such as having an average of nine comorbidities, taking more than 10 medications, requiring dosing adjustments, and using of different medication deliveries.

About half of the studies reported emotional distress. The emotional distress was described as worrying and anxiety in completing medical/nursing tasks. It is reported that caregivers' difficulty in medical/nursing tasks were associated with significant caregiver strain and depression (Giovannetti et al., 2012). In addition, when caregivers perceive the load of the care responsibilities surpasses their abilities, this could be the point of preventing care recipients from residing at home (Thoma-Lürken, Bleijlevens, Lexis, de Witte, & Hamers, 2018).

Therefore, active support from healthcare professionals should be implemented to help caregivers lessen their emotional distress and find practical answers when they face any issues from medical/nursing tasks. The support can be focused on encouraging caregivers to voice questions or concerns and facilitating frequent communication.

Dementia caregivers flagged that there was limited structured information, training, or support from healthcare professionals. This limited assistance can be perceived as unmet needs that may lead to low self-efficacy by dementia caregivers. The low self-efficacy was associated with dementia caregivers' heightened strain and depressive symptoms (Jennings et al., 2015). Although the CARE Act (2017) requires healthcare professionals to provide instructions for medical/nursing tasks to caregivers at the time of patients' discharge, dementia caregivers' voice on the constrained assistance from healthcare providers urges further efforts. An evaluation of how the provision of information has been delivered, how caregivers have been satisfied with the information, and how the system can be improved from caregivers' perspectives may be the next steps to strengthen the assistance for the caregivers.

Dementia caregivers preferred to learn medical/nursing tasks by having a qualified person demonstrate (61%) and by having hands-on training with a qualified person (53%) (NAC & AARP, 2015). Creative educational modules that reflect caregivers’ preference should be developed and tested because reflecting caregivers’ preference can increase satisfaction and effectiveness of interventions. Future research should consider how to integrate caregivers’ preferences of learning modules into their intervention models.

5.1 Limitations

Several limitations of this review should be taken into consideration. First, this review found a relatively small number of pertinent studies. Without publication year and geographical limits, only 13 studies were identified. However, with expanding attention on caregivers' medical/nursing tasks, more research is expected to be released. With an adequate number of studies, future comprehensive review of this subject can deepen understanding and the need for policy. Second, the majority (69.2%) of identified studies in this review were focused on medication management. Further studies are needed in investigating various medical/nursing tasks, such as helping with assistive devices for mobility, using meters/monitors, and operating medical equipment. Third, most of the included studies that utilized qualitative studies did not sufficiently minimize researcher bias. For example, triangulation with data (e.g., using caregivers' daily diary), member check, and co-construction (involvement of community organizations and interest groups) may help to decrease researcher bias (Aston, Hilton, Moutela, Shaw, & Maidment, 2017; Honer 2016).

6. CONCLUSION

Based on this integrative review of 13 studies, two-thirds of dementia caregivers perform medical/nursing tasks, including but not limited to medication management, wound/ostomy care, nutritional care, and symptoms/signs monitoring. Three major factors that make medical/nursing tasks challenging were identified: care recipients’ dementia process and comorbidities, caregivers’ advanced age and their own health problems, and inadequate training and education from healthcare professionals. The difficulty and complexion of medical/nursing tasks frequently distresses dementia caregivers emotionally, physically, and socially. Proactive healthcare professionals' support and creative interventions related to medical/nursing tasks will contribute to care recipients’ quality of care and the well-being of caregivers.

7. RELEVANCE TO CLINICAL PRACTICE

This integrative review may prompt healthcare professionals to further develop crucial resources for dementia caregivers regarding medical/nursing tasks. Specifically, nurses can begin with assessing caregivers' knowledge and skills of medical/nursing tasks, and then nurses can provide supportive feedback that fills their needs and gaps of the tasks (Lindauer, Sexson, & Harvath, 2017). Nurses can also provide a demonstration of medical/nursing tasks and teach hands-on skills to caregivers when the caregivers are at the bedside while care recipients are hospitalized or when they visit the outpatient department with care recipients.

This review also set the stage for future interventions to help dementia caregivers gain confidence in medical/nursing tasks by utilizing medical information and skill-based instructions as well as hands-on training. In 2018, a study tested the effectiveness of a web-based educational intervention that provided 50 common medical problems, such as constipation, pain, and dehydration and how to solve the problems (Zimmerman et al., 2018). This study demonstrated that dementia caregivers could benefit from educational intervention regarding medical/nursing tasks, as the study intervention increased caregivers’ confidence in signs/symptoms management and decreased caregiver strain. Clearly, rigorous studies, specifically randomized controlled trials with multiple sites and large samples, are needed to help authoritative bodies initiate effective policies to support the dependence on caregivers to provide medical/nursing tasks for their care recipients.

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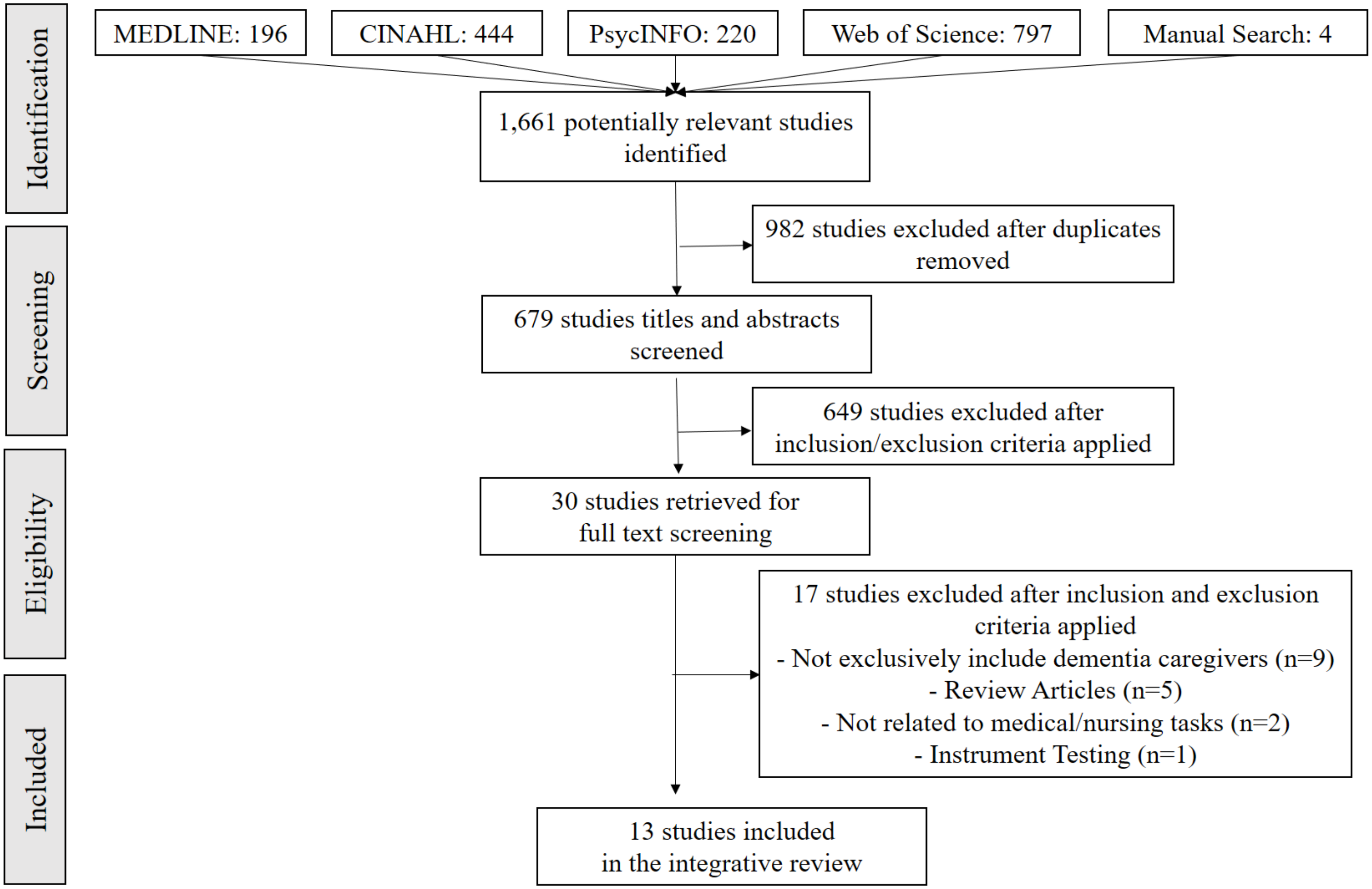

Figure 1. PRISMA Flow Chart of Article Search and Selection Process

Table 1. Summary of Reviewed Studies for Caregiver’s Medical and Nursing Tasks for Their Dementia Recipients

Authors, Years	**Country**	**Aim**	**Design**	**Sample Size**	**Analysis**	**CGs[†]’ Characteristics**	**CRs[‡]’ Characteristics**	**Caregiver Relationship with Care recipients**
Quantitative Studies								
Polenick et al., 2018	US	To evaluate the association between caregivers' medical/nursing tasks and care-related sleep disturbances.	Cross-sectional study	104 dyads[§]	Descriptive statistics; Hierarchical regressions	Mean Age: 76 59% Female CGs	Mean Age: NR Disability Status: Dementia	100% Spousal Caregivers
National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017	US	To analyze the experiences of providing unpaid care in the United States to a relative or friend diagnosed with Alzheimer’s disease, dementia, or other mental confusion	Cross-sectional study; Online Survey	372 CGs	Descriptive statistics	Mean Age: 54 58% Female CGs	Mean Age: 77 Disability Status: Alzheimer’s disease, dementia, or other mental confusion	Relatives, friends, or neighbors; Proportion was NR[¶]
Erlen et al., 2013	US	To describe the characteristics and correlates of caregiver mediated medication management.	Cross-sectional study	91 dyads	Descriptive statistics and regression analyses	Mean Age: 67 70% Female CGs	Mean Age: 80 Disability Status: Memory loss	Specific relationship with CRs was NR
Cotrell et al., 2006	US	To examine the relationship between patients' cognitive status, deficit awareness, medication management skills, and actual medication adherence.	Cross-sectional study	27 dyads	Independent and dependent t-tests	Mean Age: NR % Female CGs: NR	Mean Age: 66 Disability Status: Alzheimer's disease	93% of caregivers were a spouse of Alzheimer's disease patients
Qualitative Studies								
Maidment et al., 2017	UK	To describe and understand the key challenges, concerning medication issues, experienced by older adults with dementia and their informal carers dwelling in the community and the potential role of community pharmacists.	Exploratory qualitative study design	11 CGs and 4 CRs	Systematic cross-comparison analysis	Mean Age: NR % Female CGs; NR	Mean Age: NR Disability Status: Dementia	Specific relationship with CRs was NR
Sadak et al., 2017	US	To describe the lived experience of dementia family caregivers whose care	Qualitative study (not	20 CGs	Thematic analysis	Mean Age: 63 70% Female CGs	Mean Age: 80 Disability Status: Dementia	Child (n=3); Spouse (n=16); Sister (n=1)

Authors, Years	Country	Aim	Design	Sample Size	Analysis	CGs†' Characteristics	CRs‡' Characteristics	Caregiver Relationship with Care recipients
		recipients had a recent unplanned admission, and to identify potential opportunities for developing preventive interventions.	defined specifically)					
Ball et al., 2015	Australia	To explore the perceptions of family carers of people with dementia, with emphasis on feeding-related challenges, the burden of care attributable to nutrition support, and practical strategies developed to address these challenges.	A descriptive exploratory qualitative study	14 CGs	Thematic and Triangular analysis	Mean Age: 58 86% Female CGs	Mean Age: 78 Disability Status: Dementia	Spouses, fathers, or mothers; Proportion was NR
Gillespie et al., 2015	Australia	To explore the medication management experiences of Australian ethnic minority family caregivers of people living with dementia.	Qualitative study (not defined specifically)	29 CGs	Thematic analysis	Mean Age: NR 90% Female CGs	Mean Age: NR Disability Status: Dementia	Spouse (n=23); Adult child (n=6)
Smith et al., 2015	UK	To examine the experiences of family carers when providing medicines-related assistance for a person with dementia, to indicate how services could become more responsive to the specific needs of this group of carers.	A descriptive qualitative study	14 CGs and 5 CRs	Thematic analysis	Mean Age: NR (Age range: 45-86) 79% Female CGs	Mean Age: NR (Age range: 81-93) Disability Status: Dementia	Specific relationship with CRs were NR
Poland et al.,2014	UK	To describe the Public Patient Involvement (PPI) process which was intended to inform and validate the development of a future research proposal which could be well-informed by carers' perspective	Qualitative study (not defined specifically)	9 CGs	Thematic and narrative analysis	Mean Age: NR 89% Female CGs	Mean Age: NR Disability Status: Dementia	Specific relationship with CRs were NR
While et al., 2013	Australia	To see if there were any significant differences in their medication management experiences when compared to those of older adults without dementia and their carers	Qualitative study using grounded theory	9 CGS and 8 CRs	Thematic analysis	Mean Age: NR Female CGs: NR	Mean Age: NR Disability Status: Dementia	Specific relationship with CRs were NR

Authors, Years	Country	Aim	Design	Sample Size	Analysis	CGs†' Characteristics	CRs‡' Characteristics	Caregiver Relationship with Care recipients
Kaasalainen et al., 2011	Canada	To explore the personal experiences related to medication management of community-dwelling older adults diagnosed with dementia and their informal caregivers	Qualitative study using grounded theory	20 CGs and 11 CRs	Axial coding analysis	Mean Age: 65 79% of Female CGs	Mean Age: 69 Disability Status: Dementia	Specific relationship with CRs were NR
Hutchings et al., 2010	UK	To report the lived experience of cholinesterase inhibitors (CHEIs) users and the perceived impact of the treatment	Qualitative study (not defined specifically)	11 CGs and 12 CRs	Thematic analysis	Mean Age: NR (Age range: 46-84) 55% Female CGs	Mean Age: NR (Age range: 65-85) Disability Status: Cognitive impairment or Alzheimer's disease	Spouse (n=5); Children (n=6)

Note. CGs†: Caregivers, CRs‡: Care Recipients, Dyads§: Care recipients and Caregivers dyads, NR¶: Not Reported

Table 2. Medical/Nursing Tasks by Dementia Caregivers: Types, Prevalence, and Impact

Authors, Years	Types	Prevalence	Impact
		Quantitative Studies	
Polenick et al., 2018	1. Keeping track of medications 82% 2. Caring for skin wounds/sores 47% 3. Managing medical tasks such as ostomy care, IVs, or blood testing 22% 4. Giving shots/injections 15%	1. 52% of caregivers assisted with two or more medical/nursing tasks 2. 18% of caregivers reported performing three or more medical/nursing tasks, and 6% of them provided four tasks	1. Performing a higher number of medical/nursing tasks was significantly linked to more frequent sleep disturbances. 2. Caring for wounds/sores was significantly associated with more sleep disturbances
National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017	Giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care; Monitoring blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes	1. 67% of dementia caregivers say they perform medical/nursing tasks 2. 92% of spousal dementia caregivers perform medical/nursing tasks	Dementia caregivers are twice as likely to say that doing medical/nursing tasks is difficult than non-dementia caregivers (22% vs. 11%)
Erlen et al., 2013	Medication management	Not Reported	Not Reported
Cotrell et al., 2006	Medication management	85% of the caregivers reported assisting in managing their relatives' medication	Not Reported
		Qualitative Studies	
Maidment et al., 2017	Medication management	Not Reported	1. Emotional burden: carers expressed an obligation of being responsible for managing the medication of the person they are looking after; the medication was not improving the behaviors and cognitive problems characteristics of dementia 2. Prioritizing the health of the person they cared for over their own health
Sadak et al., 2017	Monitoring and handling ambulatory care sensitive conditions	Not Reported	Not Reported
Ball et al., 2015	Nutritional support	Not Reported	1. Especially rapid weight loss that manifested as noticeable wasting was a source of considerable anxiety by most family carers 2. Family carers reported experiencing numerous emotions including anxiety, stress, worry that the way they were caring was not ‘correct’ or that their relatives were reliant solely on them for food and nutrition
Gillespie et al 2015	Medication management	Not Reported	Not Reported

Authors, Years	Types	Prevalence	Impact
Smith et al., 2015	Medication management 1. Ordering and collecting medicines 2. Filling dosage boxes 3. Obtaining information about what, or how much, to take and potential side effects 4. Monitoring the effectiveness and in particular potential side effects of medication, often making judgements on the appropriateness of therapy and/or intervening when deemed necessary 5. Sharing information with the care recipients	Not Reported	Not Reported
Poland et al., 2014	Medication management	Not Reported	1. The difficulty of medication administration practicalities causing high levels of embarrassment in which their identities and expectations as family members were undermined 2. Medication management was a heavy burden of responsibilities; the nature of the burden was closely linked to carers' anxiety about whether they could care well enough 3. Experiencing guilt and self-remonstration when they later felt their decision had led to ill-health
While et al., 2013	Medication management 1. Advocating CRs' preferences in medicines; Keeping CRs' medicines adherence; Maintaining safety and monitoring of side effects 2. Maintaining a regular supply of medication (reordering new scripts and collecting medicines from the pharmacy) 3. Facilitating communication between the different team members (doctors, pharmacists, and case managers) about medications	Not Reported	1. Concerned the care recipient's safety when the care recipient was over or under medicated 2. Experienced anxieties about who would take over the medication management tasks and how they would communicate the routines for the person they care for should they be incapacitated in any way
Kaasalainen et al., 2011	Medication management	Not Reported	Not Reported
Hutchings et al 2010	Medication management	Not Reported	1. Positive impact: Feeling assured (a feeling that something was being done and this made carers feel more positive) 2. Negative impact: Restricting time and activities (e.g., going away for the weekend)

Table 3. Challenges of Medical/Nursing Tasks Identified by Dementia Caregivers

Challenges of Medical/Nursing Tasks	Authors, Years
Care recipients' cognitive impairment	Cotrell et al 2006; While et al., 2013; Gillespie et al 2015
Care recipients' behavioral changes and refusal	Kaasalainen et al 2011; While et al., 2013; Ball et al 2015; Gillespie et al 2015; Maidment et al 2017
Care recipients' comorbidities and complex medication regimen	Erlen et al 2013; Gillespie et al 2015; Smith et al 2015; Maidment et al 2017
Limited information and training from healthcare professionals	Erlen et al 2013; Poland et al 2014; Ball et al 2015; Gillespie et al 2015; Smith et al 2015; Maidment et al 2017; NAC in partnership with the AA, 2017
Situations that needed clinical decision making	Kaasalainen et al 2011; Poland et al 2014; Sadak et al 2017
Caregivers' advanced age and own health problems	While et al., 2013; Erlen et al 2013; Maidment et al 2017

Appendix 1. Quality Appraisal of Reviewed Studies

Table 1. Quality Appraisal for Quantitative Studies

Quantitative Studies	**Sampling strategy (e.g., random, convenience sampling)**	**Having a representative sample of the population under study (e.g., inclusion and/or exclusion criteria are explained)**	**Measurements (e.g., clear origin or validity is known, or standard instrument)**	**Acceptable response rate (e.g., 60% or above)**
Polenick et al., 2018	· 104 community-dwelling adults aged 65 and older with dementia and their co-resident spousal caregivers drawn from the 2011 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC). · Care recipients were recruited from a Medicare enrollment database using a stratified three-stage sampling design.	· Participants were eligible for NHATS if they were Medicare enrollees aged 65 and older, resided in the contiguous United States, and received health-related assistance in the last month with mobility, personal care, and/or household chores. · NHATS participants were eligible for NSOC if they had at least one family or unpaid nonfamily caregiver who provided health-related assistance with mobility, self-care, household chores, and/or medical care activities.	Not clear · Caregivers reported whether they performed four types of care tasks (1: yes, 0: no): keeping track of medications, managing medical tasks (e.g., ostomy care, IVs, testing blood), giving shots/injections, and skin wound/sore care. (Survey Questionnaires)	· Care recipients: Of the 12,411 contacted enrollees, 8,245 (71%) were interviewed for the 2011 NHATS. · Caregivers: Of the 3,362 caregivers (68%) for whom contact information was given, 2,007 (60%) completed a 30-minute telephone interview.
National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017	· Caregivers were recruited using Growth from Knowledge's national, probability-based, and online survey.	· Caregivers who were (1) providing unpaid care at any time in the last 12 months to a relative or friend 18 years or older and (2) adults (ages 18 or older).	Not clear · How difficult {is/was} it for you to do the medical/nursing tasks that {are/were} required to help your care recipient? (Questionnaires developed by National Alliance for Caregiving & AARP)	· 5% response rate given that the screening process was included
Erlen et al., 2013	· Participants were recruited from multiple community sites, geriatric practices, a memory disorders clinic, targeted mailing lists, and the patient registry through the participating university's Clinical and Translational Science Institute. Authors placed flyers advertising the study in pharmacies, libraries, and community centers.	· Care recipients have self- or caregiver-reported memory loss, reside in the community, have a family/informal caregiver, have a minimum of two co-morbid conditions for which they were prescribed medications, and be unable to self-manage their medications. · Family/informal caregivers assist with medication management, speak English, and have access to a telephone.	· The Medication Management Instrument for Deficiencies in the Elderly (MedMaIDE) assesses three areas: knowledge of medications, how to take medications, and how to procure medications; Cronbach's alpha = .71	Not clear
Cotrell et al., 2006	· Patients were recruited from the National Institute on Aging (NIA)-supported Oregon Alzheimer's Disease Core Center (OADC) clinical sites.	Not Clear (Newly admitted and regular patients who were known to be on three or more	· The Drug Regimen Unassisted Grading Scale (DRUGS) (Edelberg, Shallenberger, & Wei, 1999) uses an ecological approach to examine	Not Clear

Quantitative Studies	Sampling strategy (e.g., random, convenience sampling)	Having a representative sample of the population under study (e.g., inclusion and/or exclusion criteria are explained)	Measurements (e.g., clear origin or validity is known, or standard instrument)	Acceptable response rate (e.g., 60% or above)
	· A comparison group was recruited from a pool of volunteers over the age of 65 available through the Oregon Brain Aging Study (OBAS), a longitudinal study of healthy aging, and from local senior centers.	prescribed medications were recruited during clinic visits)	performance on tasks designed to simulate drug adherence behavior. · The following tasks were measured for each prescription medication: (1) identify medications correctly, (2) specify the correct dosage, and (3) specify the correct timing of dosage.	

Note. All studies are met the screening criteria (1) having clear research questions and (2) addressing the research questions based on the collected data

Table 2. Quality Appraisal for Qualitative Studies

Qualitative Studies	Relevant sources of qualitative data (e.g., in-depth interviews and/or group interviews, and/or observations and/or documentary sources)	Analyzed qualitative data pertinent to the research questions (e.g., thematic analysis and content analysis)	Appropriate consideration was given to how findings relate to the context in which the data were collected (e.g., the setting).	Appropriate consideration was given to how findings relate to researchers' influence (e.g., researchers critically explain how findings relate to their perspective, role, and interactions with participants)
Maidment et al., 2017	Semi-structured interview	A systematic cross-comparison analysis	· The informal carer and the person with dementia were together in the room during the interview. This allowed the person with dementia to provide further insight into what the informal carer was saying. · Data were triangulated from the perspectives of informal carers and people with dementia. · Participants were recruited from various locations, and data saturation was achieved for the complete set of interviews. · As data were obtained from face-to-face interviews, it was not avoidable the possibility that participants may have given socially desirable responses. Only a limited number of participants from the Black and Minority Ethnic community were interviewed.	Not clear
Sadak et al., 2017	Telephone semi-structured interview	Thematic analysis	· Caregivers whose care recipients were near the end stages of the dementia trajectory were not represented. · Systematic study of larger, more representative samples and triangulation of caregiver reports with data from patients' medical records is needed to better understand the degree to which acute health crises in persons with dementia might be preventable, and how best to support caregiver self-care and resilience when crises occur.	Not clear

Qualitative Studies	Relevant sources of qualitative data (e.g., in-depth interviews and/or group interviews, and/or observations and/or documentary sources)	Analyzed qualitative data pertinent to the research questions (e.g., thematic analysis and content analysis)	Appropriate consideration was given to how findings relate to the context in which the data were collected (e.g., the setting).	Appropriate consideration was given to how findings relate to researchers' influence (e.g., researchers critically explain how findings relate to their perspective, role, and interactions with participants)
Ball et al., 2015	Telephone semi-structured interview	Thematic and triangular analysis	· The study had not aimed to collect data to represent a shared experience across all family carers, but instead among a purposive and information-rich sample. The participants' varied experiences and currency of dementia care (regarding duration, reflections of caring now or in the past) may have contributed to the variability of experience about challenges observed, strategies developed, and the effects of feeding care on family carer burden.	Not Clear
Gillespie et al., 2015	Focus group interview or face to face semi-structured interview	Thematic analysis	Not clear	Not Clear
Smith et al., 2015	Face-to-face semi-structured interview	Thematic analysis	Not Clear	Not Clear
Poland et al., 2014	Focus group interview	Thematic analysis	· The "thick description" available in detailed stories from carers' personal experiences provided nuanced insights into how they identified challenging emotional, practical, ethical and conceptual issues, described in context, within the mutually supportive dialogue.	Not Clear
While et al., 2013	Face-to-face semi-structured interview	Thematic analysis	Not Clear	Not Clear
Kaasalainen et al., 2011	Face-to-face semi-structured interview	Axial coding	· Each interview took place at a location that was most convenient to the participant. · The study was comprised of a volunteer sample that was based within one particular region and only English-speaking participants. As such, these findings might not be transferable to other settings or populations. · Future work is needed to explore unregulated care providers' perspectives as well, such as personal support workers, as they may offer a unique experience of caring for older adults and their family members who live in the community.	Not Clear
Hutchings et al., 2010	Focus group interview or face to face semi-structured interview	Thematic Analysis	Not Clear	Not Clear

Note. All studies are met the screening criteria (1) having clear research questions and (2) addressing the research questions based on the collected data

Supplementary File1. PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	p. 13
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	p. 14
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	p. 15-16
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	p. 17
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Not Applicable
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	p. 18-19
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	p. 18
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	p. 18
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	p. 18-19
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	p. 20
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	p. 20-21
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	p. 19-20
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	p. 20
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	p. 20

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	p. 19-20
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Not Applicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	p. 21 Figure 1.
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	p. 21-22 Table1.
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	p. 26-27 Appendix 1
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	p. 21-27 Table 1-3
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Not Applicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	p. 26-27
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Not Applicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	p. 27-30
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	p. 30-31
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	p. 31-32
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	p. 21

CHAPTER 3: Manuscript Two

The Impact of Performing Medical/Nursing Tasks at Home among Caregivers of Individuals with Cognitive Impairment

Submitted to the *Journal of Applied Gerontology*

Abstract

Caregiving for older adults with cognitive impairment is ever more difficult as caregivers are required to perform medical/nursing tasks at home. Little is known about the medical/nursing tasks in their relationships to caregivers' caregiving characteristics and their effects on caregiver burden. Secondary data analyses were conducted with 423 caregivers of individuals with cognitive impairment from the 2015 National Alliance for Caregiving (NAC) and AARP data. In terms of caregiving context, more caregivers who performed medical/nursing tasks lived with care recipients and provided longer hours of care than caregivers who did not perform medical/nursing tasks. When caregivers delivered medical/nursing tasks, they were two times more likely to experience higher levels of caregiver burden. Medical/nursing tasks can exacerbate caregiver burden. Healthcare providers' explanations of the needs and the benefits of medical/nursing tasks, as well as education and training for the tasks, are needed to reduce caregiver burden.

Keywords

Memory, Caregiving, Community, Cognitive Impairment, Caregiver Burden, Medical/Nursing Tasks

Introduction

Caregiving, generally by family members, is critical for older adults those with cognitive impairment. Older adults with cognitive impairment have a noticeable decline in one of the intellectual domains, such as memory, language, or executive functioning (American Psychiatric Association, 2013). Up to 42% of adults, aged 65 years or older, have cognitive impairment (U.S. Preventive Services Task Force, 2016). Due to the cognitive decline, older adults with cognitive impairment need assistance in their day-to-day functions, such as balancing a checkbook, driving a car, or finding housing (Geda, 2012). More than 15 million caregivers provide care to them without any financial compensation (Alzheimer's Association, 2017). Because of the rapidly growing numbers of older adults, especially the dramatic increase in adults aged 80 and older, the importance of caregiving will be valued more in the coming years (Wimo, Jönsson, Bond, Prince, & Winblad, 2013).

Family caregiving to older adults has become far more difficult than ever. This is likely due to the advancement of medicine and technology, the complexity of acute and chronic diseases in care recipients, and reduced time in hospital stays (Keeling, 2014). Caregivers coordinate with a wide variety of healthcare providers, giving crucial information regarding healthcare history and changes in symptoms (The National Academies of Sciences, Engineering, and Medicine [NASEM], 2016). In addition, caregivers perform medical/nursing tasks that are skilled activities, such as dealing with wound and ostomy care, incontinence care, complex medication regimen as well as handling assistive mobility devices and medical equipment (Reinhard, Levine, & Samis, 2012). When caregivers perform medical/nursing tasks, they need to balance the ratio of risks and benefits of medication and the management of the acute exacerbation of the chronic diseases of care recipients (Poland et al., 2014; Sadak, Zdon, Ishado, Zaslavsky, & Borson, 2017).

Review of Relevant Literature

Delivering medical/nursing tasks for older adults with cognitive impairment can be more challenging than providing medical/nursing tasks for older adults without cognitive impairment. Caregivers of individuals with cognitive impairment (ICI) are two-times (22% vs. 11%) more likely to report difficulty in performing medical/nursing tasks than caregivers with other chronic diseases (National Alliance for Caregiving [NAC] partnership with Alzheimer's Association [AA], 2017). The noticeable difficulty of completing medical/nursing tasks among caregivers of ICI may originate from care recipients' unique disease process and co-morbidities. Cognitive impairment causes forgetfulness of important information, difficulty with counting, having distorted visual images, and making poor decisions (Alzheimer's Association, 2018). Due to those limitations, caregivers of ICI may have to be involved with simple tasks, such as daily living activities, as well as more complicated ones (i.e., medication management).

Furthermore, given that age is the greatest risk factor in cognitive impairment, most individuals with cognitive impairment are older and have increased chronic conditions, such as stroke/hypertension, diabetes, cardiac disease, musculoskeletal disabilities, and hearing or vision problems (Alzheimer's Association, 2018; Reinhard, Samis, & Levine, 2014;). Due to increased age and co-morbidities, one study reported that caregivers of ICI manage an average of nine medical conditions and administer more than 10 medications to the care recipients (Erlen et al., 2013). In addition, nearly half of ICI tend to have disruptive behaviors, such as being agitated, aggressive, suspicious, and depressed (Reinhard et al., 2014). These disruptive behaviors may exacerbate difficulties in performing medical/nursing tasks, for example, being paranoid about taking medications or thinking pills are poisonous (Kaasalainen et al., 2011).

Lastly, 53% of caregivers of ICI perform the tasks without training (NAC in partnership with the AA, 2017). Without proper support and training from healthcare professionals, caregivers of ICI may not have confidence in completing medical/nursing tasks or sometimes may even find their decisions have caused harm to the care recipients (Ball et al., 2015; Poland et al., 2014). As a result, caregivers of ICI may suffer from anxiety, worry, stress, and guilt from performing medical/nursing tasks (Ball et al., 2015; Poland et al., 2014).

Although daily and personal care in relation to caregiver burden and caregiving context have been extensively researched, there is limited evidence about medical/nursing tasks performed by the informal caregivers of ICI (Reinhard et al., 2012). Caregivers' backgrounds (age, gender, race/ethnicity, educational level, annual income, health status, and relationships to care recipients) and caregiving context (average weekly hours of care provided, length of time care provided, living with care recipients, having a choice about caregiving) may be different from those who do not perform medical/nursing tasks. Moreover, the quantitative effect of performing medical/nursing tasks on caregiver burden is vague, even though qualitative caregiving literature reports the negative impact of performing medical/nursing tasks narratively.

Aims

The aims of the study are (1) to examine differences in caregivers' background characteristics and caregiving context between the group performing medical/nursing tasks versus the group not performing the tasks, and (2) to investigate the effect of performing medical/nursing tasks on caregiver burden.

Method

This cross-sectional and correlational study used secondary data analysis. The secondary data were collected by the National Alliance for Caregiving (NAC) & the American Association of Retired Persons (AARP) and released in 2015.

Data Collection

The 2015 NAC/AARP data consist of 1,248 nationally representative caregivers in the United States (NAC/AARP, 2015). A professional market research institute, Growth from Knowledge (GfK), recruited family and friend caregivers from September 18th to November 5th in 2014. The GfK selected the possible participants by a random selection of telephone numbers and residential addresses as well as by oversampling of racial and ethnic minority groups. The participants were included if they met the following inclusion criteria: (1) informal caregivers (who provide unpaid care); (2) adult (age equal to and older than 18); (3) providing care within the last 12 months at the time of original data collection; and (4) caring for household members in the community. Those who were randomly selected and met the inclusion criteria were invited as part of a KnowledgePanel® by participating in an online interview.

Subjects

In this study, cognitive impairment is referred to as a decline in memory, because memory loss is the most common symptom and the first symptom recognized in cognitive impairment diseases as intellectual domains of the brain weaken (Alzheimer's Association, 2017; Jahn, 2013). Therefore, the 2015 NAC/AARP data analysis included informal caregivers who reported that their care recipients needed care because of a memory problem (n=451). The selected sample for this study was examined for the amount of missing data and the missing mechanism. The missing data were small (<5%) and the missing data were completely missing at random (Little's Missing Completely At Random, *p* = 0.262). The list-wise deletion was performed, given that there was no bias of list-wise deletion with missing data that was completely missing at random (Peugh & Enders, 2004). After the list-wise deletion with missing data, the total sample size was 423.

Measures

Caregivers' Background Characteristics. Informal caregivers' background characteristics included age, gender, race/ethnicity, educational level, annual income, health status, and relationships to care recipients. Race/ethnicity was categorized into White, Black, Hispanic, Asian, and other. Relationships to care recipients were categorized into parents or grandparents, spouse or partner, other relatives, and friends or neighbors. Educational level was classified as high school or less, and some college or higher. Annual income was dichotomized at $50,000, based on the 50th percentile income of the United States (DeNavas-Walt & Proctor, 2015). Caregivers' health status was measured by a five-point Likert scale of Self-Rated Health. The Self-Rated Health scale validly and sensitively reflected the current health status of caregiver and ranged from 1 = poor, 2 = fair, 3 = good, 4 = very good, and 5 = excellent (Mavaddat, Parker, Sanderson, Mant, & Kinmonth, 2014).

Caregiving Context. The caregiving context included average weekly hours of care provided, length of time care provided (years), whether the caregivers lived with the care recipients (co-residence, yes/no), whether the caregivers felt they had a choice in engaging in the caregiving role (yes/no), and performing medical/nursing tasks (yes/no). A caregiver was considered to perform medical/nursing tasks, if he or she reported that they managed medications (i.e., pills, eye drops, or injections), prepared food for special diets, administered tube feedings, managed wound care, monitored blood pressure or blood sugar, helped with incontinence, or operated medically necessity equipment (National Alliance for Caregiving, 2015).

Caregiver Burden. Caregiver burden was measured by three items including physical strain, emotional stress, and financial hardship. Each item used a 5-point Likert-scale that ranged from 1 to 5 (not a strain at all = 1; very much of a strain = 5) (Kim, Chang, Rose, & Kim, 2012). Caregiver burden was then dichotomized based on the mean of the three items' composite scores. Using this brief scale, the reliability coefficient was high for this study dataset (Cronbach's $\alpha = 0.74$).

Data Analysis

Mean Comparison using Independent t-tests and χ^2 tests. Descriptive statistics were performed to describe caregivers' background characteristics and caregiving context using means with standard deviations (*SD*s) and percentages for categorical variables. Independent *t*-tests and χ^2-tests were conducted to compare the difference of caregivers' background and caregiving context between the group performing medical/nursing tasks versus the group not performing medical/nursing tasks. The length of time provided care (years) was transformed using a natural log function for the univariate normality. Homogeneity of dependent variables was met.

Logistic Regression. Binary logistic regression (Nelder & Wedderburn, 1972) was used to identify significant predictors of being in the higher caregiver burden group. Dementia caregivers' background characteristics and caregiving context were used, and the statistical model for Pi (for being in the higher caregiver burden group), can be written as follows.

$$\text{Log}\left(\frac{\text{P}i}{1-\text{P}i}\right) = \textit{Logit}\ (\text{P}i) = \beta_0 + \beta_1\text{X}_i + \beta_2\text{X}_i + \beta_3\text{X}_i + \beta_4\text{X}_i + \beta_5\text{X}_i + \beta_6\text{X}_i + \beta_7\text{X}_i + \beta_8\text{X}_i + \beta_9\text{X}_i + \beta_{10}\text{X}_i$$

where β_1 is a slope coefficient for the relation between the logit of Pi and age, β_2 is for gender, β_3 is for relationship to the care recipient, β_4 is for annual income, β_5 is for self-rated health, β_6 is for weekly hours of care provided at average, β_7 is for length of time provided care, β_8 is for living with care recipient, β_9 is for caregiving without choice, and β_{10} is for performing medical/nursing tasks. There was no multicollinearity among independent variables (VIFs are less than 1.35) and no abnormality in the multivariate normal distribution. The level of significance of .05 and the two-tailed test were used.

Weighting. A single-stage weighting was used to produce representative estimates for national caregivers at the population level. The population weight was based on age, sex, and race/ethnicity from the Current Population Survey performed by the U.S. Census Bureau, and the NAC & AARP (2015) released the weight variable within the data set. IBM SPSS version 23 (IBM Corp, 2015) was used for all data analyses.

Results

Caregivers' Background and Caregiving Context. Caregivers' background characteristics and caregiving context are presented in Table 1. The average age of caregivers was 56.99 (*SD* = 17.27). The majority of caregivers were female (60.7%) and White (68.8%). About half of the caregivers took care of parents or grandparents (55.2%), had some college or higher education (66.1%), and had more than a $50,000 annual income (54.6%). The average self-rated health was 3.24 (*SD* = 0.99), which meant caregivers reported their overall health a little higher than good.

The average weekly hours of care were 30.45 (*SD* = 31.54) and the average length of care was 5.13 (*SD* = 9.20) years. Approximately one third of the caregivers lived with the care recipients (38%); more than half of caregivers felt they “had no choice” of caregiving (56.1%); and about two thirds of caregivers performed medical/nursing tasks (69%).

Comparison between Performing Medical/Nursing Tasks Group versus Not. Table 2 shows the group difference between the group performing medical/nursing tasks versus the group not performing medical/nursing tasks. The caregiver’s relationship to the care recipient was significantly different between the groups ($\chi^2 = 27.503$, $p < .0001$). Specifically, caregivers who performed medical/nursing tasks were more likely to be a spouse or partner of the care recipient (24.6% vs. 6.4%). Whereas, caregivers who did not perform medical/nursing tasks were more likely to be a friend or neighbor (23.9% vs. 8.7%). There was no significant difference in age, gender, income, or self-rated health between the two groups.

Significantly, more caregivers who performed medical/nursing tasks lived with care recipients (49.4% vs. 11.8%; $\chi^2 = 45.970$, $p < .0001$) and they provided longer hours of care weekly (40.1 vs. 8.3 hours; $t = 12.79$, $p < .0001$). There was no significant difference in length of time providing care (years) and having a choice about caregiving between the two groups.

Predictors of Being Higher Caregiver Burden Group. Table 3 shows the odds ratios (ORs) and unstandardized beta coefficients (b) of the binary logistic regression analyses of the effects of caregivers’ backgrounds and caregiving context on caregiver burden.

Relationships between caregivers and care recipients were identified as a significant factor of being in the higher caregiver burden group. Compared to nonfamily caregivers, when caregivers of ICI took care of other relatives than spouse/partner or parents/grandparents, they were 3.49 times more likely to be in the higher caregiver burden group (OR = 3.489, $b = 1.250$, $p = .013$). Self-rated health was a significant factor of caregiver burden. When caregivers reported better self-rated health, they were 35.9% less likely to be in the higher caregiver burden group (OR = 0.641, *b* = -.0445, *p* < .0001). Caregivers' age, gender, or annual income were not significant factors for predicting the higher caregiver burden group.

Having a choice and performing medical/nursing tasks were significant factors for predicting membership in the higher caregiver burden group. When caregivers did not have a choice about caregiving, they were 2.46 times more likely to be in the higher caregiver burden group (OR = 2.463, *b* = 0.901, *p* < .0001). Caregivers who performed medical/nursing tasks were 2.24 times more likely to be in the higher caregiver burden group (OR = 2.237, *b* = 0.805, *p* = .007). Weekly hours of caregiving, length of care (years), and living with care recipients were not significant factors for predicting the higher caregiver burden group.

The model significantly explained 21.8% (R^2 of Nagelkerke) of the variance of being in the higher caregiver burden group. The overall model prediction was 70.0% with 73.7% of specificity and 65.8% of sensitivity.

Discussion

This study provides the first nationally representative results of the effect of medical/nursing tasks on caregiver burden as well as the unique features of backgrounds and caregiving context when caregivers of ICI perform medical/nursing tasks. The most striking finding of this study is that when the caregivers performed medical/nursing tasks, they were more than two times as likely to be in the higher burden group. This finding is in line with previous studies reporting that any type of medical/nursing tasks increased the burden in *paid* home caregivers (Moorman & MacDonald, 2012); and, the number of medical/nursing tasks was associated with heightened physical caregiver stress (Polenick, Leggett, & Kales, 2017). Medical/nursing tasks can be difficult because they involve physical strain (e.g., lifting or moving), technical handling, diagnostic reasoning, hazard from bodily fluids, and possible harm to care recipient (Moorman & MacDonald, 2013; Polenick et al., 2017). Along with those risks and demands, caregivers may have little support in the form of receiving education about the diseases' condition, resources for the tasks, and skills training for home care responsibilities (Grady & Rosenbaum, 2015).

Caregivers of ICI who perform medical/nursing tasks are usually in close relationships with care recipients who may have greater care needs. This study determined that more caregivers who performed medical/nursing tasks took care of close family members, such as parents/grandparents and spouse/partner (80.2%). In contrast, almost a quarter (23.9%) of caregivers who did not perform medical/nursing tasks, took care of nonfamily members such as friends or neighbors. Close family caregivers may assume the duties, when the medical/nursing tasks are needed and have benefits for care recipients, although the tasks may require considerable responsibility and attention (McDonald, McKinlay, Keeling, & Levack, 2015). Caregivers who are not in a close relationship with care recipients may resist performing medical/nursing tasks because they may be worried about managing the tasks alone or they may be concerned that they will eventually have to conduct more tasks (McDonald et al., 2015).

In this study, caregivers who performed medical/nursing tasks and lived with care recipients, provided greater intensity of care (five times more weekly hours of care) compared to those who did not perform medical/nursing tasks. This finding is in line with a previous study that reported if caregivers of older adults managed medications or had direct interactions with healthcare professionals for care recipients, the caregivers were more likely to live with older adults and provide more hours of caregiving compared to those who did not (Wolff, Spillman, Freedman, & Kasper, 2016). Close family caregivers may opt to live with care recipients, and the co-residency often generates greater amounts of time devoted to caregiving (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Chiao, Wu, & Hsiao, 2015). Furthermore, the severity of care recipients' cognitive impairment may require living together and produce longer hours to meeting daily care needs.

Not having a choice about caregiving may be one of the strongest factors contributing to caregiver burden. Caregivers of ICI may be willing to take the caregiving role when caregivers have a good pre-caregiving relationship with care recipients, with the choice more likely to be based on affection, closeness, and reciprocity (Quinn, Clare, & Woods, 2010). However, when there is pressure from other family members, from cultural norms (filial piety), or from moral obligation, caregivers may feel no choice about providing caregiving. Lack of choice can be a barrier to having positive motivation and to finding the meaning of caregiving, resulting in feeling strain and powerlessness (Quinn et al., 2010).

In this study, when caregivers of ICI took care of other relatives (uncles, aunts) than spouse/partner or parents/grandparents, the caregivers were more likely to be in the higher burden group. This was an unexpected result because typically close kinship ties are associated with heightened caregiver burden (Chiao et al., 2015). However, a recent caregiving study provides different insights, showing that when caregivers can predict their caregiving responsibility such as supporting parents or grandparents, they are less likely to be burdened (Kim, Lee, Cheon, Hong, & Chang, 2018). In addition, weak family ties or poor current relationships with care recipients may put caregivers in the higher burden category (Kim et al., 2018; Richardson, Lee, Berg-Weger, & Grossberg, 2013). These changes regarding kinship and caregiver burden may be due to a transition of family structure. Besides the nuclear and traditional family structure, diverse forms of family structure have emerged, such as blended family, multi-partnered fertility, and living together without legal documentation (Waite, & Xu, 2015). Further examination considering the complexity of many current caregiver relationships on caregiver burden is warranted.

Lastly, in this study, caregivers' better health status (higher self-rated health) lowered the chance of being in the higher caregiver burden group. It is known that poor caregivers' health is related to greater burden and it is thought that the pre-existing physical or psychological health conditions might hinder caregivers from managing stress adequately (Chiao et al., 2015; Roth, Fredman, & Haley, 2015). Half of caregivers have at least one pre-existing medical condition and their health is even declining due to the caregiving duties (Grady & Rosenbaum, 2015). Future research is needed to investigate the determinants of poor health among caregivers and interventions to reduce those factors (Grady & Rosenbaum, 2015).

Limitations

This study has several limitations that should be taken into consideration when interpreting the results. First, this study cannot draw causal inference, given that the primary data set was cross-sectional, although this data set provided a rich analysis into caregivers performing medical/nursing tasks. Second, care recipients' cognitive impairment was based on caregivers' self-reported response. Although this method is often used in caregiving survey research, the lack of objective diagnosis makes it impossible to specify particular disease type, such as mild cognitive impairment, Alzheimer's disease, or other types of dementia. Third, this study did not include severity of care recipients' disease, such as the frequency of disruptive behaviors, the decline of functional status, and the severity of cognitive decline. Therefore, it was difficult to ascertain how the type of memory loss or the severity of care recipients' disease status specifically influenced the understanding of caregiving burden of performance of medical/nursing tasks.

Relevance to Clinical Practice and Policymakers

Healthcare professionals may support caregivers of ICI to reduce the burden from performing medical/nursing tasks by providing education and training regarding the tasks. Caregivers are more likely to assume the responsibility willingly when they comprehend the reasons and benefits of medical/nursing tasks (McDonald et al., 2015). While explaining the purpose and benefits of medical/nursing tasks, healthcare providers may reframe caregivers' conflicting feelings and negative perceptions related to the tasks (McDonald et al., 2015). Although medical/nursing tasks at home can be stressful and challenging, at the same time, the tasks are critical and direct help for care recipients is crucial (Polenick et al., 2017). When caregivers successfully manage the medical/nursing tasks through learning skills and obtaining knowledge, the caregivers experience positive caregiving gains, such as becoming closer to care recipients or feeling satisfaction with the care recipients' care (Polenick et al., 2017). Healthcare professionals' effective instructions and demonstrations of medical/nursing tasks can turn the negative impact of the tasks to positive.

Policymakers should take into account how to assist caregivers further in the delivery of medical/nursing tasks. To date, 39 U.S. states and territories have enacted the Caregiver Advise, Record and Enable Act (CARE Act) that requires the hospital to provide caregivers instructions on medical/nursing tasks at the time of discharge (Reinhard & Ryan, 2017). As a further step, special attention is needed on how to support multicultural caregivers, especially those with language barriers, to better understand discharge information as well as how to assist rural area caregivers in accessing resources for medical/nursing tasks (Reinhard & Ryan, 2017).

Conclusion

This study investigated how caregivers' background characteristics and caregiving context are different for those performing medical/nursing tasks as well as determined the effects of medical/nursing tasks on caregiver burden among caregivers of individuals with cognitive impairment. By comparing two groups performing versus not performing medical/nursing tasks, the medical/nursing tasks were frequently delivered by closer kin, requiring co-residential status with their care recipients, and resulting in longer hours of care. In addition, the delivery of medical/nursing tasks put caregivers at twice the risk for caregiver burden.

To address caregiver burden, this study has highlighted the need for healthcare providers to better understand the vulnerability and extra challenges generated by medical/nursing tasks upon caregivers. When healthcare providers explain the purpose and the benefits of medical/nursing tasks, the caregivers may be more motivated to take on the extra tasks. Offering step-by-step instructions and hands-on training for the medical/nursing tasks that they need to deliver at home may increase caregivers' ability, confidence, and feeling of less burden. Further study is warranted to help care recipients and other members within complex and multicultural families to perform medical/nursing tasks.

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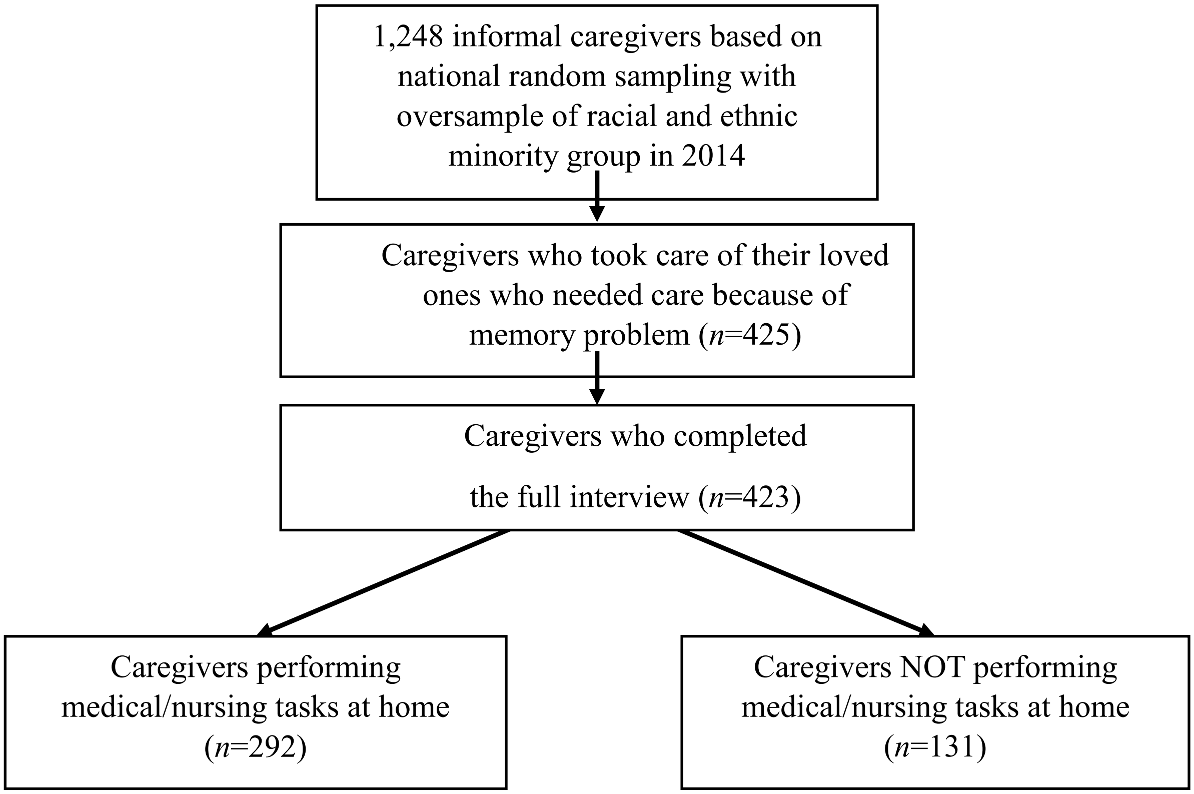

Figure 1. Flowchart of sample with the unweighted final sample (*n*=423)

Table 1. Descriptive Statistics (weighted): Demographics

Variables	M (SD) or n (%)
Age of Care Recipient	77.68 (± 13.36)
Gender of Care Recipient (Female)	62.7%
Age of Caregiver	56.99 (± 17.27)
Gender of Caregiver (Female)	60.7%
Race/Ethnicity of Caregiver	
White	68.8%
Black	11.5%
Hispanic	12.4%
Asian	4.7%
Other	2.6%
Relationship with Care Recipient	
Adult Children (parents/grandparents)	55.2%
Spouse or Partner	19.1%
Other Relatives	12.5%
Friends or Neighbors	13.3%
Education Level of Caregiver	
High School or Less	33.9%
Some College or higher	66.1%
Annual Income of Caregiver	
Less than 50,000	45.4%
Equal to or greater than 50,000	54.6%
Weekly Hours of Care Provided at Average	30.45 (± 31.54)
Length of Time Provided Care (years)	5.13 (± 9.20)
Living with Care Recipient Yes	38%
Having a Choice about Caregiving Yes	43.9%
Self-Rated Health	3.24 (± 0.99)

Table 2. Comparison of Sociodemographic Characteristics of Informal Caregivers in Performing Medical/Nursing Tasks Group Versus Not (weighted)

Variables	Levels	Performing Medical/Nursing Tasks (Weighted, *M* (*SD*) or %)	Not Performing Medical/Nursing Tasks (Weighted, *M* (*SD*) or %)	*t*-test / χ^2	*p* value
Age of Caregiver		57.23 (±17.24)	56.42 (±17.40)	0.414	0.679
Gender of Caregiver	Male	38.3%	41.3%	0.277	0.599
	Female	61.7%	58.7%		
Relationship with Care Recipient	Adult Children (parents/grandparents)	55.6%	54.1%	27.503	<0.0001***
	Spouse or Partner	24.6%	6.4%		
	Other Relatives	11.1%	15.6%		
	Friends or Neighbors	8.7%	23.9%		
Annual Income	Less than 50,000	45.8%	44.5%	0.053	0.819
	Equal to or greater than 50,000	54.2%	55.5%		
Self-rated Health		3.22 (±1.00)	3.30 (±0.97)	-0.664	0.507
Weekly Hours of Care Provided at Average		40.08 (±31.91)	8.26 (±15.40)	12.79	<0.001***
Length of Time Provided Care (years)		5.00 (±8.27)	5.41 (±11.11)	0.337	0.736
Living with Care Recipient	Yes	49.4%	11.8%	45.970	<0.0001***
	No	50.6%	88.2%		
Having a Choice about Caregiving	Yes	41.1%	50.0%	2.463	0.117
	No	58.9%	50.0%		

Note. $^*p < .05$, $^{**}p < .01$, $^{***}p < .001$

Table 3. Binary Logistic Regression Models of the Effects of Caregivers' Background Characteristics and Caregiving Context on Caregiver Burden (weighted)

Variables		Unstandardized B (SE)	*p* value	OR (95% CI)
Age of Caregiver		-0.007 (0.008)	0.374	0.993 (0.997-1.009)
Gender of Caregiver	Female	-0.219 (0.241)	0.363	0.803 (0.501-1.288)
Relationship to the Care Recipient	Adult Children (parents/grandparents)	0.340 (0.411)	0.409	1.405 (0.627-3.147)
	Spouse or Partner	0.341 (0.546)	0.532	1.407 (0.483-4.098)
	Other Relative	1.250 (0.502)	0.013*	3.489 (1.304-9.336)
Annual Income	Less than $50,000	0.356 (0.253)	0.160	1.427 (0.869-2.345)
Self-Rated Health		-0.445 (0.126)	<0.0001***	0.641 (0.501-0.820)
Weekly Hours of Care Provided at Average		0.008 (0.005)	0.089	1.008 (0.999-1.017)
Length of Time Provided Care (years)		0.080 (0.094)	0.396	1.083 (0.901-1.302)
Living with Care Recipient (Co-residence)		-0.313 (0.335)	0.350	0.731 (0.379-1.410)
Caregiving without Choice		0.901 (0.244)	<0.0001***	2.463 (1.528-3.970)
Performing Medical/Nursing Tasks		0.805 (0.298)	0.007**	2.237 (1.246-4.015)

Note. OR = Odds Ratio, **p* < .05, ***p* < .01, ****p* < .001

CHAPTER 4: Manuscript Three

Predictive Factors of Caregiver Burden in Caregivers of Individuals with Cognitive Impairment

To be submitted to the *International Psychogeriatrics*

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Abstract

Objectives. To investigate predictive factors on caregiver burden in consideration of healthcare-related factors, such as caregivers' perception of performing medical/nursing tasks, care coordination, and number of hospitalizations.

Design. Cross-sectional design using secondary data analysis.

Participants. Caregivers (N=304) who provided care for individuals with cognitive impairment (ICI) living in the community and who participated in the study of *Caregiving in the U.S. 2015,* conducted by National Alliance for Caregiving and AARP.

Measurements. Care recipients' functional status was measured by activities of daily living (ADL) and instrumental activities of daily living (IADL). Caregivers' feeling difficulty in medical/nursing tasks was measured by 5-point Likert scale and care coordination was measured by sum score of communicating and/or advocating with health care professionals. Other measures included Self-Rated Heath, Caregiver Burden scale, caregivers' backgrounds, and caregiving contexts.

Results. The overall model explained 38.4% of the variance in caregiver burden ($F = 20.48$, $p < 0.001$). When examining each factor, difficulty in medical/nursing tasks ($\beta = 0.38$, $p < 0.001$) was the most influential factor based on the standardized estimates of regression coefficients, followed by caregivers' physical health ($\beta = –0.27$, $p < 0.001$), income ($\beta = –0.13$, $p = 0.01$), and level of the care coordination ($\beta = 0.12$, $p = 0.02$).

Conclusion. Although caregivers' involvement in healthcare-related activities for ICI is necessary, this involvement has considerable impact on one's caregiver burden. Healthcare providers should be cognizant of caregiver burden related to those activities and researchers should develop interventions and community services to decrease caregivers' difficulty in performing their roles.

Keywords: Caregivers, cognitive impairment, burden, healthcare

Introduction

Cognitive impairment among older adults has become a critical issue to address, due to its social, economic, and physical impact of caring for someone with cognitive impairment, and its magnitude will likely grow exponentially with the increasing aging population and demographics shifts. According to the Alzheimer’s Association (2018), older adults with cognitive impairment required 23 times greater amounts of Medicaid payments in 2017 than those without ($8,399 vs. $358 per person) in the U.S. Currently, 5.7 million Americans live with considerable cognitive impairment, and by 2050, the number will be increased to 13.8 million (Alzheimer’s Association, 2018).

Cognitive impairment most often presents with memory loss, which is the first recognized symptom by older adults and by caregivers (Jahn, 2013). The structural and functional brain system is fundamental for intact memory, as memory needs a process of perceiving, encoding, storing, recalling, and verbal expression (Jahn, 2013). Brain changes related to cognitive impairment may start 20 or more years before symptoms show, and the symptoms become evident as the brain changes increase (Alzheimer’s Association, 2018). Cognitive impairment includes but is not limited to Alzheimer’s disease, dementia, and mild cognitive impairment (Jahn, 2013).

Caregivers such as family members, friends, and neighbors provide 83% of the care needed by older adults in the United States (Alzheimer’s Association, 2018). More than 16 million people provide care for older adults with cognitive impairment, and their unpaid care has been valued at $232 billion to the nation (Alzheimer’s Association, 2018). Without rewards or payments, caregivers considerably sacrifice or suffer their physical, emotional, and financial well-being to take care of their loved ones, and this has been conceptualized as caregiver burden (van der Lee et al., 2014).

Research shows that caregiver burden is related to care recipients' functional status, which reflects the care needs by caregivers (Riffin et al., 2018). The functional status is typically measured by activities of daily living (ADL) and instrumental activities of daily living (IADL), which represent personal care and household tasks. If a care recipient has a low functional status, the caregiver is needed to provide elevated levels of ADL and IADL such as managing finances, shopping, and bathing (Riffin et al., 2018).

Growing literature reports that many caregivers provide medical/nursing tasks along with ADL and IADL (Reinhard et al., 2012). Approximately, 67% of caregivers of individuals with cognitive impairment perform medical/nursing tasks, including providing wound management, operating specialized medical equipment, and managing complex medication regimens (National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017). The provision of medical/nursing tasks was perceived two times more difficult to caregivers of individuals with cognitive impairment compared to caregivers of individuals without cognitive impairment (National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017). When caregivers feel performing medical/nursing tasks are difficult, the negative appraisal may have on impact on caregivers' confidence in their role and dealing with the challenges (van der Lee et al., 2014). Nevertheless, the impact of feeling difficulty in medical/nursing tasks has not been examined with respect to caregiver burden.

In addition, caregivers of individuals with cognitive impairment are frequently required to be care coordinators (Wolff et al., 2016). Care coordinators have direct interaction with healthcare professionals or other groups for care recipients' care. As care recipients have limitation on their cognitive ability, caregivers are compelled to speak for as well as advocate for care recipients with health care providers, community services, or government agencies. Although research shows that caregivers of older adults feel emotional and financial difficulty with care coordination, the impact of care coordination on caregiver burden has not been addressed (Wolff et al., 2016).

Lastly, care recipients' frequency of hospitalization may be associated with caregiver burden. Older adults with cognitive impairment are repeatedly admitted to hospital and nursing facility more than (86% vs 51%) older adults without cognitive impairment (Callahan et al., 2012). Hospitalization could severely impact on the individuals with cognitive impairment because they are commonly disoriented with a new environment as well as the hospitalization may disrupt the routines of their lives (Vroomen et al., 2013). For caregivers, hospitalizations are costly and can produce financial concerns. Moreover, providing transitional care from hospitalization to home can be a time of increased care issues. The care issues are not only related with ADL and IADL, such as adapting changes to diet and complying with self-care, but also related with healthcare-activities complying with the medical plan of care, dealing with emerging care recipients' needs, and communicating healthcare providers (Altfeld et al., 2012).

This study was conducted to fill two major research gaps. First, there has been no study investigating the impact of the feeling of difficulty to perform medical/nursing tasks, the level of care coordination, and number of hospitalizations on caregiver burden. As stated above, the vulnerability in relation to healthcare-related activities among caregivers of individuals with cognitive impairment necessitates further study. Second, relatively small sample sizes (less than 150) and convenience samples were used in studies that have investigated both the care recipients' care needs and caregivers' backgrounds on caregiver burden (van der Lee et al., 2014). Therefore, a study that uses a representative sample for caregivers of older adults with cognitive impairment is required to adequately explain caregiver burden.

Specific Aim.

The aim of the study was to investigate predictive factors on caregiver burden, particularly, in consideration of healthcare-related factors. The factors were caregivers' appraisal on involvement of medical/nursing tasks, care coordination, and hospitalization by using a U.S. representative sample of caregivers of individuals with cognitive impairment.

Conceptual Framework

This study used the conceptual framework of Sorensen et al., (2006), who combined the stress process model (Pearlin et al., 1990) and caregiving appraisal model (Lawton et al., 1991). The framework was developed to establish interventions decreasing caregiver burden. This conceptual framework classified factors such as caregivers' background, primary stressors, secondary stressors, and appraisal. Caregivers' background characteristics included caregivers' socio-demographical characteristics such as age, gender, and economic status. Primary stressors demonstrate the demands and intensity of caregiving, such as care recipients' care needs and care situation. Secondary stressors include conflicts and difficulties with family, work, or social relationships because of caregiving. Appraisal is the caregivers' subjective perception on their caregiving role, including role captivity and situational control.

Guided by the conceptual framework, variables were selected and assembled into this study's statistical model based on the availability of the variables in the chosen dataset (see **Figure 1**). Specifically, for caregivers' background, variables including age, gender, race, relationship with care recipients, income, and physical health were chosen. For primary stressors, ADL, IADL, number of hospitalizations, and level of care coordination were selected for care recipients' care needs. In addition, primary caregiver status, co-residence status, duration of caregiving, and hours of care were selected for the care situation. Lastly, for appraisal, two variables were selected, including feeling a sense of choice in caregiving and feeling difficulty in performing medical/nursing tasks.

Methods

Study design

A cross-sectional, secondary data analysis of 304 caregivers was derived from the National Alliance for Caregiving and American Association of Retired Persons (NAC/AARP, 2015) dataset. The NAC/AARP is one of the major organizations advocating for caregivers and collects nationwide caregivers' data every four years starting from 1997. The 2015 NAC/AARP dataset provides the current national profile of caregivers in the U.S. (NAC/AARP, 2015).

Sample

The 2015 NAC/AARP dataset had 1,248 adult caregivers (ages 18 and older) who provided unpaid care to a family member or friend. To draw a representative sample of the U.S. population, randomly selected participants were invited to an online interview using telephone numbers and residential addresses across the U.S. In addition, to include the diverse race/ethnicity, minority groups like African Americans, Hispanics, Asians, and other minority groups were over sampled. Online interviews were conducted either in English or Spanish between September to November 2014.

Caregivers were defined as people helping a relative or friend with personal care, household chores, or medical care in the last 12 months, but caregivers did not need to live with the person (NAC/AARP, 2015). For the purpose of this study's aims, caregivers who responded that they provided care for individuals with memory problems were selected because memory problems were considered as the first noticeable symptom of cognitive impairment. In addition, among the selected caregivers, those who also provided medical/nursing tasks were included in this study to investigate their appraisal on medical/nursing tasks. The total sample size was 304. To ensure power for this study, an adequate sample size was calculated. When using a multiple regression model, in the case of eight independent variables (k=8), medium effect size [$f^2=R^2/(1-R^2)$, 0.15], power of 0.80 (β=0.20), and level of significance 0.05, a total sample size of 107 was needed (Cohen, 1992). Although there was a 5% chance of committing Type I error and 20% chance of committing Type II error, the sample size of this study (N=304) was adequately powered.

Ethical Consideration

The 2015 NAC/AARP dataset was publicly available and completely deidentified. Given that the dataset did not include any identifying information that could be linked to study subjects or potentially harm the participants, the IRB review was exempt.

Measures

Caregivers Background Characteristics. Caregivers' background characteristics were collected using standard questionnaires. Caregivers' age, gender, race/ethnicity, relationship to care recipients, annual income, and caregivers' physical health were included. Race/ethnicity was recorded as White; Black or African American; Hispanic, Spanish, or Latino descent; Asian; or other. Relationships to care recipients were adult children who took care of parents, grandparents, or in-laws, spouse or partner, other relatives, and friends or neighbors. Annual income was divided into two levels (less than or equal to or greater than \$50,000) according to the 50th percentile income of the United States (DeNavas-Walt and Proctor, 2015). A five-point Likert scale of Self-Rated Health was used to measure caregivers' physical health. The Self-Rated Health scale has been used widely because it validly and sensitively reflected the physical health of individuals (range: 1 = poor, 2 = fair, 3 = good, 4 = very good, and 5 = excellent) (Mavaddat et al., 2014).

Care Recipients Characteristics. Care recipients' characteristics included age, gender, functional status and their frequency of hospitalization. Care recipients' functional status was measured by activities of daily living (ADL) and instrument activities of daily living (IADL) (Katz et al., 1963; Lawton and Brody, 1969). The ADL indicated the basic personal care needs, such as feeding and dressing, and showed high internal consistency (Cronbach's α = 0.84) (Arik et al, 2015). The IADL identifies the complex care needs, such as managing finances and shopping, and demonstrated a good interrater reliability (0.85) (Lawton and Brody, 1969). Care recipients' frequency of hospitalization was recorded as having an overnight hospitalization in the last 12 months by self-report. The frequency was categorized as none, one time, two times, and three times or more.

Caregiving Context. Caregiving context included hours of care, duration of care, co-residence status, primary caregiver status, and level of care coordination. Hours of care was recorded as average weekly hours of care provided for the care recipients. The duration of care was recorded as the number of years that caregivers provided care for the care recipients. If caregivers lived with care recipients, it was recorded as co-residence status. If he or she considered himself or herself as the person who provided most of the care, he or she was considered as primary caregiver. Care coordination measured direct interactions with healthcare professionals for the care recipients' care. The level of care coordination was the sum score of involving (1) communicating with health care professionals about care recipients' care (Yes=1 / No=0) or (2) advocating for care recipients with health care providers, community services, or government agencies (Yes=1 / No=0) (range: 0-2).

Caregivers' Appraisal. Caregivers' appraisal included feeling a sense of choice in caregiving and feelings of difficulty in performing medical/nursing tasks. If a caregiver felt a sense of choice in taking on her or his caregiving role, it was considered as feeling a sense of choice. The level of difficulty the caregiver reported in medical/nursing tasks was measured by self-report using a 5-point Likert scale (range: 1 = not at all difficult, 5 = very difficult).

Caregiver Burden. Caregiver burden was measured by three items including physical, emotional, and financial stress, and each item was reported on a 5-point Likert-scale (range: not a strain at all = 1; very much of a strain = 5) (Kim et al., 2012). Caregiver burden was the sum score of the three items (range: 3-15) and the Cronbach's α was 0.74 for the current sample.

Data Analysis

Descriptive Statistics. The total sample of this study (N=304) was examined for the proportion of missing data and the missing mechanism. The amount of missing data was relatively small (<3%) and the missing data were completely missing at random (Little's Missing Completely At Random $p = 0.245$). Descriptive statistics were used to summarize the care recipients' and caregivers' characteristics and the caregiving context.

Correlation. Bivariate correlation statistics were used to examine the association between each variable and caregiver burden. Linearity was checked with scatter plots, and all of the variable met the linear relationship with caregiver burden. The variables were caregivers' background characteristics (age, gender, race/ethnicity, relationship with care recipients, annual income, and physical health), care recipients' care needs (ADL, IADL, number of hospitalizations), caregiving context (hours of care, duration of care, co-residence, primary caregiver status, level of care coordination), and caregivers' appraisal (feeling a sense of choice in caregiving and feeling difficulty in medical/nursing tasks). Variables significantly correlating with the caregiver burden were entered into the Hierarchical Multiple Regression model.

Hierarchical Multiple Regression. Before performing the hierarchical multiple regression, data were checked for violations of the assumptions including normality, multicollinearity, and homoscedasticity. All assumptions were met, but one variable was skewed. The duration of care (number of years that provided care) variable was transformed using a log function for the normality to adjust for the skewness.

Hierarchical multiple regression (*n*=304) was used to identify predictive factors for caregiver burden, considering interrelationships among variables. Only factors significantly correlated with caregiver burden were used in this regression analysis. The highly correlated factors were categorized as background factors, primary stress factors (care recipients' care needs and the caregiving context), and appraisal factors, based on the conceptual framework of stress process and appraisal model. After categorization, the three group of factors were put into the hierarchical multiple regression model using three steps. In the first step, caregivers' annual income and their physical health were entered as background factors. For the second step, ADL, IADL, number of hospitalizations, and care coordination level were entered as primary stress factors. Lastly, feeling a sense of choice in caregiving and feeling difficulty in medical/nursing tasks were entered as caregivers' appraisal factors.

Step 1: Caregiver Burden = $\beta_0 + \beta_1 X_i + \beta_2 X_i + \varepsilon$ (β_1: annual income, β_2: current physical health)

Step 2: Caregiver Burden = $\beta_0 + \beta_1 X_i + \beta_2 X_i + \beta_3 X_i + \beta_4 X_i + \beta_5 X_i + \beta_6 X_i + \varepsilon$ (β_3: ADL, β_4: IADL, β_5: number of hospitalizations, β_6: care coordination level)

Step 3: Caregiver Burden = $\beta_0 + \beta_1 X_i + \beta_2 X_i + \beta_3 X_i + \beta_4 X_i + \beta_5 X_i + \beta_6 X_i + \beta_7 X_i + \beta_8 X_i + \varepsilon$ (β_7: sense of a choice in caregiving, β_8: difficulty in medical/nursing task)

The statistical model for caregiver burden can be written as above, where β_1 was a slope coefficient for the relation between caregiver burden and annual income, β_2 was for current physical health, β_3 was for ADL, β_4 was for IADL, β_5 was for number of hospitalizations, β_6 was level of care coordination, β_7 was for feeling a sense of choice in caregiving, and β_8 was for feeling difficulty in medical/nursing tasks.

Weighting. A single-stage weighting was applied using the population weight variable included in the dataset. The population weight was based on age, sex, and race/ethnicity from the data of Current Population Survey conducted by the U.S. Census Bureau (National Alliance for Caregiving, 2015). To produce representative results of the United States, the population weight was used (National Alliance for Caregiving, 2015). IBM SPSS version 23 was used for all data analyses (IBM Corp, 2015).

Results

Descriptive Sample Characteristics

The characteristics of the caregivers and the individuals with cognitive impairment are presented in Table 1. The mean age of individuals with cognitive impairment was 76.94 (*SD* = 14.19) and 64% of them were female. With respect to functional status of individuals with cognitive impairment, the mean number of ADL was 2.41 (*SD* = 2.10) and the mean number of IADL was 5.69 (*SD* = 1.28). About 55% of the individuals with cognitive impairment were admitted in the hospital one or more times within the last 12 months.

The mean age of caregivers was 56.85 (*SD* = 17.28) and 63% of them were female. The majority of caregivers were White (67%) and the largest proportion of caregivers took care of parents/grandparents (56%). About 46% of caregivers earned less than $50,000 in annual income. Average weekly hours of care provided for care recipients was 40.02 (*SD* = 31.91) and average years of care was 5.01 (*SD* = 8.23). Around half of the caregivers lived with the care recipients (48%) and were primary caregivers (68%). More than two thirds of caregivers responded that they advocated for the care recipient (70%) and they communicated with health care professionals (88%). More than half of the caregivers (59%) felt that they did not have a sense of choice in caregiving.

Correlations between Caregiver Burden and Predictive Factors

Results of the correlations are presented in Table 2, which shows the relationships between caregiver burden and the factors selected based on the conceptual framework. Eight factors that were significantly related with caregiver burden were identified. Caregivers' annual income and their physical health were inversely related with caregiver burden. Caregivers who earned less than $50,000 annually ($r = –0.17$, $p < 0.001$) or caregivers who had a low level of physical health ($r = –0.32$, $p < 0.001$) were significantly more likely to suffer caregiver burden than those who earned equal or greater than $50,000 annually or had a high level of physical health. The remaining six factors were positively associated with caregiver burden. As caregivers performed more ADL ($r = 0.24$, $p < 0.001$), IADL ($r = 0.15$, $p < 0.05$), or care coordination ($r = 0.18$, $p < 0.001$), caregivers were significantly more likely to experience higher caregiver burden. Caregivers who took care of care recipients with more frequent overnight hospital admissions ($r = 0.22$, $p < 0.001$) and caregivers who felt an increased degree of difficulty in medical/nursing tasks ($r = 0.55$, $p < 0.001$), were significantly more likely to experience higher levels of caregiver burden. Lastly, caregivers who felt they did not have a sense of choice in caregiving were significantly more likely to experience increased caregiver burden ($r = 0.20$, $p < 0.001$). Other factors were not significantly correlated with caregiver burden including caregivers' age, gender, race/ethnicity, relationship with care recipients, hours of care, duration of care, co-residence, and primary caregiver status.

Hierarchical Multiple Regression Model

Results of the hierarchical multiple regression analysis are presented in Table 3, which shows predictive factors on caregiver burden. At Step 1, caregivers' physical health and income significantly contributed to the regression model with F (2, 247) = 22.19, $p < 0.001$ and explained for 14.5% of variance in caregiver burden. At Step 2, by adding ADL, IADL, number of hospitalizations, and care coordination level, the change in R^2 was 9.0% and this change was significant to the model with F (4, 243) = 8.25, $p < 0.001$. At Step 3, introducing feeling a sense of choice in caregiving and feeling difficulty in medical/nursing tasks, the change in R^2 was 14.9% and this change was also significant F (2, 241) = 30.61, $p < 0.001$. The overall model with eight factors explained 38.4% of the variance in caregiver burden with F (8, 242) = 20.48, $p < 0.001$.

Standardized beta scores were used to examine individual factors in Step 3. Feeling difficulty in medical/nursing tasks ($\beta = 0.38$, $p < 0.001$) was the most predictive factor on caregiver burden, followed by caregivers' physical health ($\beta = –0.27$, $p < 0.001$), income ($\beta = –0.13$, $p = 0.01$), and level of care coordination ($\beta = 0.12$, $p = 0.02$). Feeling a sense of choice ($\beta = 0.10$, $p = 0.06$) and number of hospitalizations ($\beta = 0.10$, $p = 0.06$) were marginally significant predictive factors on caregiver burden. ADL ($\beta = 0.05$, $p = 0.40$) and IADL ($\beta = 0.08$, $p = 0.16$) were not statistically significant factors on caregiver burden.

Discussion

This study investigated predictive factors associated with caregiver burden as it relates to the caregiving context and involvement of healthcare related activities. This study revealed that caregivers' feeling difficulty in performing medical/nursing tasks and their level of care coordination were significant predictive factors among the healthcare-related factors. To our knowledge, this is the first study that comprehensibly investigated the effect of healthcare-related factors on caregiver burden using a nationally representative sample of caregivers of individuals with cognitive impairment.

The strongest predictive factor on caregiver burden was caregivers' subjective appraisal of feeling difficulty in medical/nursing tasks, based on the standardized estimates of regression coefficients. This result is in line with previous studies that caregivers' self-efficacy and locus of control are the strongest predictive factors on caregiver burden (Bruvik et al., 2013; Contador et al., 2012). When applying the well-known stress and coping theory, the perceptions from caregivers regarding medical/nursing tasks may considerably influence levels of caregiver burden rather than the engagement of medical/nursing tasks itself (Lazarus and Folkman, 1984). Believing in ones' capabilities to take action, and having control of events, generate resilient behaviors like problem-solving strategies. On the contrary, when caregivers perceive the medical/nursing tasks as difficult, they may think those tasks are beyond their control and lose their confidence in performing those caregiving tasks. Furthermore, it is important to note that the caregivers' subjective appraisal is more influential on caregiver burden than objective clinical symptoms of care recipients, including the level of cognitive function and neuropsychiatric symptoms (Bruvik et al., 2013; Contador et al., 2012). Education and interventions that mitigate the perception of its difficulty of medical/nursing tasks should be actively developed and tested. The subjective perception is not only a powerful factor on caregiver burden but also has more room to change than objective factors.

Caregivers reporting poorer health was the second significant predictive factor on caregiver burden, and this result was consistent with previous research (Baker et al., 2010; Riffin et al., 2018). However, some studies argue that decreased caregivers' evaluation on their current health is due to the effect from caregiver burden (Abdollahpour et al., 2014; Elliott et al., 2010). Unfortunately, the directionality between caregivers' self-rated health and caregiver burden is unclear in this study due to its cross-sectional design. Further longitudinal study is required to investigate the causal process or bidirectional relationship between caregivers' current health and caregiver burden.

Caregivers' annual income was the third significant predictive factor on caregiver burden. More specifically, having less than a median household income ($50,000) negatively affected caregivers. This result is consistent with previous study findings of significant impact of low-income on caregiver burden (Chiao et al., 2015; Papastavrou et al., 2011). Although social financial sources, such as the Medicaid program, support low-income families, the annual out-of-pocket expenses are over $10,000 (Alzheimer’s Association, 2018). The financial pressure one might feel from caring for someone with cognitive impairment might be compounded over time considering the duration of the illness is typically 4-8 years and additional medical and health services would be needed as the disease progresses (Alzheimer’s Association, 2018). Due to this financial pressure, caregivers may not perceive the caregiving role as a positive experience, but rather they may see the role as strained and exhausting (Papastavrou et al., 2011). Anticipating the increasing prevalence of cognitive impairment and the serious social demand from it, dynamic health policy stressing on economic preparedness is needed.

This study also found that the level of care coordination with healthcare systems and healthcare providers was a significant predictor of caregiver burden, which supports previous research (Polenick et al., 2017; Riffin et al., 2018). Research shows that care coordination may be consuming to caregivers because it means scheduling several appointments between the providers and navigating the complex healthcare systems (Polenick et al., 2017). Furthermore, caregivers are often asked to be the healthcare proxy for their loved ones with cognitive impairment (Livingston and Cooper, 2015). Making decisions on behalf of their care recipients may not be easy. They tend to choose healthcare services for diagnosis and treatment and they may need to determine end-of-life decisions. Healthcare professionals should be aware of the level of a caregivers’ burden related to care coordination and provide adequate support and information to support the role of caregivers.

Another predictive factor was the caregivers’ perception on having a sense of choice in caregiving, but this factor was marginally significant. Feeling a sense of choice in caregiving means involvement of unwanted responsibility or feeling trapped in the role of the caregiver (van der Lee et al., 2014). When caregivers feel that there is no choice about the caregiving role but to provide care, caregivers are more likely to suffer from depressive symptoms and more likely to choose long-term care placement of care recipients (Cepoiu-Martin et al., 2016; Givens et al., 2014). As a result, interventions should be developed for those who do not feel there is an option for the caregiving role and to assist those caregivers in finding meaning and positive aspects of providing care.

The influence of care recipients' number of hospitalizations on caregiver burden was also marginally significant. This result is in line with previous literature that shows hospitalization events of care recipients may make caregivers suffer from higher stress, and the increased stress may be due to unplanned or emergency hospitalizations (Vroomen et al., 2013). In times of hospitalization and after the hospitalization, active support should be provided to caregivers. Caregivers may benefit from adequate information on care plans for their care recipients as well as from trusted relationships with healthcare professionals. Moreover, case management programs may reduce unnecessary hospitalization. The case management program typically offers regular home visits to examine caregiving environment and initiates prompt consultations with general providers before care problems become serious issues (Vroomen et al., 2013).

Although ADL and IADL were significant factors that related to caregiver burden in the bivariate analyses, they failed to maintain their significance when they were included in the multivariate analyses. This result is a departure from previous research showing ADL and IADL were significantly associated with caregiver burden in both bivariate and multivariate analyses (Kim et al., 2012). However, in Kim's study (2012), the caregivers' involvement in healthcare-related activities was not taken into consideration in the analyses; only caregivers' backgrounds, caregiving characteristics, and ADL/IADL were included. The different results between the previous and current study show that the importance of interrelationships among the factors. The ADL/IADL may have substantial effect on caregiver burden compared to caregivers' backgrounds and caregiving characteristics. Moreover, healthcare-related factors may be more important factor than ADL and IADL on caregiver burden. Performing healthcare-related tasks may cause more stress on caregivers compared to the personal care and household tasks.

Limitations

This study has several limitations that need consideration. First, care recipients' cognitive impairment status was measured by questionnaires completed by caregivers. Therefore, it is unclear what types of cognitive impairment care recipients suffered from and thus the self-report of cognitive impairment is not as valid as the usage of clinical measurements with objective measures of decline in cognition. Second, causal inferences are limited due to the cross-sectional dataset. Prospective longitudinal studies are needed to further explain the causal relationship between various factors and caregiver burden. Third, factors that were not included in the analyses may explain more of the variance in caregiver burden. Secondary stressors such as job and family conflicts should be considered in future studies.

Conclusion

This is the first study that comprehensively examined the effect of healthcare-related factors on caregiver burden. Caregivers' perception of medical/nursing tasks and level of care coordination were significantly predictive of the level of caregiver burden, and the number of hospitalizations of the care recipients was marginally significant. To date, interventions and community services have been focused on helping caregivers with day-to-day tasks to mitigate caregiver burden. This study asserts that healthcare professionals, researchers, and healthcare policy makers should be aware of caregivers’ difficulty and challenges in relation to healthcare-related activities. Providing sufficient education for medical/nursing tasks, facilitating mutual communication between providers and caregivers, and developing health policies to decrease caregivers’ burden concurrently and after hospitalizations are required.

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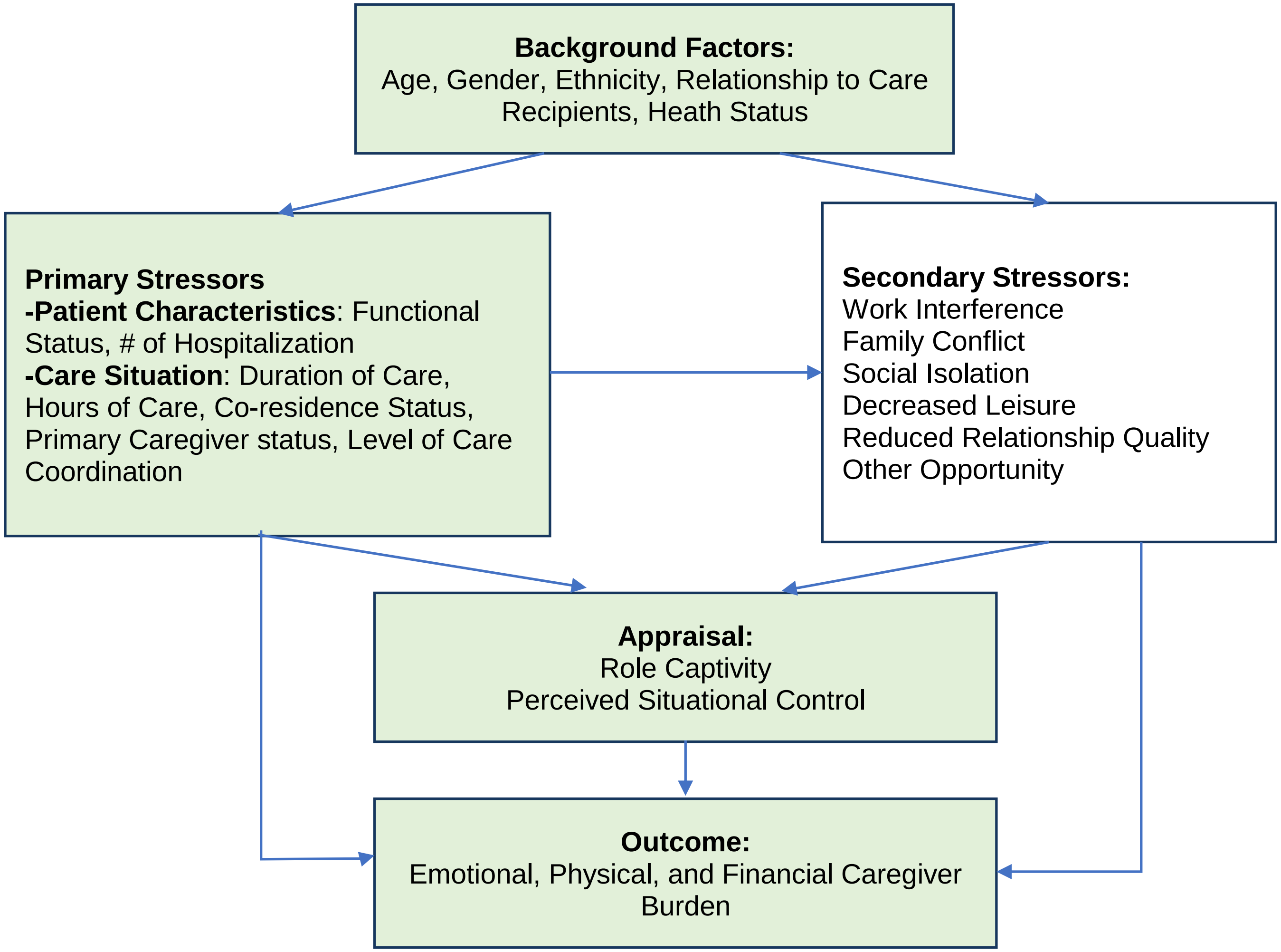

Figure 1. Conceptual Framework of Combination of Stress Process and Caregiving Appraisal Model (Sörensen et al., 2006). Note. The colored boxes were examined in this study.

Table 1. Characteristics of Caregivers of Individuals with Cognitive Impairment (Weighted)

	Mean ± SD
Care recipient	
Age (years)	76.94 ± 14.19
Sex (Female)	63.7%
Activities of Daily Living (ADL)	2.41 ± 2.10
Instrumental Activities of Daily Living (IADL)	5.69 ± 1.28
Number of hospitalizations last 12 months	
None	44.8%
One time	21.5%
Two times	16.1%
Three times or more	17.6%
Caregiver	
Age (years)	56.85 ± 17.28
Sex (Female)	62.7%
Race/Ethnicity	
White	67.0%
Black or African American	12.6%
Hispanic, Spanish, or Latino descent	14.7%
Asian	3.7%
Other	1.9%
Relationship to Care Recipient	
Adult Children	56.0%
Spouse/partner	24.1%
Other relatives	11.5%
Friends/neighbors/other non-relatives	8.4%
Annual Income	
Less than 50,000	45.9%
Equal to or greater than 50,000	54.1%
Current Self-Rated Health	3.23 ± 1.0
Average Weekly Hours of Care	40.02 ± 31.91
Duration of Care (years)	5.01 ± 8.23
Living with Care recipient (Yes)	48.4%
Primary Caregiver Status (Yes)	68.4%
Care Coordination	1.06 ± 1.14
Advocating for Care Recipient	70.2%
Communicating with Health Care Professionals	87.6%
Feeling a Sense of Choice in Caregiving (Yes)	41.3%
Feeling Difficulty in Medical/Nursing Tasks	2.40 ± 1.14
Caregiver Burden Level	8.63 ± 3.04

Table 2. Correlations for Background Factors, Primary Stressors, and Appraisal Factors on Caregiver Burden (Weighted)

	Burden	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Age	.023	1														
Sex	-.014	-.040	1													
Race	-.020	-.348**	.011	1												
Relationship	-.050	.205**	-.050	-.090	1											
Income	-.171**	.161**	-.040	-.088	-.173**	1										
Current Health	-.324**	.019	.004	.090	-.096	.247**	1									
ADL	.241**	-.098	-.081	.085	.008	-.118	-.090	1								
IADL	.152*	.133*	-.104	-.099	-.011	.019	.006	.203**	1							
Hospitalization	.217**	-.198**	-.058	.033	.024	-.018	-.120	.203**	.106	1						
Hours of Care	.098	.212**	.059	.074	.024	-.107	-.052	.175**	.336**	-.052	1					
Duration of Care	.101	.134*	-.006	-.063	-.029	.019	-.082	-.073	.055	.018	.032	1				
Co-Residence	-.051	-.335**	.121	.092	-.049	.126*	.197**	.026	-.245**	.194**	-.396**	-.181**	1			
Primary	.044	-.171**	-.097	.068	-.169**	.048	-.004	-.019	-.221**	.157*	-.272**	-.055	.362**	1		
Care Coordination	.184**	.160**	.021	-.127*	-.071	.106	-.037	-.012	.265**	.022	.099	.145*	-.166**	-.134*	1	
Having a Choice	.197**	.108	-.036	.018	-.100	.130*	-.095	-.094	-.023	-.027	.050	.079	-.080	.004	.217**	1
Feeling Difficulty in MNT	.511**	-.056	-.096	-.022	-.040	-.013	-.113	.255**	.125*	.191**	.048	.007	.020	.042	.123*	.185**

*$p < 0.05$, **$p < 0.001$, Variables that were highly correlated were bolded as the ones used in the hierarchical regression

Table 3. Summary of Hierarchical Regression Analysis for Predictive Factors on Caregiver Burden (Weighted)

	Predictive Factors	B	SE	β	*P* value	Adj. R^2	Δ R^2
Step 1	Income	-.583	.368	-.095	.115	.145	.145**
	Physical health	-1.078	.182	-.356	.000		
Step 2	Income	-.672	.353	-.110	.058	.235	.090**
	Physical health	-.940	.175	-.310	.000		
	ADLs	.181	.087	.122	.038		
	IADLs	.201	.146	.082	.170		
	Number of hospitalizations	.419	.152	.158	.006		
	Care Coordination Level	.815	.274	.172	.003		
Step 3	Income	-.819	.319	-.134	.011	.384	.149**
	Physical health	-.808	.158	-.266	.000		
	ADLs	.068	.080	.046	.396		
	IADLs	.187	.132	.076	.157		
	Number of hospitalizations	.256	.138	.097	.064		
	Care Coordination Level	.572	.251	.120	.024		
	Feeling a Sense of Choice	.615	.326	.099	.060		
	Difficulty in MNT	1.035	.147	.381	.000		

*$p < 0.05$, **$p < 0.001$, β = Beta Coefficient, ADL = activities of daily living, IADL = instrumental activities of daily living, MNT = Medical/Nursing Tasks

CHAPTER 6: Conclusion

Caregiving is a key component to caring for older adults with cognitive impairment. With help from informal caregivers, family members or friends, individuals with cognitive impairment are often able to maintain their lives living within the community. Traditionally, the role of caregiving was thought to be primarily for providing personal care and daily tasks such as feeding, cleaning, or shopping. Currently, this role has expanded from daily tasks to including medical/nursing tasks (Reinhard et al., 2012). In addition to the role, it has been unavoidable for caregivers not to deliver medical/nursing tasks for individuals with cognitive impairment at home due to the advancement in medication treatment and medical technology. This dissertation study conveys a summary of caregivers' involvement in medical/nursing tasks using an integrative review of the literature and analyses showing the influence of medical/nursing tasks on caregiver burden using one of the national caregiving datasets.

The first dissertation manuscript (integrate review) highlighted that 67% of caregivers for older adults with dementia perform medical/nursing tasks, such as complex medication management, wound/ostomy care, and nutritional management. The caregivers experienced challenges in performing medical/nursing tasks, including but not limited to the care recipients' cognitive deficits, behavioral problems and refusal of care, and limited information and training from healthcare professionals. As a result, the caregivers reported emotional distress, such as worrying, anxiety, feeling the difficulty, sleep disturbance, and restricted caregivers' activities.

In the second manuscript, the unique caregiving features of those who perform medical/nursing tasks among caregivers of individuals with cognitive impairment were identified. Secondary data analyses were conducted with 423 caregivers from the 2015 National Alliance for Caregiving (NAC) and AARP data. The data sample was randomly selected, and it included an oversample of ethnic minority groups across the nation. In terms of the caregiving context, caregivers who performed medical/nursing tasks were more likely to live with care recipients and provide longer hours of care than caregivers who did not perform medical/nursing tasks. When caregivers delivered medical/nursing tasks, they were two times more likely to also experience higher levels of caregiver burden. This is the first study that has examined the quantitative effect of medical/nursing tasks on caregiver burden and reported the significantly different caregiver features related to medical/nursing tasks.

The third manuscript examined the predictive value of caregivers' appraisal of their involvement in medical/nursing tasks on caregiver burden along with other healthcare-related factors including care coordination with healthcare system and frequency of hospitalizations of their care recipients. Caregivers' appraisal of the involvement in medical/nursing tasks was measured by caregiver's degree of feeling difficulty in performing medical/nursing tasks, and to capture this effect on caregiver burden. Only caregivers who performed medical/nursing tasks were included in the 3rd manuscript (n=304). The multivariate model revealed that caregiver's involvement in healthcare-related activities such as medical/nursing tasks and care coordination were stronger predictive factors on caregiver burden than caregivers' assistance in daily tasks (e.g., ADL, IADL). The model explained nearly 40% of the variance in caregiver burden. This result contributes to the existing caregiving literature in that identifying the hidden aspect of caregiving (i.e., performing medical/nursing tasks) which explains a considerable proportion of one's caregiver burden.

There are several implications of this study for healthcare providers, researchers, and healthcare policy makers. First, healthcare providers should know more about the burden of medical/nursing tasks upon caregivers and should play a crucial resource for them. Particularly nurses can begin with assessing caregivers' knowledge and skills of medical/nursing tasks, and then nurses can provide supportive feedback that fills their needs and gaps of the tasks (Lindauer, Sexson, & Harvath, 2017). In addition, nurses can show a demonstration of medical/nursing tasks and teach hands-on skills to caregivers when they visit the outpatient department with care recipients, or when the caregivers are at the bedside while care recipients are hospitalized. Lastly, nurses can use handouts to deliver step-by-step information in performing medical/nursing tasks. Recently, a series of articles were released to help nurses provide caregivers with structured medical information such as ostomy care, wound care, and administration of subcutaneous injections (American Journal of Nursing, 2017).

In addition, this paper can provide researchers evidence to consider medical/nursing tasks in designing interventions and guidelines to decrease caregiver burden. Medical information and skill-based instructions, as well as hands-on training in medical/nursing tasks, should be further developed and tested to help caregivers gain confidence in performing medical/nursing tasks. In 2018, the effectiveness of a web-based educational intervention that provided 50 common medical problems such as constipation, pain, and dehydration and how to solve the problems (Zimmerman et al., 2018) was conducted. This web-based intervention targeted dementia caregivers and contained skill-based instructions. After the intervention, caregivers showed increased confidence in managing the signs/symptoms and lower levels of caregiver strain. This study demonstrated that caregivers could benefit from educational interventions regarding medical/nursing tasks. Clearly, rigorous studies, specifically randomized controlled trials with multiple sites and large samples, are needed to help authoritative bodies set the stage for effective policies to support the dependence on caregivers to provide medical/nursing tasks for their care recipients.

Currently, the most outstanding policy change in terms of caregivers' medical/nursing tasks is including caregivers in the discharge process and providing needed information on medical/nursing tasks that they will conduct at home. Further policy efforts on how to assist healthcare professionals in providing support for caregivers is needed. Expanding the use of technologies and adapting innovations of healthcare systems may help healthcare professionals efficiently deal with extra tasks related to medical/nursing tasks, such as issues of assessment, education, and communication with caregivers (Gould, 2018).

Future studies are warranted to broaden our understanding of caregiver burden. Studies using longitudinal prospective design should be conducted to further explain the causal relationship between medical/nursing tasks factors and caregiver burden. In addition, future studies should consider collecting data with objective clinical data regarding care recipients' disease status. The clinical data may validate the care recipients' disease status and allow for future analyses on different disease types and its effect on the caregivers' involvement in medical/nursing tasks. Relationship conflict, between the caregiver and care recipient, is also another area of interest that may influence the caregiving role and further explain the variance of caregiver burden.

This is the first study that comprehensively examined the caregivers' involvement in medical/nursing tasks and its' impact when they provide care for individuals with cognitive impairment. Caregivers largely engaged in medical/nursing tasks and the burden from it was more substantial than providing personal care or housework. Increasing awareness among healthcare professionals, researchers, and community resource providers should be the first step to help caregivers in this matter. Providing sufficient education, designing innovative interventions, and developing community services and health policies to decrease caregivers' burden from medical/nursing tasks are required.

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