

2019

Synthesis of the Literature: Variables Influencing Caregiver Use or Nonuse of Supportive Services

Kristina M. Childers

Follow this and additional works at: https://researchrepository.wvu.edu/faculty_publications



Part of the [Nursing Commons](#)

Synthesis of the Literature: Variables Influencing Caregiver Use or Nonuse of Supportive Services

SAGE Open Nursing
Volume 5: 1–12
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2377960819838411
journals.sagepub.com/home/son



Kristina M. Childers, MSN, APRN, FNP-BC¹ 

Abstract

Two out of three caregivers (CGs) of persons with dementia (PWD) living in the community do not use supportive services or resources, and three out of four underutilize available support. These findings are troubling because CGs report many unmet needs in providing support to PWD. What predisposing, enabling, and need variables influence CGs to use or not use support services are poorly understood. This article reviews the literature on CG of PWD to find characteristic variables that are related to CG's decisions to use or not use support services. Instruments used in research studies were named to determine recommendations for future studies. The article organizes the variables following Anderson's model of predisposing, enabling, and need characteristics. It also supports future research to examine CG use or nonuse of resources that could inform practice, funding of programs, and policy.

Keywords

caregivers, dementia, resource use, use or nonuse of services, support services

Date received: 3 August 2018; revised: 11 February 2019; accepted: 21 February 2019

Introduction

More than 16.1 million Americans are informal (unpaid) CGs to persons with Alzheimer's disease or another dementia (Alzheimer's Association, 2018). These CGs help persons with Alzheimer's disease and related dementias to overcome a devastating chronic illness, with no cure, little treatment, and many challenges. Persons with dementia (PWD) experience loss of memory, judgment, communication skills, personality, control of behavior, and altered relationship experiences (Alzheimer's Association, 2014). CGs with PWD experience negative physical, psychosocial, and psychological effects related to the CG role. Impaired immune response, depression, and financial strain have been reported. Furthermore, an exorbitant amount of time is spent in the CG role; the Alzheimer's Association (2014) estimates a cumulative 18.4 billion hours of care provided to PWD. Unfortunately, despite reported unmet caregiving needs, two out of three CGs of PWD living in the community do not use supportive services or resources, and three out of four CG underutilize available support

(Brodaty, Thomson, Thompson, & Fine, 2005; Brown & Chen, 2008; Robinson, Buckwalter, & Reed, 2013; Wilks & Croom, 2008). Understanding the factors associated with decisions to use or not use available resources are important to health-care providers who can, in turn, use such information to assess CG needs and implement effective interventions, thus improving outcomes for PWD and their CGs.

Anderson's model of health-care utilization (Andersen, 1995; Andersen & Newman, 1973; Babitsch, Gohl, & von Lengerke, 2012) is a conceptual framework for understanding use of health-care resources with three underlying components: predisposing factors (demographic, social, health beliefs, and health services

¹School of Nursing, West Virginia University Health Sciences Center, Morgantown, WV, USA

Corresponding Author:

Kristina M. Childers, School of Nursing, West Virginia University Health Sciences Center, 1 Medical Center Drive, PO Box 9600 Morgantown, WV 26506-9600, USA.

Email: kristikylechilders@gmail.com



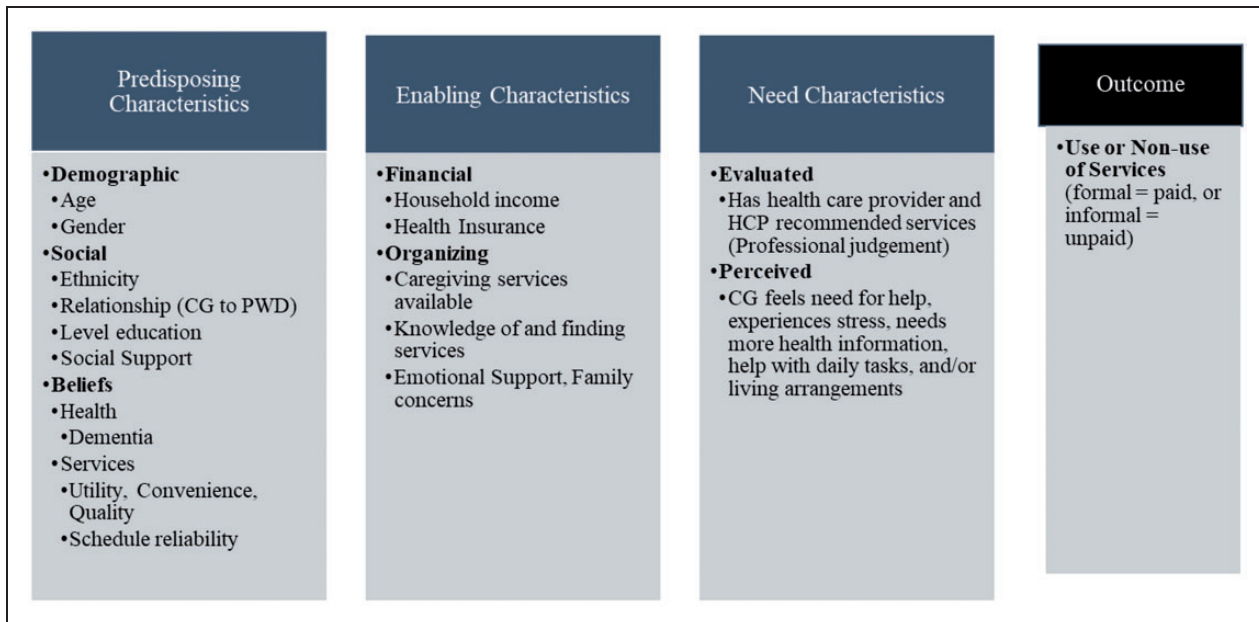


Figure 1. Flow diagram of literature search.
CG = caregivers; PWD = persons with dementia.

beliefs); enabling factors (community, personal financial, and organizing resources); and need factors (evaluated and perceived). The purpose of this article is to synthesize the available literature on CG of PWD use of support services, show commonly used measures, and determine characteristic variables related to decisions to use or not use both formal and informal support services. The article organizes the variables that relate to use or nonuse of services following substructured Andersen's model of predisposing, enabling, and need characteristics (Figure 1). This review is designed to aid researchers to select appropriate variables for understanding and measuring resource use by CG of PWD within their own research. Extrapolated from Phase 5 of Andersen's Behavioral Model of Health Service Use (Andersen, 2008, p. 651) by Kristina M. Childers.

Methods

A comprehensive literature search process following Torraco's (2005, 2016) guidelines led to the analysis and synthesis of 16 articles that measured variables influencing CG use or nonuse of supportive services (Figure 2). The following major databases were searched electronically: Academic Search Complete (1946–2018), Health and Psychosocial Instruments Database (1985–2018), MEDLINE (1946–2018), Mental Measurements Yearbook with Tests in Print (1938–2018), PsycINFO (1887–2018), MEDLINE (1946–2018), and CINAHL (1937–2018). Keywords including “characteristics,” “dementia,” and “caregivers,” were combined with

terms such as “help seeking,” “use of services,” “use of social support,” “use of resources,” “service use,” and “resource use.” The search was limited to English language, human subjects, and years 2005 to July 2018. The abstracts included descriptive, comparative, and predictive research designs. In all, 165 citations were retrieved; 111 were excluded during abstract review; and 54 studies were reviewed in full text. Studies were reviewed using predetermined inclusion and exclusion criteria. Inclusion criteria were as follows: target population made up of CGs of PWD; objective quantitative measures of service use were included; at least one independent variable that could influence service use was included; outcomes showed associations between service use and independent variable(s). Studies were excluded if they used only a qualitative design, were older than 13 years, or did not have use or nonuse of services as a variable of interest. Ultimately, 16 articles meeting criteria were synthesized to identify and conceptually organize variables influencing CG's use or nonuse of services (Brodaty et al., 2005; Burgio et al., 2009; Ervin & Reid, 2015; Jarrott, Zarit, Stephens, Townsend, & Greene, 2005; Lethin et al., 2016; Martindale-Adams, Nichols, Zuber, Burns, & Graney, 2016; Mast, 2013; Moon & Dilworth-Anderson, 2015; O'Connell, Hawkins, Ostaszkiwicz, & Millar, 2012; Phillipson, Jones, & Magee, 2014; Phillipson, Magee, & Jones, 2013; Ploeg et al., 2009; Robinson, Buckwalter, & Reed, 2005; Robinson et al., 2013; Sun, Roff, Klemmack, & Burgio, 2008; Vecchio, Fitzgerald, Radford, & Fisher, 2016). The literature reviewed included studies in Australia (Brodaty et al., 2005;

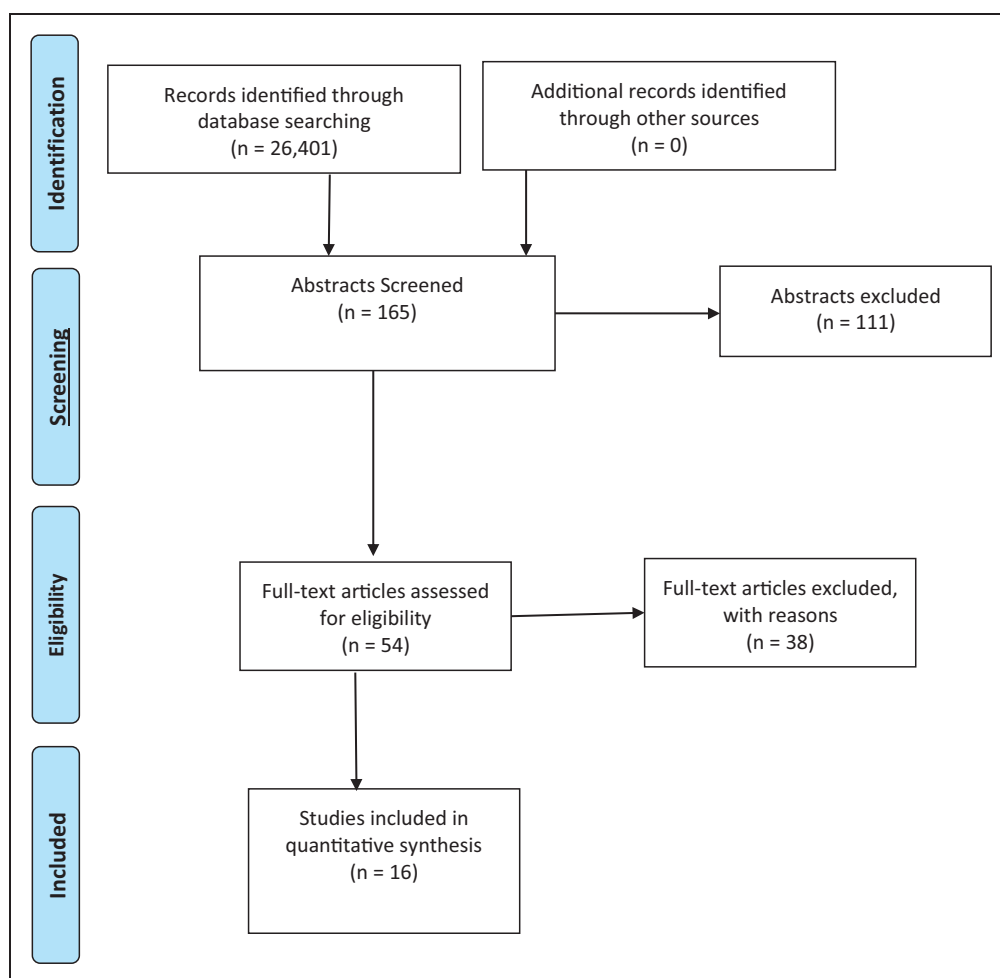


Figure 2. Variables influencing caregiver use or nonuse of services from literature review. CG = caregivers; CR = care recipient. Moher, Liberati, Tetzlaff, Altman, & PRISMA Group (2009) Format.

Ervin & Reid, 2015; O’Connell et al., 2012; Phillipson et al., 2013, 2014; Vecchio et al., 2016), Europe (Lethin et al., 2016; Moon & Dilworth-Anderson, 2015); Canada (Ploeg et al., 2009); and the United States (Burgio et al., 2009; Jarrott et al., 2005; Martindale-Adams et al., 2016; Mast, 2013; Robinson et al., 2005, 2013; Sun et al., 2008) with CG of PWD.

A variety of quantitative methods are represented in the review. However, there were no randomized clinical trials in the reviewed CG literature about measures on the use of supportive resources. Phillipson et al. (2014) completed a literature review from 1990 through 2011 regarding CG use of respite services, reporting cross-sectional surveys and convenience samples; other studies of variables related to CG use or nonuse of services were either a cross-sectional survey (O’Connell et al., 2012) or secondary data analyses of services used (Brodaty et al., 2005; Martindale-Adams et al., 2016; Moon & Dilworth-Anderson, 2015; Robinson et al., 2005, 2013; Sun et al., 2008; Vecchio et al., 2016). Brodaty et al. (2005) did use a

typography to assess the data from the Victorian Carer’s Project (VCPRJ). Ploeg et al. (2009) used a cross-sectional predictive, descriptive study, telephoning adults older than the age of 50 years, who were asked to answer questions based upon a vignette as if they were caring for a parent with dementia. Mast (2013) completed a literature review of characteristic of CGs influencing use of services, guided by Andersen’s model. There were no longitudinal studies noted in the reviewed literature, although Phillipson et al. (2014) noted four experimental longitudinal studies in 1997–1999. Table 1 presents a summary of the systematic review.

Variables influencing CG of PWD use of support services included the availability, convenience, quality, cost, and ability of support services, and the CGs perceived need of the service in supplying care to PWD (Mast, 2013).

Variables influencing CG of PWD nonuse of support services included lack of awareness of support services, no access to support resources, inconvenient operating hours, and costs of the help (Brodaty et al., 2005).

Table 1. Summary of Systematic Review.

Author and year	Methodology and conceptual framework (if none reported = x)	Measures of resource use or nonuse	Respondent required to be CG of PWD in community	Reliability	Validity
Brodaty et al. (2005)	Typography applied to secondary data from population-based study 1991–1994 VCP x	General survey from VCP—community services: general home help, specific home help, community nursing, meals service, home maintenance, transport service, respite care	No PWD may live in residential care	None reported by Brodady et al. CG $\alpha = .66$ (N = 955 in 1993) and $.70$ (N = 605 in 1994); and for non-CG, $\alpha = .59$ (N = 219 in 1993) and $.60$ (N = 181 in 1994) ^a	No Reported Measures
Johnston et al. (2011)	Cross-sectional telephone survey to screen memory impairment followed by in-home interview and assessment of positive screen memory impairment x	Measure of needs of resources more than use or nonuse of services. John's Hopkins Dementia Care Needs Assessment	No Screened person who answered for memory impairment, then friend or family member to be present if consented to interview and assessment	No reported measures	Content validity per evidence-based guidelines for dementia ^b ; concurrent validity with quality-of-life measures ^c
O'Connell et al. (2012)	Cross-sectional, descriptive study with self-report x	Respite care -Day center -In-home -Residential -Regular outings -Cottage care Carers' Perceptions of Respite Services	Yes	Internal consistency $\alpha = .84$ No test-retest reliability available	No reported measures
Phillipson et al. (2014)	Narrative synthesis of literature guided by Andersen's Behavioral Model of Health Service Use	14 studies reviewed	Yes	Internal consistency: CG and PWD factors with association ($p < .05$) with nonuse of diverse types respite services were then categorized according to Andersen's Behavioral Model of Health Service Use	Content validity—articles independently coded by researchers for nonuse of service via data extraction form—any discrepancy resolved by third coder
Robinson et al. (2005)	Secondary data analysis using repeated measures from Buckwalter's National Caregiver Training Project x	Community services—support groups, informal help, professional help, adult day care SPS	Yes	SPS: $\alpha = .53$ – $.70$ for each of four-item subscales, for total score $\alpha = .85$ ^d	None reported
Robinson et al. (2013)	Secondary data analysis from Buckwalter's National Caregiver Training Project x	See earlier 24-item SPS	Yes	See above please Internal consistency (coefficient alpha) reported for each of the subscales ranged from $r = -.33$ (reassurance of worth) to $r = -.56$ in a sample of college students and from $.61$ to $.76$ in a sample of teachers (Russel, Altmaier, & Van Veltzen, 1987). ^e The authors report test-retest reliabilities ranging from $.37$ to $.66$ for the subscales, with total scale test-retest reliability of $.37$ to $.66$ (Cutrona, Russell, & Rose, as cited in Cutrona & Russell, 1987).	Construct validity—six-factor structure that corresponds to the six social provisions confirmed by factor analysis ^d

(continued)

Table 1. Continued.

Author and year	Methodology and conceptual framework (if none reported = x)	Measures of resource use or nonuse	Respondent required to be CG of PWD in community	Reliability	Validity
Sun et al. (2008)	Secondary data analysis from interviews REACH I Guided by Pearlín's Coping Stress Model	Scale developed by REACH I research team (Gitlin et al., 2003 as cited in Sun et al., 2008) measured use services: homemaker, home health, visiting nurse, meals delivered to home. Three types of out-of-home services included transportation, day care, and support group services help with transportation, emotional support, informational support	Yes	Internal consistency $\alpha = .60$	Construct validity-factor analysis of items had loadings on single factor, scores ranging 0–33

Note. CG = caregiver; PWD = persons with dementia; REACH I = Resources for Enhancing Alzheimer's Caregiver's Health; SPS = Social Provision Scale; VCP = Victorian Carer's Program.

^aSchofield et al. (1997, p. 651).

^bBlack et al. (2013).

^cBlack et al. (2012).

^dDukes-Holland and Holahan (2003).

^eWeckwerth and Flynn (2006).

Research on Variables Influencing CG Use or Nonuse of Services

There are many reasons CGs of PWD may use or not use support services. Guided by Andersen's model (Andersen, 1995, 2008; Babitsch, Gohl, & von Lengerke, 2012), there are predisposing, enabling, and need factors influencing the CG decision to use or not use formal or informal support. Predisposing variables include demographic data such as gender and age, social supports, CG health beliefs, and CG service beliefs. For example, female CGs may prefer a day care service as opposed to in-home support (Phillipson et al., 2014). Enabling variables include organizing (services available in area) and financing characteristics such as income or health insurance coverage (Phillipson et al., 2014). Need variables include the CG perceived need for support in the caring role. Evaluated need includes the health-care provider recommending services to the CG for the PWD (Phillipson et al., 2014).

One literature review was found that applies Anderson's model to organize factors that influence CG use or nonuse of services, and it was limited to "respite services," one type of formal service available (Phillipson et al., 2014, p. 1). Two studies used Andersen's Behavioral Model as a guide (Phillipson et al., 2013; Vecchio et al., 2016). Sun et al. (2008) analyzed existing data from the Resources for Enhancing Alzheimer's Caregiver's Health (REACH I) study, focused on African American and Caucasian CGs ($N = 720$, $n = 165$ male, and $n = 555$ female) from Gitlin et al. (2003). Gitlin et al. (2003) developed a measure of use of formal services for the REACH I study composed of seven questions about the CG using or not using a formal service within the last month. The REACH I and II studies were multisite, longitudinal research projects funded by the National Institute on Aging, REACH I September 15, 1995 through August 31, 2000, and REACH II September 30, 2001 through September 31, 2004 (Stanford Medicine Older Adult and Family Center, 2015). The researchers evaluated multicomponent interventions on White, Hispanic, and African American CGs of PWD (American Psychological Association, 2015). They reported a Cronbach's α of .60 for these questions. The dependent variables were use of formal services and use of informal support (Sun et al., 2008). Formal service use included in-home services of homemakers, home health care, visiting nurses, meals delivered to the home, out-of-home services of transportation, day care, and group support. Informal support included helps with transportation, others listening or showing concern, or offering suggestions (Sun et al., 2008). The findings from the Sun et al. (2008) study showed male CGs used more in-home services than female CGs, although females used more transportation services. Females in this study reported using more informal support resources.

Brody et al. (2005) used findings from a literature review to identify CG motive for nonuse of services and develop a typography of CG service nonuse. The researchers then applied the typography to data collected from 1991 to 1994 from the VCP (Brodaty et al., 2005). The VCP was a national population-based longitudinal survey conducted in Australia, investigating the effects of caregiving for persons with various "disabilities or special needs" (Schofield, Herrman, Bloch, Howe, & Singh, 1997, p. 60) to understand caregiving in the community. The VCP researchers used the Australian Institute of Family Studies' computer-assisted telephone interviewing system (Schofield, 1998; Schofield et al., 1999; Schofield & Herrman, 1993). The questionnaire for the VCP incorporated questions from many instruments, including a measure of life satisfaction derived from Heady and Wearing 1981, CG overload (Pearlin, Mullan, Semple, & Skaff, 1990), and caring role resentment (Murphy et al., 1997). The authors were contacted to obtain more information regarding the measures used to construct the VCP survey, and other articles were obtained (Howe, Schofield, & Herrman, 1997; Schofield et al., 1999 [refers reader to Schofield, Murphy, Bloch, Herrman, & Singh, 1997 that was no longer in print for psychometrics and measures]; Schofield & Herrman, 1993; Schofield, Herrman, Bloch, Howe, & Singh, 1997). Brodaty et al. (2005) reported that despite describing many unmet needs, one primary reason CGs described for not seeking services was their belief they did not need the services. Schofield and Herrman (1993, p. 3) reported that their questionnaire was developed with the inclusion of measures of service use; however, there were no psychometric properties reported for instruments in the 1993 article. Brodaty et al. (2005) reported that despite describing many unmet needs, one primary reason CGs described for not seeking services was their belief they did not need the services.

Service nonusers lived with PWD (78%) and were spouses (77%), were older, reported more depression, and received less social support (Robinson et al., 2013). Predisposing factors such as relationships, gender, ethnicity, rurality, health beliefs, service beliefs, and perceived need factors are important explainers of formal and informal service use. In addition, enabling factors such as the access to transportation, health insurance, and awareness of personal and community services are persuasive in accessing resources. Increased use of services was associated with worsening PWD behavior or memory problems according to literature findings.

Predisposing Characteristic Variables

Predisposing characteristics include demographics, social, beliefs about health, and beliefs about services (Andersen,

1995). Phillipson et al. (2013) conducted a quantitative descriptive survey using mailed questionnaires, as well as those distributed in person by participating medical providers, and Alzheimer's Association Telephone helpline in Australia to identify factors associated with CG nonuse of day care or residential respite services. The researchers used the theory of planned behavior (Fishbein & Ajzen, 1975), within an expanded Andersen's Behavioral Model of Health Service Use (Andersen, 1995) to obtain self-completed surveys from 113 CGs of PWD. Phillipson et al. (2013) summarized items about beliefs of health and services from past studies, as well as dichotomous questions about predisposing, enabling, and need variables (pp. 413–414). Their survey questionnaire included predisposing factor questions for both CG/PWD dyad about age; gender; relationship of CG to PWD; coresidency; language spoken; 11 health belief statements (embarrassing to take PWD in public, self-conscious in public with PWD, avoid in-home visitors, dementia as a mental illness, embarrassment about PWD memory issues); four questions regarding the efficacy of dementia treatment including medications; and two questions about the government's role (provide more services, and help for at-home CGs; Phillipson et al., 2013, p. 413). They also included nine questions about service beliefs, including the CG belief about potential positive outcomes for the PWD, benefits to PWD and CG, PWD or family refusal to use services, access to services, suitability (centers able to meet physical and emotional needs of PWD), and CG belief he or she must perform all care duties for PWD or is not fulfilling CG tasks. Enabling factors were assessed using questions about CG income, educational level, availability of informal support in the caregiving role, and geographic location (Phillipson et al., 2013). Phillipson et al. (2013) measured need variables using questions about PWD activities of daily living (ADLs), wandering, behavior, and cognitive status and employed the Zarit Burden Screener (Bédard et al., 2001) and center for epidemiologic studies depression scale (CES-D) depression screener (Radloff, 1977) to assess CG need, assessing burden and depressive symptoms, respectively. Two of their four hypotheses were supported: that negative behavior beliefs were associated with day or residential respite service nonuse, and negative service beliefs were more strongly associated with service nonuse than negative health (dementia) beliefs (Phillipson et al., 2013). Although CGs reported needing day and residential care respite, more than 40% were not using day services, and 60% were not using residential services (Phillipson et al., 2013). The strongest associated factor for day (OR 13.11); 95% CI [3.75, 45.89] or residential (OR 6.13); 95% CI [2.02, 18.70] respite service nonuse was the predisposing belief the respite use would result in a negative outcome for the PWD (Phillipson et al., 2013). These studies suggest that nonuse of services has a critical impact on care recipients (CRs).

Phillipson et al. (2014) conducted a literature synthesis guided by Andersen's Behavioral Model of Health Service Use, to determine factors associated with CG's nonuse of respite services. Phillipson et al. reviewed 14 articles, including six cross-sectional studies, one longitudinal, one retrospective cohort, and one quasi-experimental pre- and posttest intervention measuring factors associations with use of adult day centers. In addition, they examined cross-sectional studies including two that used interviews and surveys measuring in-home and day center use separate dependent variables, a CG survey investigating factors associated with short-term use of residential care, and one assessing factors associated with the use of day center programs and in-home services. A retrospective cohort study designed to examine variables influencing the use of 10 CG services was included (Phillipson et al., 2014). There were 10 types of CG services described by Douglass and Fox (1999) cited in Phillipson et al. (2014).

Phillipson et al. (2014) reported nonusers of respite service tended to be spouses, especially females older than the age of 70 years. Obviously, if a CG was unaware of available services, he or she was a nonuser (Phillipson et al., 2014). Likewise, if a CG did not believe a service was useful, he or she was a nonuser of the resource. CGs living in less densely populated areas and those who were embarrassed to be seen in public with the PWD tended to be nonusers of in-home services according to Phillipson et al. CGs with a sense of duty did not use day center respite services (Phillipson et al., 2013). CGs using services were inclined to value reliability in schedules. Service nonuse associated with predisposing variables CG/PWD age and gender, and spouses were more prone to service nonuse, especially with respite care (Phillipson et al., 2014). Nonspousal CGs used more respite care resources than spouses did. Findings for ethnicity about use of services were mixed (Phillipson et al., 2014). Phillipson et al. (2014) reported use of in-home respite services was associated with embarrassment to be in public with the person with dementia, although it was not associated with day center use.

The literature about individual predisposing characteristics suggested from Phillipson et al.'s (2013, 2014) findings support nonuse of formal and informal services is affected by CG belief of negative outcome for the PWD, and CG negative beliefs about service were more strongly associated with nonuse than negative beliefs about health (dementia). If CGs believed respite use would lead to a negative outcome for the PWD, they are more likely not to use a respite support.

Enabling Characteristic Variables

Enabling characteristics include both financing and organizing variables. Financing enabling characteristics

affecting the use or nonuse of support services include the income or financial resources of the CG/PWD dyad. Organizing enabling characteristics include supportive services available.

A quantitative cross-sectional descriptive study used self-report data to explore CG of PWD ($N=62$) experiences using respite care, including the motivation for using the service, impact on both the CG and PWD, degree of satisfaction with the respite help, and request suggestions for enhancement (O'Connell et al., 2012). O'Connell et al. (2012) reported CG of PWD indicated the main reasons for use of respite services were to attend to CG own health-care needs, cope with the duties of CG role, and to have time off from the tasks of caregiving. O'Connell et al. (2012) utilized the Carers' Respite Survey and the Carers' Perceptions of Respite Services Scale (CPRSS). The Carers' Respite Survey included questions about demographics of the CG and PWD (one form), and the first and second most commonly used forms of respite (O'Connell et al., 2012) in the previous 12 months. The researchers assessed frequency, cost, adequacy, CG satisfaction, and perceptions of the respite care on the CG and PWD using the CPRSS (O'Connell et al., 2012). The CPRSS has a reported $\alpha = .84$, but there are no data available regarding test-retest reliability. Day care respite was the most used service ($n=18$, 29%), followed by residential ($n=14$, 23%), then in-home ($n=9$, 15%), cottage ($n=6$, 1%), and finally regular outings ($n=2$). Respite services were day center (day care in a community center), in-home, residential (day and night care for more than a few days), regular outings (excursions of 1 day), or cottage care (overnight care in a house or cottage for short periods of a day or weekend). CGs in the O'Connell et al. (2012) study suggested respite care services need a higher quality of care and administration, accommodating schedules, permanent staff, increased communication, and more affordable pricing. O'Connell et al. reported the main reasons for CG nonuse of respite care were the CG's own health and CG needs regarding the CG role. CG who were employed outside the CG role tended to use respite services (O'Connell et al., 2012). O'Connell et al.'s study supported inclusion of available respite services and degree of CG satisfaction with the services, in addition to CG information about level of education, age, status of employment, and CG health issues. CG health status and perceived needs were primary reasons explaining use or nonuse of formal and informal services (O'Connell et al., 2012).

Canadian researchers conducted a cross-sectional descriptive study using a telephone survey ($N=1,152$) to gain a description of an awareness of community resources and then used a vignette methodology to gather information from participants about hypothetical situations about caring for a parent with dementia

(Ploeg et al., 2009). Vignettes, fictional short narratives that were like everyday situations, were used by the researchers to gain an understanding of the decision-making process of respondents and identified relevant use of resources in a narrative format (Ploeg et al., 2009). A professional firm hired to conduct the telephone survey also coded the responses, collaborating with the researchers during coding (Ploeg et al., 2009). Content validity was assessed per peer check and interrater reliability among professional firm and researchers when sorting interview data initially to 150 themes, then into 20 "meaningful" themes.

The respondents were a combination of CGs ($n=474$) and non-CGs ($n=678$). CGs found the first choice of help as physicians (25%), followed by informal sources (20%), then home health services (19%), community support services (9%), and finally long-term care (8%; Ploeg et al., 2009). The only statistically significant demographic variable was "increasing age, $\chi^2(4, n=1,152)=11.2, p=.03$;" Ploeg et al., 2009, p. 365. Ploeg et al.'s results showed that participants named the physician as the first choice of support (37%), followed by informal support (33%), with home health services the third choice (31%). As CG age increased, they were less likely to suggest informal support resources. CGs in this study who were females were 40% more likely to identify the physician as a source of support, and if the CG had a higher level of education, the odds increased by 250% he or she would identify the physician as a source of support (Ploeg et al., 2009). Participants in the study who were married were less likely to identify informal support (Ploeg et al., 2009). Being a CG was not a statistically significant associated variable with identifying community health or support service resources (Ploeg et al., 2009). The individual need characteristics related to nonuse of services suggested age, level of education, and both formal and informal support identification as important study variables in understanding CG use of services.

Robinson et al. (2005) performed a secondary analysis of data from a prior multisite longitudinal 1-year study (National Caregiver Training Project; Buckwalter et al., 1999; Robinson et al., 2005, pp. 128–129). The sample consisted of 241 CG/PWD dyads living in the community (Robinson et al., 2005). The researchers employed the Social Provision Scale (SPS; Cutrona & Russell, 1987). Robinson et al. reported variables effecting use of community resources were the PWD frequency of ADL problems ($p=.003$), PWD frequency of memory or behavior problems ($p=.012$), CG spousal relationship to PWD ($p=.001$), and CG social support ($p=.002$). Spousal CG were significantly less likely to use services ($r=-.232$), but the strongest relationship with use of services was PWD frequency of problem behaviors and memory problems (ADLs, $r=.35$; memory problems,

$r = .34$). This differs from O'Connell et al. (2012), whose findings suggested CG health and needs were the strongest contributors to CG use or nonuse of services. Researchers found informal and professional resources used as respite service or caregiving aid (Robinson et al., 2005). Robinson et al. (2005) reported CGs who were spouses were less likely to use respite services.

In the Robinson et al. (2013) study, the 24-item SPS (Cutrona & Russell, 1987) measured perceived social support of the CG. Robinson et al. (2013) reported the SPS (Cutrona & Russell, 1987) had *good* ($\alpha = .85-.92$) reliability across varying populations, with individual subscales ranging from $\alpha = .64$ to $\alpha = .76$ (Dukes-Holland & Holahan, 2003). The researchers report validity of the SPS was supported by Cutrona (1996), Russell and Cutrona (1991), and Dukes-Holland and Holahan (2003) added factor analyses. In the literature review, the SPS was thus the most frequently used instrument to assess CGs and was important to include.

Services used by family CG in the study were community services, support groups, informal help, professional help, and adult day care (Robinson et al., 2013). Robinson et al. report PWD problem behaviors and relationships with CG were strongly associated with the CG use of services ($p < .001$, and $p = .001$, respectively). CG using both caregiving assistance and respite were significantly younger than CG using neither service ($p = .010$). The average informal service use of CG in the study was 9 hours per week and 4 hours of professional help (in home or adult day care; Robinson et al., 2013). Service nonusers lived with PWD (78%) and were spouses (77%), were older, reported more depression, and received less social support (Robinson et al., 2013). The nonservice user CG provided fewer hours of care to a PWD with milder cognitive, functional, and behavioral complications (Robinson et al., 2013). Robinson et al. (2013) findings suggested nonusers were older, more depressed, received less social support, but provided fewer hours of care per week to the CR that had less cognitive and functional deterioration and fewer behavioral problems. Data collected by Buckwalter and analyzed by Buckwalter et al. supported use of the SPS as a reliable measure of social support to include in a study of CG use/nonuse of formal and informal resources (Robinson et al., 2005, 2013).

Need Characteristic Variables

Ploeg et al. (2009) indicated the first choice for help in caregiving is the physician, especially if the CG is female and has a higher level of education (Ploeg et al., 2009). Phillipson et al. (2013) reported no need factors were significantly associated with nonuse of day centers.

Jarrott et al. (2005) described a significant outcome when formal care hours increased, which was a negative association with indicators of CG stress (CG stressors decreased with the addition of formal care hours). Phillipson et al. (2013) indicated the needs of the PWD (such as help with ADLs) were associated with nonuse of respite services, such that those PWD who needed no help with ADLs and were less cognitively impaired, were more likely to not use the service.

Discussion and Implications for Future Research

It is estimated that informal CGs, typically spouses or adult children, provide 80% of the long-term care in the case of diseases such as Alzheimer's (American Psychological Association, 2006). While the review supplied valuable information on the use or nonuse of services by CG of PWD, there are few validated instruments used in the past 10 years. Phillipson et al. (2013) did not indicate a specific instrument used to measure CG use or nonuse of services, and noted a variety of measures was used, as well as a diverse collection of respite services. Identified need and use of services are not consistent, although nonusers of services reporting many unmet needs (Phillipson et al., 2013).

Instruments measured CG use or nonuse of services in the reviewed literature were the CPRSS (O'Connell et al., 2012), which measures CG satisfaction and perceptions of the effects of respite to self and PWD. The reliability was good ($\alpha = .84$), but this does not measure the outcome of interest, use of services. The SPS as published in two studies (Robinson et al., 2005, 2013) examined the same data set. The reliability ($\alpha = .85-.92$) is particularly good for the instrument, although individual subscales range slightly lower than may be desired ($\alpha = .64-.76$), so piloting in the population of interest would be recommended. The SPS validity was confirmed via factor analysis for social provision from support groups and informal (unpaid) sources, such as family and friends. Thus, the use or nonuse of social resources could be measured by the SPS.

Ploeg et al. (2009) encouraged participants to name known community services based upon an imagined scenario of a parent with dementia but did not interview current CG of PWD. Sun et al. (2008) used a questionnaire developed by the REACH I researchers (Gitlin et al., 2003) to answer questions about use of seven services in the past month and had a lower reliability than the 0.80 desired ($\alpha = .60$; Brodaty & Donkin, 2009). Data from the VCP used a questionnaire composed of many scales, one of which was the Provision of Social Relations Scale to measure perceived social support (Schofield et al., 1999); it had fair reliability and good validity. However, the VCP included a variety of questions for which the psychometric

data are not currently available (Brodaty & Donkin, 2009). This VCP would be an added tool to use when assessing social support use if the main measurement tool did not include this area.

At the time of writing, there is not a primary measure of CG use or nonuse of services that can be recommended for all studies. The Family Caregiver Alliance/National Center on Caregiving and the Benjamin Rose Institute on Aging, the Margaret Blenkner Research Institute (2012) "Selected caregiver assessment measures: a resource inventory for practitioners" can guide choice of resources to measure. Validated tools that might be combined in examining CG use and nonuse of services could be the SPS and the Perceived Stress Reactivity Scale (PSRS) (Schlotz, Yim, Zoccola, Jansen, & Schulz, 2011) of the VCP, supplemented by checklists based on the work of (Brodaty & Donkin, 2009) and Sun et al. (2008).

To be inclusive, additional instruments of interest that might be abstracted to select any resources not included in the validated tools may include the Assistance with Caregiving (Braithwaite, 1996 as cited in FCANCC, 2018), Helping Network Composition (FCANCC, 2018), Negative Services Attitudes (FCANCC, 2018), Negative Services Experiences (FCANCC, 2018). These scales measure CG help with caregiving, presence, and helpfulness of services, as well as attitudes and experiences with service use. The Service Use: Formal and Informal measure (Feinberg, Whitlatch, & Tucke, 2000; Whitlatch, Feinberg, & Tucke, 2005) is a six-item scale with no reported psychometrics that investigates 13 distinct types of CG help, CG satisfaction with the service, CG need of further support, and information about CG potential use of paid help.

Another consideration for future research is to format the questions about specific service use differently. Rather than asking if a service was used within a prior month, ask if a service has ever been used. If the service was used, and then stopped, researchers could gather evidence as to the reasons the CG stopped the service. If a service was never used, information about the reasons of nonuse may direct future practice. Selections might include that the CG is unaware of the service, does not feel the service is necessary, the PWD is refusing the assistance, or the resource is not accessible to the CG/PWD dyad. As evidence is gathered on use and nonuse of resources, the data can be used to inform practice, patient education, public health, provider education, health systems by way of discharge teaching and planning, and health policy.


Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Kristina M. Childers  <http://orcid.org/0000-0003-2873-5140>

References

- Alzheimer's Association. (2014, February 27). *Alzheimer's disease facts and figures*. Retrieved from http://www.alz.org/alzheimers_disease_facts_and_figures.asp#prevalence.
- Alzheimer's Association. (2018). *Facts and figures*. Retrieved from <https://www.alz.org/alzheimers-dementia/facts-figures>.
- American Psychological Association. (2006). *The high costs of caregiving*. Retrieved from <https://www.apa.org/research/action/caregiving.aspx>.
- American Psychological Association. (2015). *Caregiving facts*. Retrieved from <http://www.apa.org/pi/about/publications/caregivers/faq/index.aspx>.
- Andersen, R., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly- Health and Society*, 51(1), 95–124. doi:10.2307/3349613.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10. doi:10.2307/2137284.
- Andersen, R. M. (2008). National health surveys and the Behavioral Model of Health Services Use. *Medical Care*, 46(7), 647–653. doi:10.1097/MLR.0b013e31817a835d.
- Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998-2011. *GMS Psycho-Social-Medicine*, 9, Doc11. doi:10.3205/psm000089.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist*, 41(5), 652–657. doi:10.1093/geront/41.5.652.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues Clin Neurosci*, 11(2), 217–228.
- Braithwaite, V. (1996). Understanding stress in informal caregiving: Is burden a problem of the individual or of society? *Research on Aging*, 18(2), 139–174. doi:10.1177/0164027596182001.
- Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20(6), 537–546. doi:10.1002/gps.1322.
- Black B. S., Johnston, D., Morrison, A., et al. (2012). Quality of life of community residing persons with dementia based on self-rated and caregiver-rated measures. *Qual Life Res*, 21, 1379–1389. doi: 10.1007/s11136-011-0044-z.
- Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C., Samus, Q. M. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *Journal of the American Geriatric Society*, 61(12), 2087–2095. doi: 10.1111/jgs.12549.

- Brown, J., & Chen, S. (2008). Help-seeking patterns of older spousal caregivers of older adults with dementia. *Issues in Mental Health Nursing, 29*(8), 839–852. doi:10.1080/01612840802182854.
- Buckwalter, K. C., Gerdner, L., Kohout, F., Hall, G. R., Kelly, A., Richards, B., & Sime, M. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Arch Psychiatr Nurs, 13*(2), 80–88. Retrieved from [https://www.psychiatricnursing.org/article/S0883-9417\(99\)80024-7/pdf](https://www.psychiatricnursing.org/article/S0883-9417(99)80024-7/pdf).
- Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & Decoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging personnel: The REACH OUT program. *The Gerontologist, 49*(1), 103–116. doi:10.1093/geront/gnp012.
- Cutrona, C.E. (1996). Social Support as a Determinant of Marital Quality. In *Handbook of Social Support and the Family* (pp. 173–194). doi:10.1007/978-1-4899-1388-3_8.
- Cutrona, C. E., & Russell, D. W. (1987). The provisions of social relationships and adaptation to stress. *Advances in Personal Relationships, 1*, 37–67.
- Douglass, C., & Fox, P. J. (1999). Health care utilization among clients with Alzheimer's disease: Public policy implications from the California Alzheimer's disease diagnostic and treatment center program. *Journal of Applied Gerontology, 18*(1), 99–121. doi:10.1177/073346489901800106.
- Dukes-Holland, K., & Holahan, C. K. (2003). The relation of social support and coping to positive adaptation to breast cancer. *Psychology & Health, 18*(1), 15–29. Retrieved from <https://www.tandfonline.com/doi/abs/10.1080/0887044031000080656>.
- Ervin, K., & Reid, C. (2015). Service utilisation by carers of people with dementia in rural Victoria. *Australasian Journal on Ageing, 34*(4), E1–E6. doi:10.1111/ajag.12162.
- Family Caregiver Alliance/National Center on Caregiving. (2018). *Caregivers count too! Section 3: What should family caregiver assessments include?* Retrieved from <https://www.caregiver.org/caregivers-count-too-section-3-when-should-family-caregiver-assessment-happen>.
- Family Caregiver Alliance/National Center on Caregiving and the Benjamin Rose Institute on Aging, the Margaret Blenkner Research Institute. (2012). Selected caregiver assessment measures: A resource inventory for practitioners (Family Caregiver Alliance (FCA) and the Benjamin Rose Institute on Aging, Trans.) In *Selected caregiver assessment measures: A resource inventory for practitioners* (2nd ed., p. 79). San Francisco, CA: Author. Retrieved from <https://www.caregiver.org/selected-caregiver-assessment-measures-resource-inventory-practitioners-2012>.
- Feinberg, L. F., Whitlatch, C. J., & Tucke, S. (2000). *Final report: Making hard choices: Respecting both voices* (pp. 1–123). San Francisco, CA: Family Caregiver Alliance. Retrieved from <https://www.caregiver.org/making-hard-choices-respecting-both-voices>.
- Fishbein, M., & Azjen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.
- Gitlin, L. N., Burgio, L. D., Mahoney, D., Burns, R., Zhang, S., Schulz, R., . . . , Ory, M. G. (2003). Effect of multicomponent interventions on caregiver burden and depression: The Resources for Enhancing Alzheimer's Caregiver Health (REACH) multisite initiative at 6-month follow-up. *Psychology and Aging, 18*(3), 361–374. doi:10.1037/0882-7974.18.3.361.
- Howe, A. L., Schofield, H., & Herrman, H. (1997). Caregiving: A common or uncommon experience? *Social Science and Medicine, 45*(7), 1017–1029. doi:10.1016/S0277-9536(97)00017-8.
- Jarrott, S. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2005). Instrumental help and caregivers' distress: Effects of change in informal and formal help. *American Journal of Alzheimer's Disease & Other Dementias[®], 20*(3), 181–190. doi:10.1177/153331750502000308.
- Johnston, D., Samus, Q. M., Morrison, A., Leoutsakos, J. S., Hicks, K., Handel, S., . . . , Black, B. S. (2011). Identification of community-residing individuals with dementia and their unmet needs for care. *International Journal of Geriatric Psychiatry, 26*(3), 292–298. doi:10.1002/gps.2527.
- Lethin, C., Leino-Kilpi, H., Roe, B., Soto, M. M., Saks, K., & Stephan, A. . . . RightTimePlaceCare Consortium (2016). Formal support for informal caregivers to older persons with dementia through the course of the disease: An exploratory, cross-sectional study. *BMC Geriatrics, 16*, 32. doi:10.1186/s12877-016-0210-9.
- Martindale-Adams, J., Nichols, L. O., Zuber, J., Burns, R., & Graney, M. J. (2016). Dementia caregivers' use of services for themselves. *The Gerontologist, 56*(6), 1053–1061. doi:10.1093/geront/gnv121.
- Mast, M. E. (2013). To use or not to use. A literature review of factors that influence family caregivers' use of support services. *Journal of Gerontological Nursing, 39*(1), 20–28. doi:10.3928/00989134-20121107-02.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine, 6*(7), e1000097. doi:10.1371/journal.pmed.1000097.
- Moon, H., & Dilworth-Anderson, P. (2015). Baby boomer caregiver and dementia caregiving: Findings from the National Study of Caregiving. *Age and Ageing, 44*(2), 300–306. doi:10.1093/ageing/afu119.
- Murphy, B., Schofield, H., Nankervis, J., Bloch, S., Herrman, H., & Singh, B. (1997). Women with multiple roles: The emotional impact of caring for ageing parents. *Ageing and Society, 17*, 277–291.
- O'Connell, B., Hawkins, M., Ostaszkievicz, J., & Millar, L. (2012). Carers' perspectives of respite care in Australia: An evaluative study. *Contemporary Nurse, 41*(1), 111–119. doi:10.5172/conu.2012.41.1.111.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583–594. doi:10.1093/geront/30.5.583.
- Phillipson, L., Jones, S. C., & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health & Social Care in the Community, 22*(1), 1–12. doi:10.1111/hsc.12036.
- Phillipson, L., Magee, C., & Jones, S. C. (2013). Why carers of people with dementia do not utilise out-of-home respite

- services. *Health & Social Care in the Community*, 21(4), 411–422. doi:10.1111/hsc.12030.
- Ploeg, J., Denton, M., Tindale, J., Hutchison, B., Brazil, K., Akhtar-Danesh, N., . . . Plenderleith, J. M. (2009). Older adults' awareness of community health and support services for dementia care. *Canadian Journal on Aging*, 28(4), 359–370. doi:10.1017/S0714980809990195.
- Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385–401. doi:10.1177/014662167700100306.
- Robinson, K. M., Buckwalter, K. C., & Reed, D. (2005). Predictors of use of services among dementia caregivers. *Western Journal of Nursing Research*, 27, 126–140. doi:10.1177/0193945904272453.
- Robinson, K. M., Buckwalter, K. C., & Reed, D. (2013). Differences between dementia caregivers who are users and nonusers of community services. *Public Health Nursing*, 30(6), 501–510. doi:10.1111/phn.12041.
- Russell, D. W., Altmaier, E., & Van Velzen, D. (1987). Job-related stress, social support, and burnout among classroom teachers. *J Appl Psychol*, 72(2), 269–274. Retrieved from https://www.researchgate.net/publication/19577908_Job-Related_Stress_Social_Support_and_Burnout_Among_Classroom_Teachers.
- Russell, D. W., & Cutrona, C. E. (1991). Social support, stress, and depressive symptoms among the elderly: Test of a process model. *Psychology and Aging*, 6(2), 190–201. doi:10.1037/0882-7974.6.2.190.
- Schofield, H. (1998). *Family caregivers: Disability, illness and ageing*. London, England; St. Leonards, NSW: Allen & Unwin in association with the Victorian Health Promotion Foundation[London: UCL] [distributor].
- Schofield, H., & Herrman, H. (1993). Characteristics of carers in Victoria. *Family Matters*, (34), 21–26. Retrieved from Australian Institute of Family Studies website: <https://www.family-advocacy.com/assets/Uploads/Downloadables/10143-Characteristics-of-Carers-in-Victoria.pdf>.
- Schofield, H., Murphy, B., Bloch, S., Herrman, H., & Singh, B. (1997). Family caregiving: Measurement of emotional wellbeing and various aspects of the caregiving role. *Psychological Medicine*, 27, 647–657. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/9153685>.
- Schofield, H. L., Bloch, S., Nankervis, J., Murphy, B., Singh, B. S., & Herrman, H. E. (1999). Health and well-being of women family carers: A comparative study with a generic focus. *Australian and New Zealand Journal of Public Health*, 23(6), 585–589. Retrieved from <http://search.proquest.com/docview/215709096?accountid=2837>.
- Schofield, H. L., Herrman, H. E., Bloch, S., Howe, A., & Singh, B. (1997). A profile of Australian family caregivers: Diversity of roles and circumstances. *Australian and New Zealand Journal of Public Health*, 21(1), 59–66. doi:10.1111/j.1467-42X.1997.tb01655.x.
- Schlotz, W., Yim, I. S., Zoccola, P. M., Jansen, L., & Schulz, P. (2011). The perceived stress reactivity scale: Measurement invariance, stability, and validity in three countries. *Psychological Assessment*, 23(1), 80–94. doi:10.1037/a0021148.
- Stanford Medicine Older Adult and Family Center. (2015). *REACH I and II: Resources for Enhancing Alzheimer Caregiver Health*. Retrieved from <http://med.stanford.edu/oafc/projects/reach.html>.
- Sun, F., Roff, L. L., Klemmack, D., & Burgio, L. D. (2008). The influences of gender and religiousness on Alzheimer disease caregivers' use of informal support and formal services. *Journal of Aging and Health*, 20(8), 937–953. doi:10.1177/0898264308324652.
- Torraco, R. J. (2005). Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review*, 4(3), 356–367. Retrieved from <http://search.proquest.com/docview/221810269?accountid=2837>.
- Torraco, R. J. (2016). Writing integrative literature reviews: Using the past and present to explore the future. *Human Resource Development Review*, 15(4), 404–428. Retrieved from <http://economywork.com/docs/Torraco2016HRHR.pdf> doi:10.1177/1534484316671606.
- Vecchio, N., Fitzgerald, J. A., Radford, K., & Fisher, R. (2016). The association between cognitive impairment and community service use patterns in older people living in Australia. *Health & Social Care in the Community*, 24(3), 321–333. doi:10.1111/hsc.12212.
- Weckwerth, A. C., & Flynn, D. M. (2006). Effect of sex on perceived support and burnout in university students. *College Student Journal*, 40(2), 237–249. Retrieved from <http://search.ebscohost.com.www.libproxy.wvu.edu/login.aspx?direct=true&db=a9h&AN=21375546&site=ehost-live>.
- Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*, 45(3), 370–380. doi:10.1093/geront/45.3.370.
- Wilks, S. E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging & Mental Health*, 12(3), 357–365. doi:10.1080/13607860801933323.