

## Family support in late life: A review of the literature on aging, disability, and family caregiving

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### ABSTRACT

For older adults and people with disabilities in the United States, family caregiving is an important part of remaining at home and in the community. As care recipients and caregivers age, family dynamics change, and the health, social, and financial impacts of this (largely unremunerated) work have implications for individuals, families, and social policy. In this review, the authors map the literature across multiple fields related to disability and aging to understand caregiving in late life, what it means to be an older caregiver and/or to care for older people. The authors summarize the findings of 97 articles to address the care, services, and supports family caregivers provide for older adults; negative and positive impacts for caregivers serving in this role; supports that family members use or need; and societal impact of family caregiving. Much of the literature describes the work family caregivers provide and negative impacts of caregiving. Less attention is devoted to caregiving benefits, supports used by family caregivers, and societal impacts. The authors conclude with an agenda for future research that attends to the need for research that includes: more diverse samples, new types of caregivers, longitudinal data, qualitative data and analysis, and comparative research.

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Family caregiving is an issue of national priority with implications for individuals, families, and society (National Alliance for Caregiving (NAC) & AARP Public Policy Institute, 2015; Reinhard, Feinberg, Choula, & Houser, 2015; Talley & Crews, 2007; Zivin, Wharton, & Rostant, 2013). In 2014, nearly 34 million people provided unpaid care, support, or services to an adult older than age 50 years at any time in the previous 12 months (NAC & AARP Public Policy Institute, 2015). Family caregiving in the United States was valued at an estimated \$470 billion, assuming an hourly equivalent rate of \$12.51 hour for the nearly 37 billion hours provided in 2013 (Reinhard et al., 2015). Despite the significance of family caregiving, research on the topic has been split across multiple disciplines/fields and population types. For example, in the aging literature, the field of gerontology has generated a number of significant literature reviews and meta-analyses on the impacts of caregiving, caregiver interventions, and disparities in caregiver outcomes by race/ethnicity (Dilworth-Anderson, Williams, & Gibson, 2002;

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Gallagher-Thompson & Coon, 2007; Pinquart & Sörensen, 2005, 2011). However, these have been separate from fields related to disability and rehabilitation and have therefore been isolated from other reviews focused on the implications of “aging” on the families of people with intellectual and developmental disabilities (IDDs) (Heller, 2008; Heller, Caldwell, & Factor, 2007; Heller & Factor, 2008; Heller, Gibbons, & Fisher, 2015).

In this review, we map the caregiving literature across multiple fields related to disability and aging to better understand caregiving in late life, what it means to be a caregiver older than age 50 and/or to provide services, supports, and care for people older than age 50. We will address four research questions: (1) What care, services, and supports do family members currently provide to older adults with disabilities? (2) What impacts arise for these family members? (3) What supports do these family members use to assist them as caregivers? and (4) What is the impact of family caregiving in late life on society? Given the varied roles of social workers in the planning, evaluation, and management of disability, aging, and family support programs, answering these questions has implications for social work practice and policy. Furthermore, this literature review provides a basis on which to ensure that aging caregivers and family caregivers of older adults are integrated into future strategic research plans on family caregiving in the United States.

## Method

To identify publications for this review, an electronic database search of PubMed was conducted using ten different combinations of the following key terms: (1) *aging, late life, older adults, or elderly*; (2) *family caregiving or family support*; and (3) *disability, disabilities, mental illness, autism, developmental disabilities, or intellectual disabilities*. Search parameters were limited to English language publications in peer-reviewed journals in the 10-year period between 2005 and 2015. Additionally, a snowball technique was used to search for relevant citations within selected articles (Pham et al., 2014).

To be included in this review, articles needed to meet three criteria. First, articles needed to focus on the U.S. population. That is, articles with samples from countries outside of the United States were excluded even if they were published in English or in U.S. journals. Second, articles needed to include empirical data and analysis. Review articles and conceptual/theoretical papers were excluded. Lastly, to keep the focus on aging, the mean age of either family caregivers or care recipients (i.e., older adults, disabled people) needed to be at least age 50 years.

Based on the search criteria, more than 400 articles were initially identified for review. To determine appropriateness of inclusion, articles were examined in three stages: by title, then abstract, and finally, by the text of the article. If an article did not meet the inclusion criteria at one stage (i.e., title), it was not reviewed in later stages (i.e., abstract or text).

The primary author conducted the literature searches, directed research assistants to obtain articles, conducted all title reviews as well as the abstract and article reviews for literature included in the response to Questions 2, 3, and 4. The second author conducted abstract and article reviews for the response to Question 1. Additional articles for inclusion in the review were identified via snowball by the primary author. In total, 97 articles were included in this review. See [Table 1](#) for more information about each study.

### ***Descriptive summary of articles reviewed***

Of the 97 articles included in this review, 37% ( $n = 35$ ) provided information on the types of support, care, and services that family members provide for, and as, older adults (Research Question 1). The overwhelming majority of articles ( $n = 62$ ) were focused on the impacts of caregiving (Research Question 2). One-third of articles ( $n = 33$ ) examined the caregiving supports available to, or desired by, family caregivers (Research Question 3). Only two articles addressed the societal impact of caregiving in late life and/or for adults (Research Question 4).

Nearly three-fourths ( $n = 61$ ) of the articles that provided information on racial/ethnic composition ( $n = 87$ ), included at least two different racial/ethnic groups, with two articles focused exclusively on people of color (Magaña & Smith, 2006, 2008). Another 19 articles had samples that were at least 90% White. The remaining seven articles exclusively focused on a specific racial/ethnic group, (i.e., Korean Americans, Blacks/African Americans, and Hispanic/Latinos). Although one-third ( $n = 15$ ) of the more diverse studies identified bi- or multi-racial individuals, less than one-third ( $n = 13$ ) included Asian Americans, Native Hawaiians, or Pacific Islanders and less than 10% ( $n = 4$ ) included Native Americans.

The majority (70%,  $n = 68$ ) of studies included multiple caregiver types (e.g., parents, spouses/partners, adult children, etc.). Spouses were the most frequent ( $n = 15$ ) focus for studies with only one caregiver type, followed by parents ( $n = 11$ ), with one study focused solely on fathers (Ghosh & Greenberg, 2009) and four on mothers (Barker et al., 2011; Magaña & Smith, 2006, 2008; Smith et al., 2010). One study each focused exclusively on siblings (Burke, Taylor, Urbano, & Hodapp, 2012), adult children (Fingerman, VanderDrift, Dotterer, Birditt, & Zarit, 2011), and grandparents (Minkler & Fuller-Thomson, 2005).

Articles addressed a wide array of care recipient disability types, (i.e., care recipient physical, intellectual, and/or cognitive characteristic(s) that make family caregiving a necessary component of community living). One-third ( $n = 28$ ) of studies focused on family caregivers across disability types, divided between general (e.g., cerebral palsy, developmental disability, as in Berry, Elliott, Grant, Edwards, & Fine, 2012;  $n = 14$ ) and old age-specific (e.g., dementia, heart attack, stroke, as in DeFries, McGuire, Andresen, Brumback, & Anderson, 2009).

**Table 1.** Key information for studies about family caregiving in late life ( $n = 97$ ).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Anderson et al. (2013)	1, 2, 3	2009 BRFSS	Representative samples, regular care or assistance to a friend or family member	24.8% White, 28.6% Black, 21.4% Hispanic, 24% other/multiracial/non-Hispanic	Mixed disabilities
Aschbrenner et al. (2014)	1	Pre-post program evaluation, qualitative interviews	28 care recipients 13 relatives (majority siblings)	100% White	Mixed disabilities
Aschbrenner et al. (2009)	2	WLS	145 parents 3,063 peers	100% White	Mental illness: bipolar IDD
Barker et al. (2011)	2	Ongoing longitudinal study	379 mothers	93.1% White, 5.8% people of color (Black, Hispanic, Native American, Asian/Pacific Islander)	
Bass et al. (2012)	1, 2	Structured telephone interviews (Partners in Dementia Care)	486 family caregivers (71% wives)	83% White, 17% people of color	Dementia
Bass et al. (2013)	3	Evaluation (Partners in Dementia Care)	394 and 324 caregivers (primarily spouses)	81% White; 19% people of color	Dementia
Belle et al. (2006)	3	Evaluation (REACH II)	642 caregiver/care recipient dyads (spouse, nonspouse, adult child, sibling, other)	34% White, 33% Black, 33% Hispanic	Dementia
Berry et al. (2012)	3	Randomized clinical trial (CLUES)	147 caregivers (mothers, husbands, wives, daughters, fathers, sisters, aunts, grandparents, other)	74.8% White, 23.8% Black, 1.4% Hispanic	Mixed disabilities
Bertrand et al. (2012)	2	Caregiver SOF	194 continuous caregivers 148 former caregivers 574 continuous noncaregivers	87.6% White	ADL/IADL assistance
Blonder et al. (2007)	2	Convenience sample	20 patient/spousal caregiver dyads	Not reported	Stroke
Brown et al. (2009)	2	AHEAD cohort of the HRS	3,376 elderly married individuals	Representative sample	ADL/IADL assistance
Brown et al. (2013)	2, 4	H-EPESE	1,009 care recipients	100% Hispanic	ADL/IADL assistance
Burgio et al. (2009)	3	Evaluation (REACH II)	272 caregivers/recipient dyads (spouses, adult children)	60% White, 39% Black	Dementia

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Burke et al. (2012)	1	National sample (American Sibling Survey)	757 siblings	91% White	IDD
Calasanti & Bowen (2006)	1	Interviews and support group observations	22 caregivers (primarily spouses)	Not reported	Dementia
Calasanti & King (2007)	2, 3	Interviews and support group observations	22 spousal caregivers	95% White	Dementia
Caldwell (2008)	2, 3	Illinois Home Based Support Services program	225 female family caregivers (primarily mothers)	69.3% White, 20.4% Black, 7.6% Hispanic, 2.7% Asian	IDD
Chen et al. (2010)	1, 3	Evaluation, Family Caregiver Support Program (Washington state)	164 caregivers (spouses, adult children)	Not reported	Age-related impairments
Choi and Bohman (2007)	2	HRS	8,030 spouses (39% male, 61% female)	Male: 89.3% White, 6.5% Black, 4.1% Hispanic Female: 87.2% White, 8% Black, 4.7% Hispanic	Mixed disabilities
Chow et al. (2010)	3	Random digit dialing, caregivers in California	1,643 caregivers (12.2% spouses, 87.8% other)	61% White, 6% Black, 25% Hispanic, 5% Asian/ Native Hawaiian/PI	Age-related impairments
Chung et al. (2010)	2	Convenience sample	109 caregivers (primarily spouses)	93.6% White	Heart disease
Clay et al. (2013)	2	REGARDS study; Caring for Adults Recovering from the Effects of Stroke study	146 dyads (91 cohabiting)	57.5% White, 42.5% Black	Stroke
Cummings & Kropf (2015)	1, 2	Convenience sample, telephone interviews	96 caregivers (spouse, adult child, sibling, other)	76.8% White, 21.1% Black, 2.1% Other	Mental illness
DeFries et al. (2009)	1, 2	2005 North Carolina BRFSS	279 caregivers of people with cognitive impairments (spouse, other family, nonfamily member, paid caregiver) 389 peers	Caregivers: 76.7% White, 15.4% Black, 3% Hispanic, 4.9% other/multirace Peers: 74.1% White, 21.8% Black, 1.7% Hispanic, 2.4% other/multirace	Age related impairments

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Elliott et al. (2009)	3	Randomized clinical trial (CLUES)	81 caregivers/care recipients dyads (mothers, husbands, daughters, fathers, sisters, aunts, grandparents, other)	67.9% White, 32% Black	Mixed disabilities
Erickson & LeRoy (2015)	1	Cross-sectional study	11 family caregivers	Not reported	IDD
Fingerman et al. (2011)	3	Convenience sample	216 caregivers (adult children)	65% White, 35% Black	Age-related disabilities
Forducey et al. (2012)	3	Study 3: randomized clinical trials	11 caregivers	100% Black	Dementia
Fredman et al. (2006)	2	SOF	179 caregivers (primarily spouses)	89% White, 11% Black	ADL/IADL assistance
Fredman et al. (2008)	2	Health ABC Study	680 caregivers	52% White, 48% Black	Mixed disabilities
Fredman et al. (2009)	2	Caregiver—SOF	901 respondents (37% caregivers)	88% White	ADL/IADL assistance
Fredman, Cauley, et al. (2010)	2	Prospective cohort study; Caregiver—SOF	375 caregivers (47.7% spouses) 694 noncaregivers	88% White, 12% Black	Dementia
Fredman, Doros, et al. (2010)	2	Caregiver—SOF	338 female caregivers 583 female noncaregivers	88% White, 11.7% Black	Dementia
Freedman & Spillman (2014)	1	2011 NHATS	8077 caregivers (children, spouses/partners, other household or social network members)	80.5% White, 8.1% Black, 6.7% Hispanic, 4.6% other	ADL/IADL assistance
Freedman et al. (2014)	2	2009 PSIDD; Use of Time supplement	4,392 randomly selected diary entries (from 394 couples)	97.1% White, 2.9% Black	Mixed disabilities
Ghosh & Greenberg (2009)	2, 3	WLS	95 caregiving fathers; 95 comparison fathers	100% White	Mental illness
Ghosh et al. (2012)	1, 2	WLS	120 parents (children with SMI) 107 parents (children with DD) 1,463 parents (nondisabled children)	100% White	Mixed disabilities

*(Continued)*

**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Gitlin et al. (2010)	3	Randomized trial (COPE)	209 dyads (37.8% spouses, 62.2% non-spouses)	Caregiver: 69.9% White, 27.8% African American, 2.4% other Care recipient: 70.3% White, 27.3% African American, 2.4% other	Dementia
Godwin et al. (2013)	2	Convenience sample	30 caregiver/care recipient dyads (spouses)	Caregiver: 63.3% White, 16.7% Black, 20% Hispanic Care recipient: 66.7% White, 16.7% Black, 16.7% Hispanic	Stroke
Hall et al. (2014)	3	Focus groups	32 coresiding caregivers	80% White	Mixed disabilities
Handley & Hutchinson (2013)	1, 3	Semistructured interviews	7 family caregivers (mothers, fathers, sisters, aunts), 4 residential caregivers	Not reported	IDD
Hanks et al. (2007)	2	Southeastern Michigan Traumatic Brain Injury System within the TBI Model Systems Project	60 caregivers (parents, spouses/partners, siblings, adult children, other relative)	26.7% White, 70% Black, 1.7% Hispanic, 1.7% Asian	TBI
Heller & Caldwell (2006)	3	Pre-post intervention evaluation (The Future is Now)	38 caregivers (primarily mothers)	27.1% Black, 54.2% White, 18.8% other	IDD
Heller et al. (2012)	1, 2	Self-Directed Supports Survey	372 family caregivers (primarily parents)	73% White, 14% Black, 6% Hispanic, 7% other	IDD
Heru & Ryan (2006)	2	Convenience sample	38 caregivers (spouses, adult children, other relative or friend)	97.3% White, 2.6% Black	Dementia
Hodgson et al. (2014)	1	Project ACT	272 patient caregiver dyads (51% spouses)	69.9% White, 27.2% Black, 2.9% other	Dementia
Hoffman et al. (2012)	2	2009 California Health Interview Survey	5,688 informal caregivers (spouses, adult children, other relatives, nonrelatives) 12,941 non-caregivers	Caregivers: 63.1% White, 6% Black, 19.5% Hispanic, 8.5% Asian/ Hawaiian/PI, 2.9% Alaska Native/ American Indian, multiracial	ADL/IADL assistance
J.-H. Kim & Knight (2008)	1, 2	Convenience sample	87 caregivers 87 peers	100% Korean American	Age-related impairments

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
H. Kim et al. (2012)	1, 2	NAC/AARP	302 caregivers (spouse, parents, adult children, other relative, friend/nonrelative/neighbor)	75.8% White, 12.6% Black, 8.6% Hispanic, 2.3% Asian, 0.7% missing	Dementia
Leggett et al. (2010)	2	Lewy Body Dementia Association (survey)	611 caregivers (wives, husbands, daughters/daughters-in-law, sons/sons-in-law, others)	Not reported	Dementia
Li et al. (2015)	2	Phase II of the National Survey of MIDUS	67 active caregivers, employed and with a supervisor	Not reported	Mixed disabilities
Lucksted et al. (2013)	3	Evaluation (NAMI Family-to-Family)	158 family members or significant others	64% White	Mental illness
Lutz et al. (2009)	3	Evaluation (mixed methods -Patient Health Questionnaire, surveys, interviews)	18 veterans 14 caregivers (primarily spouses)	Veterans: 83% White, 17% Black	Stroke
Lyons et al. (2015)	2	Caregiver-SOF	992 female caregivers and noncaregivers (54.27% spouses)	88.1% White	ADL/IADL assistance
Lyons et al. (2009)	2	Parkinson's Spouse's Project	255 spouses	97% White	Parkinson's disease
Magaña & Smith (2006)	2	NHIS	162 mothers coresiding with child with DD 2,754 peers not coresiding	48.8% Black, 51.2% Hispanic	IDD
Magaña & Smith (2008)	2	NHIS	162 mothers coresiding with child with DD 2,754 peers not coresiding	48.8% Black, 51.2% Hispanic	IDD
Magaña et al. (2006)	2	Convenience sample	153 family caregivers (primarily mothers)	100% Hispanic (71% Cuban/Cuban American, 9% Puerto Ricans, 7% Colombians, 13% other Hispanic)	IDD

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Marquez & Ramírez García (2013)	3	Interviews	17 caregivers who used NAMI services (mothers, sisters, husbands) 15 caregivers who did not use NAMI services (mothers, fathers, sisters, husband, grandmother)	100% Hispanic	Mental illness
Martire et al. (2010)	2	Randomized clinical trial (Major depressive disorder in older adults)	244 caregiver/care recipient dyads	Caregivers: 86.9% White Care recipients: 88.9% White	Mental illness: depression
Mastel-Smith & Stanley-Hermanns (2012)	2, 3	Focus groups	29 family caregivers (adult children, spouses, other relative)	76% White, 17% Black, 3% Hispanic, 3% Asian	Age-related disabilities
Mausbach et al. (2008)	2	Alzheimer's Caregiver Program	16 caregivers	81.2% White, 18.8% Hispanic	Dementia
McKibbin et al. (2005)	2	Convenience sample	73 spousal caregivers (primarily wives)	93% White	Dementia
Menne et al. (2014)	3	Evaluation (Reducing Disability in Alzheimer's Disease)	219 caregivers using Alzheimer's Association services or other aging agencies (70.3% spouses)	90.7% White	Dementia
Minihan et al. (2014)	1, 3	Convenience sample	125 family caregivers (primarily parents) 683 paid caregivers	Not reported	Mixed disabilities
Minkler and Fuller-Thomson (2005)	1	Census 2000 Supplementary Survey/ACS	2,362 grandparent caregivers 40,148 peers	100% Black	ADL/IADL assistance
Neely-Barnes et al. (2008)	1, 2	Washington State's 2004 NCI Adult Family Survey	547 family caregivers (primarily mothers)	81.5% White, 3.1% Black, 4% Hispanic, 5.5% Native American, 5.7% Asian	Mixed disabilities
Noël-Miller (2010)	1	HRS	789 husbands 778 wives	Husbands: 86.4% White Wives: 85.9% White	Age-related impairments
Noël-Miller (2011)	1	HRS	2,544 caregivers (spouses, adult children, other relatives, nonkin)	Married: 81.9% White, 13.6% Black, 4.5% other Cohabiting: 63% White, 27.6% Black, 9.4% other	Age-related impairments

(Continued)

**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Ostwald et al. (2009)	2	CAReS Study	131 stroke survivors and their spousal caregivers	Survivors: 58% White, 17.6% Black, 16.8% Hispanic, 3.8% Asian, 3.8% other Caregivers: 58.8% White, 16.8% Black, 17.6% Hispanic, 3.8% Asian, 3.1% other	Stroke
Parish et al. (2010)	2, 4	SIPP	753 parents	64.9% White, 18.1% Black, 4.9% other	IDD
Park et al. (2013)	1	Reducing Risk in Cardiac Rehabilitation: Partners Together in Health Intervention	35 spousal caregivers	94% White, 6% Hispanic	Coronary artery bypass surgery
Park-Lee et al. (2009)	2	Caregiver—SOF	954 respondents (35% caregivers)	87.2% White	ADL/IADL assistance
Perkins (2010)	1, 3	Case study	1 female caregiver	Not reported	Mixed disabilities
Perkins & Haley (2010)	1, 2	Surveys during semistructured interviews	91 parents (primarily mothers)	92.3% White, 4.4% Black, 2.2% Hispanic, 1% Pacific Islander	IDD
Perkins et al. (2013)	1, 2	REGARDS study	3,710 family members (spouse, parent, child, sibling, other)	58.5% White, 41.5% Black	Stroke
Pernice-Duca (2010)	3	In-depth structured interviews	169 consumers	Mostly White	Mental illness
Piazza et al. (2014)	2	WLS	139 parents	100% White	IDD
Pickett-Schenk et al. (2006)	3	Evaluation (Journey of Hope)	462 family members (parent, sibling, adult child, spouse, other)	Not reported	Mental illness
Poulin et al. (2010)	1, 2	Caregiver report (via Palm Pilot over 7 days)	73 spousal caregivers (63% wives)	98.6% White, 1.4% Black	Age-related impairments
Rhee et al. (2009)	1	HRS	990 individuals (47.8% with caregivers, 34.4% spouses, 30.5% daughters)	69.5% White, 18.6% Black, 9.6% Hispanic, 1.8% other, 0.1% missing	Age-related impairments
Riffin et al. (2013)	2	Medicare Primary and Consumer-Directed Care Demonstration	312 dyads (30% spouses)	Not reported	ADL/IADL assistance

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Rivera, Elliott, Berry, Grant, & Oswald (2007)	2	Convenience sample	60 familial caregivers (primarily mothers)	85% White, 11.7% Black, 3.3% Hispanic	TBI
Rivera et al. (2008)	3	Convenience sample	33 caregivers in intervention 34 caregiver control	Intervention: 93.9% White, 6% Black Control: 76.5% White, 17.6% Black, 5.9% Hispanic	TBI
Roth et al. (2009)	1, 2	REGARDS study	5,159 caregivers (parents, spouses, adult children, siblings, other)	51.6% White; 48.4% Black	Stroke
Roth, Haley, Wadley, Clay, & Howard (2007)	1	REGARDS study	32,957 individuals (80.4% potential caregivers)	52.8% White, 47.1% Black	Stroke
San Antonio et al. (2010)	1, 2	Independent Choices, Arkansas Cash and Counseling Demonstration and Evaluation program	19 caregivers (daughters/in-law, sons/in-law, nieces, grand-nieces/daughters, neighbor's, children or friends, acquaintances)	31.5% White, 68.4% Black	Mixed disabilities
Scharlach et al. (2006)	1, 2, 3	Focus groups	76 caregivers (adult children, spouses, other family members, neighbors, friends)	15.7% Black, 7.5% Hispanic; 50% Asian, 13.9% Native American, 11.4% Russian	Age-related impairments
Scharlach et al. (2008)	1, 2, 3	Convenience sample	1,508 caregivers (adult children, spouses, other)	61% White, 6% Black, 25% Hispanic, 5% Asian, Hawaiian, PI	Age-related impairments
Schulz et al. (2008)	2	REACH study	1222 dementia patient/caregiver dyads (48.2% spouses)	Caregivers: 56% White, 24.2% Black, 19% Hispanic, 0.8% other Patients: 55.9% White, 24.6% Black, 18% Hispanic, 1.6% other	Dementia
Seltzer et al. (2011)	2, 3	WLS	220 parents of people with IDD, 1,042 parents of people without IDD	100% White	IDD
Smith et al. (2010)	1, 2, 3	Eight days of diary entries (MIDUS)	96 mother of individuals with ASD 230 peers	Mothers: 92% White Peers: 91% White	IDD
Stokes (2014)	2, 3	Interviews	24 caregivers with HIV/AIDS (aunts, grandmothers)	100% Black	HIV/AIDS
Thai et al. (2015)	2, 3	Convenience sample	42 caregivers (spouse, adult child, other relative, friend)	60% White, 5% Black, 5% Hispanic, 26% Asian, 5% other	Age-related impairments

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**Table 1.** (Continued).

Authors	Research question	Data source	Sample size & caregiver role	Racial breakdown	Disability type
Vitaliano et al. (2009)	2	Convenience sample	122 spousal caregivers 117 noncaregiving spouses	93% White	Dementia
Wolff & Kasper (2006)	1	NLTCSIC Survey	6,701 caregivers (spouses, adult children)	Not reported	ADL/IADL assistance
Yamaki et al. (2009)	1, 2	Illinois BRFSS; State-wide health survey of adults with IDD	206 female caregivers (primarily mothers)	Middle age ( $n = 130$ ): 80% White, 13.8% Black, 3.1% Hispanic, 3.1% other Older age ( $n = 76$ ): 84% White, 9.3% Black, 4% Hispanic, 2.6% other	IDD

*Note.* BRFSS = Behavioral Risk Factor Surveillance System; WLS = Wisconsin Longitudinal Study; IDD = intellectual and developmental disabilities; REACH II = Resources for Enhancing Alzheimer's Caregiver Health; SOF = Study of Osteoporotic Fractures; ADL = activities of daily living; IADL = instrumental activities of daily living; AHEAD = Asset and Health Dynamics; HRS = Health and Retirement Study; H-EPESE = Hispanic Established Populations for Epidemiologic Study of the Elderly; ASD = autism spectrum disorder; DD = developmental disabilities; REGARDS = REasons for Geographic and Racial Differences in Stroke; Health ABC = Health, Aging, and Body Composition; NHATS = 2011 National Health and Aging Trends Study (NHATS); PSIDD = Panel Study of Income Dynamics and Disability; SMI = serious mental illness; COPE = Care of Persons with Dementia in their Environments; TBI = traumatic brain injury; NAC/AARP = National Alliance for Caregiving & AARP Public Policy Institute; MIDUS = Midlife Development in the United States; NHIS = National Health Interview Survey; NAMI = National Alliance on Mental Illness; ACS = American Community Survey; NCI = National Core Indicators; CARES = Committed to Assisting with Recovery after Stroke; SIPP = Survey of Income and Program Participation; NLTCSIC = National Long-Term Care Survey and Informal Caregiver.

Another 12 studies identified family caregivers on the basis of their provision of activities of daily living (ADL) or instrumental ADL assistance rather than a specific condition. Studies focused on caregivers of individuals with specific disability types included dementia ( $n = 19$ ), intellectual or developmental disabilities (IDD) including autism spectrum disorder (ASD;  $n = 16$ ), and mental illness ( $n = 8$ ). Studies also focused on caregivers of older adults recovering from stroke ( $n = 8$ ), traumatic brain injury (TBI;  $n = 3$ ), and heart disease ( $n = 2$ ). One study was unique in that it focused on women who were HIV positive, but their HIV status was related to their role as family caregivers not care users (Stokes, 2014).

This literature review presents data from 85 quantitative and 12 qualitative studies (including one case study). In terms of design, quantitative studies were most frequently cross-sectional ( $n = 44$ ), followed by longitudinal ( $n = 26$ ), program evaluations ( $n = 9$ ), and randomized clinical trials ( $n = 5$ ). One-third of the quantitative studies relied on data from national (e.g., National Health Interview Study) or state (e.g., Wisconsin Longitudinal Study) efforts, or from large-scale research and demonstration projects (e.g., Study of Osteoporotic Fractures).

## Results

### ***Question 1. Care, services and supports provided by family caregivers***

In the United States, family caregivers provide various forms of care, services, and supports in late life (for our purposes, age 50 years and older) and/or to community-dwelling older adults. Depending on care recipient functional need, tasks completed by family members vary greatly. Across disability types, assistance with ADLs (e.g. toileting, bathing, dressing, grooming, feeding, transferring), IADLs (e.g., cooking, finances, laundry, shopping, transportation) and access to medical services were most common (Katz & Akpom, 1976; Lawton & Brody, 1969).

### ***Activities of daily living and instrumental activities of daily living***

Across the literature on family caregiving and older adults, assistance with ADLs and IADLs were the most frequently researched forms of care. Indeed, more than one third ( $n = 34$ ) of studies used the provision of ADL or IADL assistance as part of the operational definition of *caregiver*.

Family caregivers for older adults, primarily spouses and adult children, provided ADL and IADL assistance with personal care, mobility, household tasks, shopping, and transportation (Wolff & Kasper, 2006). Korean American family caregivers of older adults frequently assisted with ADLs and IADLs (J.-H. Kim & Knight, 2008). In Washington state, family caregivers of older adults regularly performed personal care and household chores, but transportation was the most commonly reported task by caregivers (Chen, Hedrick, & Young, 2010). Caregivers for older adults with dementia also frequently provided ADL and IADL assistance, with one study reporting nearly four in five older Veterans with dementia needed assistance with at least one, and on average four, of the following: bathing, dressing, grooming, toileting, eating, and getting around inside the home (Bass et al., 2012; H. Kim, Chang, Rose, & Kim, 2012).

Among spousal caregivers for individuals who had coronary artery bypass surgery, transportation was identified as one of the most demanding caregiver tasks, along with household tasks, providing assistance outside the home, and challenging behaviors, whereas assistance with communication, mobility, and personal care were described as less difficult (Park et al., 2013).

Spousal caregivers also frequently helped with meal preparation, mobility assistance, and toileting (Poulin et al., 2010). Additionally, caregiving husbands and wives engaged in a previously unidentified form of invisible care work: preserving the gender identity of the care recipient; work that is intimately intertwined with ADL assistance (e.g., bathing, dressing, grooming; Calasanti & Bowen, 2006).

Older participants of a consumer-directed, Medicaid-funded personal support attendant program in Arkansas (Cash and Counseling), reported greater satisfaction when hiring family members (rather than agency staff)

and attributed this, in part, to the comfort they felt with a family member completing tasks that were intimate (e.g., toileting) or that agency staff could, or would not, offer (e.g., shopping assistance; San Antonio et al., 2010).

Basic hygiene, like toileting and toothbrushing, are ADLs that often require caregivers to provide assistance multiple times each day. Family caregivers of older adults with IDD were less likely to assist with brushing twice a day but more likely to encourage flossing than paid staff, even though both types of caregivers felt more confident assisting with brushing than flossing and paid staff were more likely than family caregivers to have received formal training in these areas (Minihan et al., 2014).

In North Carolina, nearly two thirds of family members providing care to older adults with dementia provided help with at least one ADL and were significantly more likely to help with cognitive tasks and less likely to assist with mobility (DeFries et al., 2009). Family caregivers also provided assistance in the area of money management, for adults with IDD and those with dementia (Burke et al., 2012; H. Kim et al., 2012; Neely-Barnes, Graff, Marcenko, & Weber, 2008; San Antonio et al., 2010).

### ***Medical care and medication management***

Additionally, caregivers also facilitated access to medical appointments and assisted with medication management. Caregivers helped older adults, including those with mental illness, by scheduling and/or accompanying them to appointments, supporting them with medical decision making, picking up prescriptions, and monitoring care quality (Aschbrenner et al., 2014; San Antonio et al., 2010).

Several studies listed medication management as an IADL with which caregivers assisted (Chen et al., 2010; H. Kim et al., 2012; J.-H. Kim & Knight, 2008; Park et al., 2013; Wolff & Kasper, 2006). In old age, spousal caregivers assisted with administering medications as well (Poulin et al., 2010). In terms of knowledge, family caregivers of adults with IDD scored as well as direct support workers on tests of health literacy and medical administration (Erickson & LeRoy, 2015). For older adults with dementia, caregivers managed multiple types of medication and helped older adults manage and medicate pain (Hodgson, Gitlin, Winter, & Hauck, 2014).

### ***Care coordination***

Given the complicated disability and aging service systems, family members offer important assistance by coordinating services that support community living. Siblings of adults with IDD anticipated interacting with service systems once their parents were no longer able to do so (Burke et al., 2012). For the older adults in Cash and Counseling, family members were representatives, assisting consumers with service coordination and hiring and managing paid caregivers, including other family members (San Antonio et al., 2010). Spouses of older

adults who had coronary artery bypass surgery also assisted with the coordination of services and supports (Park et al., 2013).

### ***Companionship & emotional support***

Siblings of individuals with IDD intended to provide companionship and emotional support to their siblings in the future (Burke et al., 2012). Spouses of individuals who had coronary artery bypass surgery currently provided emotional support, describing it as a demanding task (Park et al., 2013). Unlike paid staff, family caregivers who provided bereavement support to individuals with IDD, had personal connections to the deceased and needed to grieve the loss themselves before informing care recipients. However, similar to paid staff, family caregivers appreciated responses that matched their own emotions (e.g., crying) and had difficulty with responses that were outside their expectations (e.g., behavioral issues; Handley & Hutchinson, 2013).

### ***Compound caregiving***

Parents of adult children with mental illness or IDD engage in lifelong-caregiving relationships. As they acquire new caregiving relationships (aging parents, ill spouses, or expanding responsibilities for siblings with ID) they begin careers as compound caregivers (Perkins, 2010). Unlike the notion of the sandwich generation (i.e., parents taking care of their children and aging parents until the children leave the family home), compound caregiving recognizes the unique situation of undertaking new, long-term care responsibilities in addition to and simultaneous with existing, lifelong caregiving relationships. In one sample of parents of adults with IDD, one-third were currently compound caregivers (most frequently for the caregiver's mother) and another one third had previously been (Perkins & Haley, 2010). Compared to caregiving parents of adults with IDD, those of adult children with severe mental illness were significantly more likely to have spouses develop disabilities over a 10-year period, indicating the potential for compound caregiving (Ghosh, Greenberg, & Seltzer, 2012).

### ***Hours of assistance provided vary by caregiver type and race***

For older adults in the United States, the help that was provided by multiple family caregiver types that allowed them to live at home and in the community varied in intensity (i.e., hours of care) based on caregiver type and race/ethnicity.

***Caregiver type.*** Nearly all Medicare enrollees received informal support ( $\bar{x} = 164$  hours/month) and adult children were the most frequent caregivers, followed by spouses, with others, including friends and granddaughters, accounting for 14% (Freedman & Spillman, 2014). Among caregivers of frail elders, average hours of care per week varied based on caregiver type: Spouses performed the most hours of care (41 hours per week) versus adult

children (37 hours) and other relatives and friends (33 hours; Wolff & Kasper, 2006). Another study found that in the month prior, roughly one fourth of respondents had engaged in caregiving for a friend or family member with a long-term illness and that caregivers were more likely than noncaregivers to be in the “near Medicare” age category (age 50 to 64 years), women, married, Black rather than of other racial/ethnic groups, and to have had some college education (Anderson et al., 2013).

Some studies focused specifically on spousal caregivers and/or comparing spousal caregivers with the caregiving provided by unmarried, cohabiting romantic partners. Cohabiting older adults were less likely to receive care from their partner than those who were married, even though the hours of care (when provided) were the same across both relationship types (Noël-Miller, 2011). Hours of care varied by gender for older, married couples, with wives providing more care to their husbands whose ADL functioning worsened but husbands reducing the amount of care provided when wives ADL needs increased, placing them at risk for unmet need (Noël-Miller, 2010). In their last year of life, married older adults were less likely than unmarried ones to receive informal family care, whereas older adults who lived with their grown children caregivers received the most informal care (Rhee, Degenholtz, Lo Sasso, & Emanuel, 2009).

A variety of individuals were hired as support workers by adults with IDD through a Medicaid-funded, self-directed support program in Illinois, with parents accounting for half of those hired and the remaining split almost evenly between other family members, friends, or agency staff (Heller, Arnold, van Heumen, McBride, & Factor, 2012). Another analysis in Illinois found that mothers accounted for nearly nine in 10 of women family caregivers for people with IDD, followed distantly by sisters (11%) and grandmothers (3%; Yamaki, Hsieh, & Heller, 2009).

Among adults with IDD using a self-directed support program, parents and siblings provided the greatest number of hours, nearly 30 hours weekly, whereas agency staff provided roughly half that amount (Heller et al., 2012). For older adults with dementia, family caregivers (including adult children, spouses, and others) spent an average of 25.5 hours each week (H. Kim et al., 2012).

***Coresidence.*** Caregivers living with care recipients was common, particularly for parent and/or spouse/partner caregivers, and for adults with IDD (Ghosh et al., 2012; Perkins & Haley, 2010; Smith et al., 2010) and those with age-related disabilities (Noël-Miller, 2011; Perkins et al., 2013; Rhee et al., 2009; Roth, Perkins, Wadley, Temple, & Haley, 2009). Across caregiver types, coresidence was associated with both greater care recipient service need and hours provided by family caregivers.

However, even when caregivers did not coreside, the level of contact could still be high. Among family caregivers of older adults with serious mental illness

(SMI), fewer than four in 10 caregivers coresided, but nearly three fourths had daily contact with the older adult with mental illness (Cummings & Kropf, 2015). Additionally, compound caregiving increased the total number of hours of caregiving, with parents of adults with IDD adding 12 more hours each week on top of their existing 39-hour caregiving schedule (Perkins & Haley, 2010).

**Race/ethnicity.** Among a racially/ethnically diverse set of caregivers in California, Latino caregivers who were not born in the United States provided the most caregiving hours (62 hours/week) and non-Hispanic White caregivers the least 37 hours (Scharlach, Giunta, Chow, & Lehning, 2008). For adults poststroke, two studies found that African Americans were more likely than White caregivers to coreside with ill family members and to provide 30 or more hours of care each week (Perkins et al., 2013; Roth et al., 2009). Additionally, the sole grandparent study in this review focused on African American grandparents, finding nearly one in 20 African Americans older than age 45 were raising grandchildren (Minkler & Fuller-Thomson, 2005). Nearly one-half of African American grandparent caregiver households included a person with a disability, in many cases a grandparent (potentially the caregiver). Despite the under-representation of Asian Americans across the studies in this review, two studies highlighted the high rates of coresident caregiving among various Asian American ethnicities (e.g., Korean, Vietnamese, Chinese; J.-H. Kim & Knight, 2008; Scharlach et al., 2006).

## **Question 2. The impact of family caregiving in late life**

This section summarizes the literature that assesses the impact of caregiving ( $n = 62$ ) in late life. Many articles ( $n = 31$ ) focused on the negative impacts of caregiving, though some also identified individual and familial factors that act to mediate or buffer these. Only 16 addressed positive caregiving outcomes, whereas another 15 found mixed results.

### **Negative impacts of family caregiving in late life**

Provision of care, support, and services in late life and/or to older adult family members can affect multiple domains of life, including a caregiver's mental and physical health, social participation, and economic standing.

**Greater depression.** Caregivers across disability and relationship type reported greater levels of depression than noncaregivers. Parents of adult children with mental illness reported higher levels of depression than parents without children with mental illness (Aschbrenner, Greenberg, & Seltzer, 2009; Ghosh & Greenberg, 2009; Ghosh et al., 2012). Additionally, parents of adults with IDD reported greater depression, especially those who lived with adult children (Piazza, Floyd, Mailick, & Greenberg, 2014; Seltzer,

Floyd, Song, Greenberg, & Hong, 2011). From ages 40 to 54, Latina caregivers of adult children with IDD were twice as likely to report depressive symptoms than similarly age noncaregivers (Magaña & Smith, 2006).

Spouses in mid- and late life reported higher rates of depression when providing care, support, and services than spouses who were not. In midlife, family caregivers reported higher rates of depression when they experienced greater family strain and limited work supervisor support (Li, Shaffer, & Bagger, 2015). Among older adults, spousal caregiving was associated with greater depression for older men more than women (Choi & Bohman, 2007). High rates of depression were reported among spousal caregivers of older adults recovering from stroke (Blonder, Langer, Pettigrew, & Garrity, 2007) and heart failure (Chung, Pressler, Dunbar, Lennie, & Moser, 2010). Activity restrictions (i.e., the disruption of access to everyday pleasurable activities, see Williamson & Shaffer, 2000) accounted for nearly 90% of the variance in depression scores between spousal caregivers of individuals with Alzheimer's disease showing symptoms and those who did not yet have them (Mausbach, Patterson, & Grant, 2008).

Higher rates of depression were also found among mixed caregiver samples. In mid- and late life, caregivers with high emotional strain reported significantly higher levels of depression than those with less strain (Roth et al., 2009). Family caregivers for older adults with Alzheimer's disease reported depression rates between 40% and 50% (Bass et al., 2012; Schulz et al., 2008). For family caregivers of older adults with SMI, one study found nearly one fourth of caregivers had clinical symptoms of depression with those providing care for older adult men with SMI reporting greater levels of depression (Cummings & Kropf, 2015).

***Diminished mental well-being and cognitive processing.*** Self-reported mental health (as measured by distress, mentally unhealthy days, affect, etc.) was diminished for caregivers compared to noncaregivers, across multiple relationship and disability types. Caregivers in late life reported greater levels of mental distress than same age noncaregivers and emotional strain was negatively correlated with mental health for mid- and late-life caregivers (Anderson et al., 2013; Roth et al., 2009). Comparisons of older women's stress levels across caregiving trajectories (i.e., those who started caregiving, those who stopped, and those who never provided care) illustrated that caregiving intensity (measured by number of ADLs/IADLs) predicts caregiving stress (Lyons, Cauley, & Fredman, 2015).

Among caregivers, those age 65 and older reported significantly lower rates of mental distress than those of working age (Anderson et al., 2013). However, women caregivers of adults with IDD in Illinois reported poorer mental health outcomes at ages 45 to 54 and 65 and older compared to their age counterparts in the general population (Caldwell, 2008). Further, older women caregivers of adults with IDD in Illinois reported more

mentally unhealthy days (4.65) in the last 30 days than noncaregivers of the same age (2.3 days; Yamaki et al., 2009).

Parent caregivers, including older adult parents of individuals with IDD (Seltzer et al., 2011), fathers of children with schizophrenia (Ghosh & Greenberg, 2009), and mothers who coreside with adolescents or adults with ASD (Smith et al., 2010) reported diminished psychological health compared with parents without children with disabilities. Spousal caregivers of older adults with Alzheimer's disease demonstrated worse cognitive processing at baseline and showed a greater decline in follow-up years than demographically similar noncaregivers, with depression mediating the relationship between caregiving status and decline in cognitive function (Vitaliano et al., 2009).

Care recipient, caregiver, and family characteristics were associated with caregiver mental health. For caregivers helping family members with stroke recovery, the total number of stroke-related impairments (e.g., ADLs, IADLs, cognition, sensory impairments) was negatively correlated with caregiver mental health (Clay et al., 2013). Compared to other parent caregivers of adults with mental illness, those with a personal history of mental illness were significantly more likely to report poor mental health (Aschbrenner et al., 2009). In terms of family functioning, higher levels of care recipient behavioral problems were positively associated with family burden and individual caregiver psychological distress among Hispanic caregivers of people with IDD (Magaña, Schwartz, Rubert, & Szapocznik, 2006).

*Caregiver strain and burden.* Family caregivers for older adults reported strain related to shifting familial roles, confidence in caregiving abilities, and caregiving burden. Nearly three-fourths (74%) of caregivers for older adults with Lewy Body Dementia reported moderate to extreme caregiver burden (Leggett, Zarit, Taylor, & Galvin, 2010). Forty percent of caregivers for older adults with dementia reported high levels of emotional strain (Bass et al., 2012). Ninety percent of caregivers of individuals with TBI reported dissatisfaction related to caregiver burden and the limited mastery they felt in performing caregiving tasks (Hanks, Rapport, & Vangel, 2007). Family caregivers of older adults with major depressive disorder also reported moderate to high levels of caregiver burden (Martire et al., 2010).

Over a decade, spouses of individuals with Parkinson's disease reported an increase in all components of caregiver strain (global strain, strain from worry, strain from manipulation, and strain from increased tension), with husbands experiencing a significantly lower rate of increase in strain over time than wives (Lyons, Stewart, Archbold, & Carter, 2009). Higher rates of strain among caregivers for older adults with dementia were

associated with poor family functioning (Heru & Ryan, 2006); a combination of role strain, personal strain, and worry about caregiving performance (Leggett et al., 2010); the frequency of behavioral challenges (Bass et al., 2012); and coresidence combined with ADL and/or IADL assistance need (H. Kim et al., 2012).

Across studies, caregiver burden differed by race and gender. White caregivers and women caregivers for older adults recovering from stroke reported some or severe caregiving strain more often than African American or men caregivers, with the highest levels of strain reported by those coresiding (Perkins et al., 2013). Among caregivers of older adults in California, U.S.-born Latinos were the most likely to report emotional strain and Latinos born outside of the United States the least likely (Scharlach et al., 2008).

***Diminished quality of life.*** Both parents of adults with IDD and those of adults with mental illness reported poorer health-related quality of life than parents of children who were nondisabled, regardless of coresidence (Seltzer et al., 2011). Over time, parents of adults with mental illness reported a decrease in health related quality of life (Gosh, Greenberg, & Seltzer, 2012).

For spousal caregivers, poor health and perceived stress 12 months after stroke were associated with a decline in life satisfaction at 24 months post-stroke (Ostwald, Godwin, & Cron, 2009). In interviews, more than one half of caregivers for older adults described diminished quality of life in the period of time while caregiving. Caregivers identified three reasons for this change: (1) prioritizing caregiving over their own needs, (2) their own declining health, and (3) the emotional burden of seeing someone they loved suffer (Thai, Barnhart, Cagle, & Smith, 2015).

***Poor physical health, increased activity limitations.*** Compared to noncaregivers of the same age or middle-aged caregivers, family members providing care, support, and services in old age or for older adults were more likely to report both poorer overall health and increased limitations in daily activities. Although caregivers, regardless of age, reported lower appraisals of overall health and greater physical distress (Anderson et al., 2013), older caregivers of adults with IDD experienced more physically unhealthy days than middle age caregivers (Yamaki et al., 2009). When caregiving history and metabolic indicators were considered, older adult caregivers showed significantly larger decreases in walking speed than older adults not engaged in caregiving (Fredman, Doros, Cauley, Hillier, & Hochberg, 2010) and providing family care was associated with greater functional decline for White and women caregivers (Fredman et al., 2008). Despite self-reported positive health, Korean Americans caregivers of older adults had elevated blood pressure and cortisol levels when compared to ethnically similar noncaregivers (J.-H. Kim & Knight, 2008).

Caregiving was also associated with poor health for arent caregivers of adults with disabilities. Non-coresiding mothers of individuals with IDD reported poorer health than similar fathers (Seltzer et al., 2011), whereas caregiving fathers of children with schizophrenia reported markedly poorer health compared to fathers of children who were nondisabled (Ghosh & Greenberg, 2009). Psychological distress among mixed-ethnicity Hispanic caregivers of adults with IDD was negatively associated with family function and self-reported health (Magaña et al., 2006).

Poorer caregiver physical health was positively associated with the age of the caregivers and social support received among caregivers helping family members recover from stroke (Clay et al., 2013). Although the relationship between age and caregiver health might be expected, the findings about social support were surprising and interpreted as an indication of need (i.e., there is an inverse relationship between health and need for social support). In a study that included an array of caregivers for older adults with ADL/IADL assistance needs, low agreeableness on the part of the care recipient was associated with poorer self-reported health by caregivers (Riffin, Löckenhoff, Pillemer, Friedman, & Costa, 2013). Spousal caregivers of older adults with moderate to severe Alzheimer's disease were more likely to experience diminished sleep quality and an impaired activity level during the daytime because of sleepiness than caregivers of older adults with mild to moderate Alzheimer's disease and noncaregivers (McKibbin et al., 2005). In another study, approximately one fourth of the caregivers for older Veterans with dementia reported that caregiving negatively affected their health, predicted most strongly by the number of care recipient co-occurring, chronic medical conditions; high levels of personal care dependence; and frequent challenging behaviors (Bass et al., 2012).

Caregivers for older adults and in old age also reported greater limitations in daily activities. Caregivers for older adults with cognitive impairment had higher rates of disability and substantial limitations in activity than other caregivers (DeFries et al., 2009). Older women caregivers for adults with IDD had nearly twice the rate of limitations in daily activities than their age cohort and two and a half times greater than middle-age caregivers (Yamaki et al., 2009). Further, coresiding parent caregivers of adults with IDD reported more ADL limitations than those who did not live with their grown children (Seltzer et al., 2011).

*Increased risk of specific negative health outcomes.* Women caregivers of adults with IDD had higher rates of health conditions. Middle-age (40–59 years) caregivers reported higher rates of diabetes and high cholesterol compared to their noncaregiving counterparts in the same age group, and caregivers age 60 and older were more likely to report arthritis (2 times), high blood pressure (1.8 times), and osteoporosis (3.5 times) than their middle-age peers (Yamaki et al., 2009). Further, by early old age, coresiding parents of individuals with IDD reported more cardiovascular problems and higher average Body Mass Indexes (BMIs) than

parents who did not coreside or who had children who were nondisabled (Seltzer et al., 2011). Coresiding mothers are at unique risk, with these mothers of adults with IDD demonstrating elevated BMIs compared to similar fathers (Seltzer et al., 2011) and these mothers of adolescents or adults with ASD reporting fatigue more frequently than mothers who live with adolescents or adults who were nondisabled (Smith et al., 2010).

This elevated risk for coresiding mothers applies to women of color, as well. Compared to noncaregivers of the same age, co-residing Latina caregiving mothers age 40 and older were more than twice as likely to have heart problems and arthritis. Those age 55 years and older were five times more likely to have a heart condition and nearly four times as likely to report arthritis than their noncaregiving counterparts. Older Black coresiding caregiving mothers were four times more likely to report arthritis and uniquely, diabetes as a condition limiting physical activity (Magaña & Smith, 2006).

***Negative health behaviors.*** Beyond negative health outcomes, caregivers were also more likely to engage in behaviors that could lead to poorer health over time. Controlling for demographic factors (age, race, gender), social resources (neighborhood, education, marital status, employment), and levels of psychological distress, Baby Boomer caregivers were approximately 1.3 times as likely to engage in negative health behaviors overall than their noncaregiving peers, and similarly more likely to smoke, drink soda, or consume fast food regularly (Hoffman, Lee, & Mendez-Luck, 2012). Neither caregiver type (i.e., spousal vs. adult child or other relative) nor total hours of caregiving influenced the likelihood of these behaviors.

Additionally, Latina mothers caring for their adult children with IDD were more likely to smoke than their counterparts with children who are nondisabled (Magaña & Smith, 2008). Among older women, nonspouse caregivers were less than half as likely, and spouse caregivers nearly 90% as likely, to be physically active than married noncaregivers (Fredman, Bertrand, Martire, Hochberg, & Harris, 2006).

***Limited healthcare access, less healthcare utilization.*** In mid- and late life, family caregivers were less likely to have accessed health care services, including medications, than the general population. Black and Latina coresiding, caregiving mothers of grown children with IDD were less likely to have attended to their own health care needs (i.e., seen a doctor in the last year) than their noncaregiving counterparts, and Black mothers experienced financial barriers to medication and mental health services (Magaña & Smith, 2008). In Illinois, health care access was a significant predictor of better physical and mental health for women caregivers of adults with IDD across four age categories (35–44, 45–54, 55–64, and 65+), with nearly 40% of differences in access predicted by a combination of caregiver age, income,

unmet need, and out-of-pocket costs (Caldwell, 2008). For caregivers of older adults with dementia, African American and Latino caregivers were significantly less likely to use antidepressants than White caregivers; spousal caregivers (regardless of race) were less likely to use antidepressants than other family caregiver types; and caregivers for women were less likely to use antidepressants than those caring for men (Schulz et al., 2008).

***Reduced longevity.*** Controlling for age, race (Black or White), and health status, highly strained caregivers of individuals recovering from stroke had nearly twice the mortality rate at the 5-year follow-up than similar caregivers who reported no strain or some strain (Perkins et al., 2013). Black women and White caregivers who provided 24 or more hours of care weekly had an increased mortality risk over an 8-year period when compared to their race-sex matched noncaregiving counterparts (Fredman et al., 2008).

***Decreased marital satisfaction, increased likelihood of divorce.*** Marital experience varied by caregiver type, with spouses reporting greater marital dissatisfaction and parents reporting higher divorce rates. For spousal caregivers of stroke survivors, marital satisfaction was inversely associated with care recipient depression levels (Blonder et al., 2007). High levels of mutuality (i.e., reciprocity, common values, and shared experiences) offered a protective effect against marital strain for wives caring for spouses with Parkinson's disease, but not husbands (Lyons et al., 2009). Fathers of children with schizophrenia reported significantly less marital satisfaction compared to fathers of children who are nondisabled (Ghosh & Greenberg, 2009).

In their midsixties, parents of adult children with bipolar disorders were significantly more likely to be divorced than parents of adult children without disabilities (Aschbrenner et al., 2009). In midlife (early fifties) and old age (midsixties), parents whose adult children with IDD lived outside the home were less likely to be married to their first spouse (i.e., the biological parent of the individual with IDD) when compared to coresiding parents and parents of children who are nondisabled (Seltzer et al., 2011).

***Limited labor force participation and less job satisfaction.*** Caregiving in mid- and late life was associated with decreased job satisfaction and labor force participation. In their midsixties, parents of adult children with bipolar disorder were significantly more likely to report lower levels of job satisfaction than parents of adult children without disabilities (Aschbrenner et al., 2009). Among caregivers in midlife, a combination of high family strain and low supervisor support was associated with significantly lower job satisfaction (Li et al., 2015).

In California, caregivers were, on average, more likely to be well educated, but significantly less likely to work (participate in the labor force) than noncaregivers

(Hoffman et al., 2012). In another study, one in 10 caregivers assisting family members recovering from heart failure were in the process of quitting a job or taking early retirement to focus more on caregiving responsibilities (Chung et al., 2010). Coresiding mothers of adolescent or adults with ASD reported workday interruptions nearly three times more often than mothers coresiding with their children who are nondisabled (Smith et al., 2010).

***Increased risk of income and asset poverty.*** For families of children with IDD, rates of asset poverty (i.e., when debts are greater than assets such that a person cannot afford the basic requirements of life) and rates of income poverty when measured at the level of the European Union (EU) (i.e., 60% of median income, rather than the restrictive U.S. federal poverty level) were high across all parental caregiver age cohorts. There was a curvilinear relationship between parental caregiver age and multiple financial measures (asset poverty, EU measure of income poverty, familial net worth, and annual household income), with caregivers age 45 and younger, and those age 65 years and older, experiencing the greatest economic deprivation. Specifically, annual household income was highest for those with a head of household age 45 to 54 and dropped markedly for the next oldest group and again for the oldest group, potentially indicating obstacles to career advancement in midlife for parents of children with IDD (Parish, Rose, & Swaine, 2010). In a study of ethnically diverse caregivers in California, Asian American, Native Hawaiian, and Pacific Islanders most frequently experienced financial difficulties related to caregiving, whereas non-Hispanic Whites were least likely (Scharlach et al., 2008).

***Reduced social participation.*** Multiple types of caregivers reported spending less time on social activities and/or being socially isolated in comparison to their noncaregiving counterparts. Mothers with coresiding adolescents or adults with ASD spent, on average, almost 2 hours more each day on childcare activities, one additional hour on chores, and one hour less on leisure than a sample of mothers with coresiding children who are nondisabled (Smith et al., 2010). By early old age, coresiding parents of children with IDD were less likely to visit with friends or relatives than those who did not coreside and were less likely to have a close friend compared to both parents who do not coreside and parents of individuals who are nondisabled (Seltzer et al., 2011).

Approximately nine out of 10 caregivers of older adults with Lewy Body Dementia expressed isolation, which was significantly associated with role strain, personal strain, and worries about caregiving (Leggett et al., 2010). For caregivers of older veterans with dementia, more than one half reported high levels of isolation, which was highly associated with the level of personal care (i.e., ADL) need and frequency of challenging behaviors of the care recipients (Bass et al., 2012). Among a sample of diverse caregivers in California, Latinos

born outside of the United States were the racial/ethnic group least likely to have access to emotional and social support (Scharlach et al., 2008).

***Compound caregiving: Negative impacts.*** For those lifelong caregivers who undertake a second set of caregiving responsibilities for another relative (i.e., compound caregiving), there are unique mental health, physical health, and financial challenges compared to other caregivers. Across two points in time (1992–1994 and 2004–2006), parents of adults with mental illness were more than twice as likely to have a spouse develop a disability as parents with a child who was nondisabled or child with IDD (Ghosh et al., 2012). Parent caregivers whose spouse developed a disability in this time period reported more negative health symptoms, diminished psychological health, greater levels of depression, and increased financial strain compared to those whose spouses remained nondisabled (Ghosh et al., 2012).

Compound caregiving may contribute to the potential institutionalization of older adults with disabilities. Perkins and Haley (2010) found that coresiding parents of adults with IDD who engage in compound caregiving expressed an increased desire for alternate housing options. The authors offer that compound caregiving may initiate the future planning process with conversations about where an adult with ID will live if the parent falls ill or is unable to provide the same level of care. For aging parents of middle-income Mexican Americans, greater functional limitation was associated with higher risk of institutionalization, with larger family size (i.e., more children) protective for older women (Brown, Herrera, & Angel, 2013).

#### ***Positive impacts of family caregiving in late life***

In addition to the volume of studies reporting on the negative impacts of caregiving, there is a growing body of research on the positive outcomes of family caregiving in the following domains: mental health, physical health, caregiver satisfaction and reward, and financial opportunities.

***Lower levels of depression, better mental health outcomes.*** African American caregivers stand in contrast to research findings on the increased risk for depression among family caregivers, consistently reporting lower depression rates than White caregivers. Among caregivers of family members recovering from stroke, African Americans were significantly protected in terms of mental health, demonstrating resilience and reporting fewer depressive symptoms than their White counterparts (Clay et al., 2013). Caregiving was not meaningfully associated with depressive symptoms for Black women caregivers of adults with IDD in midlife or old age (Magaña & Smith, 2006). Black women living with HIV who cared for younger family members (i.e., nieces, nephews, grandchildren) identified the role of social support via

family, spirituality, and HIV/AIDS support groups as central to their mental health, sense of well-being, and as resources for resiliency (Stokes, 2014).

Husbands providing spousal care for their wives with Alzheimer's disease reported low levels of caregiving stress. Using the feminist concepts of gender ideals (i.e., masculinity) and structural positions (i.e., husband), the men's stress and coping strategies were understood in terms of the gender repertoire of masculinity. This allows for a reframing of carework as a job with new tasks to be mastered, especially those not previously part of the role of husband (e.g., housekeeping, toileting assistance, etc.; Calasanti & King, 2007).

For caregivers of adults with IDD, secondary engagement (i.e., accommodation, including cognitive reframing and acceptance as per Conner-Smith & Flachsbart, 2007) has a buffering effect for caregiver stress, associated with less depression (Piazza et al., 2014). Mothers of adolescents and adults with ASD demonstrated a pattern of reduced anxiety and stable levels of depression over time, illustrating resiliency among mothers who gain caregiving skills and expertise (Barker et al., 2011). Caregivers of family members recovering from stroke reported significant reductions in caregiver depression over a 3-year period but no changes in caregiver burden or health-related quality of life (Godwin, Ostwald, Cron, & Wasserman, 2013). For Hispanic mothers of adults with IDD, higher rates of acculturation were associated with lower rates of psychological distress (Magaña et al., 2006).

*Better caregiver well-being.* In a small number of studies, family caregivers were found to have better self-reported health and reduced prevalence of negative health outcomes than noncaregivers. Care recipient agreeableness was positively associated with greater self-reported health by caregivers of older adults with disabilities (Riffin et al., 2013). On average, in Illinois, mid- and late-life caregivers of adults with IDD reported better health than women in the general population, with older adult caregivers experiencing heart attacks less frequently than their counterparts in the general population (11.2%; Yamaki et al. 2009).

For older spousal caregivers, many of whom were caring for a spouse with Alzheimer's disease or other dementia, hours spent on caregiving were positively associated with caregiver affect, especially for those reporting a high level of interdependence. For feeding assistance and medication management, interdependence mediated the relationship between caregiving hours and positive affect (Poulin et al., 2010). Controlling for demographic and health variables, positive affect was associated with reduced likelihood of becoming frail for older women caregivers and noncaregivers (Park-Lee, Fredman, Hochberg, & Faulkner, 2009).

Surprisingly, older women caregivers who assisted with more ADLs reported better physical functioning at baseline and less decline in physical functioning over two annual follow-ups than those providing less assistance

or not caregiving (Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009). Additionally, caregivers who climbed stairs at least 15 minutes daily were four times more likely to engage in physical activity than noncaregivers (Fredman et al., 2006). In terms of race and gender, White men and women caregivers, and Black women caregivers, engaged in more physical activity than their noncaregiving counterparts (Fredman et al., 2008).

***Improved cognitive outcomes.*** For some individuals, caregiving continuously resulted in improved cognition. Tests of verbal recall and processing speed assessed cognitive performance to examine the validity of a healthy caregiver hypothesis, one that presumes older adults who continuously provide care will have better health than those who cease to be, or never were, caregivers. Controlling for demographic and health variables, continuous caregivers were able to recall, on average, almost three more words than continuous noncaregivers, the equivalent of a decade difference in cognitive performance (Bertrand et al., 2012).

***Decreased mortality risk.*** Two studies found evidence that caregivers may experience increased longevity, with stress identified as a greater risk for mortality than caregiving status. Compared with low-stress noncaregivers, high stress caregivers were 1.4 times as likely to die within 3 years, whereas high-stress noncaregivers were 1.7 times as likely. Over the 8-year period of study, low-stress caregivers had a 33% lower mortality risk than low-stress noncaregivers and specifically, those not stressed by caregiving had a 43% lower mortality risk than all noncaregivers. These results may be explained by caregiver reward (having a sense of purpose) and the physical activity associated with caregiving. (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010). In another study, controlling for demographic and health variables, caregiving spouses who provided a minimum of 14 hours of weekly care had a reduced mortality risk over a 7-year period compared to noncaregiving spouses (Brown et al., 2009).

***Improved life satisfaction.*** Studies of caregivers for individuals poststroke and those with Alzheimer's disease reported increased life satisfaction over time. One study found that spousal caregivers reported increased life satisfaction over time as their spouse recovered from stroke, even without a specific caregiver intervention. In the time period between 12-months post-stroke and 24-months poststroke, average life satisfaction scores for survivors of stroke declined whereas those for spouses increased, widening the gap in mean scores by more than a factor of five. High levels of relationship mutuality and caregiver confidence were significantly, positively associated with a sustained increases in caregiver life satisfaction (Ostwald et al., 2009).

Husbands caring for their wives with Alzheimer's disease experienced satisfaction in a (caregiving) job well done and received external validation for their efforts in doing women's work as part of their caring (Calasanti & King, 2007). In one interview study, quality of life improved for about one fifth of caregivers of older adults, attributed to feelings of caregiver reward and/or gaining "expertise" and confidence as a caregiver (Thai et al., 2015).

*Caregiver reward and satisfaction.* In contrast with approaches to family caregiving that emphasize the burden associated with caregiving duties, some studies focus on the reward and the satisfaction that accompanies providing care, support, and services to older family members. Caregivers of older adults with dementia continued to report greater caregiver reward than burden even as the ADL assistance needs of the older adults increased (Heru & Ryan, 2006). For caregivers of older adults with SMI, caregiver health and perceived reward were associated with lower caregiver depression (Cummings & Kropf, 2015). Family caregivers of older adults in Texas described increased intimacy in their relationship with care recipients, personal growth, and, in the wake of a care recipient's death, comfort that the care provided was the best that could have been offered (Mastel-Smith & Stanley-Hermanns, 2012).

Across multiple ethnic groups in California, cultural views on family and caregiving framed caregivers experiences of happiness, feelings of fulfillment, and gratitude for the opportunity to develop a deep emotional commitment to the care recipient (Scharlach et al., 2006). For specific cultural groups (Chinese, Native American), caregiving was additionally described as part of ethnic traditions that afforded the transmission of cultural values across the generations (Scharlach et al., 2006). Ethnically Chinese American caregivers of older adults offered filial piety (as opposed to financial reasons) as the justification for providing care at home, invoking ideas about tradition and cultural practice (Thai et al., 2015). Among middle age (40–60 years) adults, Black parents were more likely than White parents to be caring for their own parents, even when accounting for caregiver resources and care recipient needs (Fingerman et al., 2011). However, the strongest predictors of parental care, regardless of race, were caregiver reward and sense of familial obligation (Fingerman et al., 2011).

For spousal caregivers, older wives experienced more happiness providing care than doing chores, whereas, for older husbands, there was no significant relationship between chores and happiness nor spousal care and happiness. Negative well-being was related to the work of caring rather than a spouse's disability status, with no relationship found between well-being and spousal disability (as distinct from providing care for a spouse; Freedman, Cornman, & Carr, 2014).

In one study, caregivers of older adults with major depressive disorder reported less overall burden (at the trend level) and significantly less

depression-specific burden after older adults received depression medication for 6 weeks. During the course of the study, one half of the older adults remitted and their caregivers experienced significant reduction in caregiver burden whereas caregivers of those who did not remit, had no change (Martire et al., 2010).

In one study of consumer-directed support programs, family involvement was associated with increased caregiver satisfaction with services, perceived competence of case worker, as well as greater access to services for care recipients (Neely-Barnes et al., 2008). Family caregivers for adults with IDD participating in a self-directed program had the greatest satisfaction when siblings were hired as the personal support worker, with parents and other family members close behind, and agency workers associated with the least satisfaction (Heller et al., 2012).

**Financial opportunities.** Family members hired as caregivers under the Arkansas Cash & Counseling Demonstration and Evaluation (CCDE) reported positive benefits including paid work, training in a field that might lead to future employment, flexible work schedule, and an opportunity to get closer to a family member. This program also provided the benefit of freeing up time for unpaid family caregivers to return to work (or other activities) while they coordinated the provision of care through a paid nonfamily caregiver (San Antonio et al., 2010).

### ***Question 3. Supports utilized by those caring for older adults or in late life***

One-third of studies ( $n = 33$ ) in this review focused exclusively on the supports utilized by older family caregivers and/or those providing care, support, and services to older adults. Collectively, they examined how older caregivers and caregivers of older adults interacted with, benefited from, and expressed unmet need for: Social and emotional support, spiritual practice, support groups, caregiver assistance services, and caregiver education and support interventions.

#### ***Social and emotional support***

Informal social support, in the form of family or friends to help caregivers blow off steam or process emotional moments, was part of modeling the caregiver experience. Informal social networks, including noncaregiving family members (Handley & Hutchinson, 2013; Pernice-Duca, 2010; Seltzer et al., 2011) and friends (Bass et al., 2013; Handley & Hutchinson, 2013; Perkins, 2010; Seltzer et al., 2011), provided caregivers with opportunities for emotional support (Handley & Hutchinson, 2013; Perkins, 2010) and reduced caregiver burden (Bass et al., 2013). However, supports may be more elusive for caregiving men, who have larger familial and smaller friend

networks than women (Pernice-Duca, 2010) and for caregivers of adult children with IDD, who reported fewer confidantes when not coresiding and fewer social visits when they do (Seltzer et al., 2011). Social support was also significantly predicted variance in reported caregiver burden, relationship satisfaction, and mastery for caregivers of individuals with TBI (Hanks et al., 2007).

In terms of emotional support, across both working age (18–64) and old age (65+), the overwhelming majority of caregivers had access to at least some, with only about fewer than one in 10 rarely or never having access to such support (Anderson et al., 2013). By contrast, family and friends of older Veterans with dementia reported limited access to emotional support (Bass et al., 2013). Over an 8-day period, mothers of adolescents and adult children with ASD received emotional support from people in their social network an average of 3 days and provided support to others 1 to 4 days (Smith et al., 2010). African American aunts and grandmothers who were HIV positive who provided informal kinship care identified family members as one of the main forms of emotional support helping them remain resilient (Stokes, 2014).

Across eight ethnically or racially distinct groups (African American, Chinese, Filipino, Hispanic, Korean, Native American, Russian, and Vietnamese), caregivers were more inclined to rely on extended family networks and neighbors than formal caregiving services. In part, this was due to limited knowledge of available services, mistrust of the government and/or service providers, and frustration with the lack of culturally or linguistically appropriate services. For example, in the Hispanic focus group, caregivers lamented the availability of services that affirmed traditional Mexican ways of caregiving (Scharlach et al., 2006).

### *Spiritual practice*

Spirituality took many forms for family caregivers, providing them with comfort, opportunities for reflection, and shared moments of faith with others. Family caregivers of older adults in Texas, identified spirituality as a self-care strategy (Mastel-Smith & Stanley-Hermanns, 2012). Additionally, the Black women who were HIV positive caring for their kin described their relationship with God and the Bible as sources of emotional strength and renewal (Stokes, 2014). And though nearly eight in 10 caregivers for older adults in California engaged in regular prayer or meditation at least once a week, there was great variability by racial ethnic category with Latinos born outside of the United States and African Americans, more connected to spirituality than other racial/ethnic groups (Scharlach et al., 2008).

### **Support groups**

Family caregivers accessed information, social connections, and emotional support via caregiver support groups. In a case study of compound caregiving, Kay, a 60-year-old mother of an adult with Down SYNDROME took on four consecutive additional caregiving roles (her mother-in-law, sister, and parents) while maintaining a parent support group that she founded two decades prior (Perkins, 2010). For fathers of adults with schizophrenia, the National Alliance on Mental Illness (NAMI) was a key provider of support; however, more than one half of the fathers in one study were not members and were not receiving these supports (Ghosh & Greenberg, 2009). One study found that just over one half of Latino caregivers of individuals with mental illness used NAMI services. and when compared to their non-NAMI peers, were less likely to be depressed, believe in folk practices, or identify folk practices, stigma, or *verguenze* (shame) as barriers to service use (Marquez & Ramírez García, 2013).

### **Caregiver assistance services**

Family caregivers across relationship and disability type sought services to help ensure their family members could avoid institutionalization and continue their lives at home and in the community. These services also allowed caregivers to retain employment, gain new skills, and identify and access support groups.

Two studies explored the degree to which family caregivers of older adults utilized a set of 11 caregiver assistance services (organized in five broad categories: Information, help accessing services, training, emotional support, and respite) in their respective states. About one-half of caregivers in Washington state used two or more services and nearly seven in 10 caregivers in California used a minimum of one (Chen et al., 2010; Scharlach et al., 2008).

In Illinois, among older (age 55+) caregivers of adults with IDD, nearly one in five reported unmet need for assistance with day programs and social opportunities for care recipients, homemaker services, routine dental care, and respite service; more than one-fourth needed legal assistance; and one-third access to home modifications (Caldwell, 2008). For caregivers of older adults in Washington state, there was a mismatch between the most frequent types of assistance provided by caregivers (e.g., transportation) and the three most accessed caregiver assistance services (information, respite, systems navigation) indicating an increased likelihood of caregiver unmet need (Chen et al., 2010). Caregiver education was also a concern, based on family caregiver reports of limited training for tasks they frequently and regularly performed, including medication management for older adults and at-home oral care for adults with IDD (Chen et al., 2010; Minihan et al., 2014).

In terms of gender, a qualitative study with husbands caring for their wives with Alzheimer's disease found that the majority used adult day care services

(a form of respite) at least 1 day each week. However, they also accessed other caregiver assistance services, including paid direct support staff, cleaning help, and financial help (i.e., a bookkeeper), as part of a larger strategy to help their wives remain at home (Calasanti & King, 2007).

Although no racial differences in access to caregiver support were found in a diverse sample of caregivers for older adults in California, there were differences in the types of services used: Asian Americans were more likely to use in-home respite and financial services, Whites to participate in support groups, and African American caregivers to use educational resources, respite at nighttime, and legal information (Chow, Auh, Scharlach, Lehning, & Goldstein, 2010). Similar to earlier research, they also found that though White caregivers were more likely to rely on only formal supports, Asian Americans only had access to informal supports, and African Americans had a mix of both (Chow et al., 2010; Scharlach et al., 2006).

### ***Caregiver education and support interventions***

A number of interventions for caregivers of older adults and older caregivers have been piloted, evaluated, and, in some cases, scaled up to the state level. Through these interventions, caregivers gained information, learned new skills, and mitigated caregiver burden and negative outcomes of caregiving. Interventions were focused in four areas: (1) caregiver education, (2) improving problem-solving skills, (3) connecting caregivers through family-led program, and (4) exploring technological innovation.

***Caregiver education.*** After completing a multicomponent intervention delivered in-home and by phone, a racially diverse set of caregivers for older adults with dementia experienced less depression, and for White and Latino/Hispanic caregivers, and Black spousal caregivers, improved quality of life compared to their counterparts in the control group (Belle et al., 2006). With Reducing Disability in Alzheimer's Disease (RDAD), a statewide program in Ohio, caregivers of older adults with dementia reported, on average, four fewer unmet needs after completing 12, one-hour sessions and caregivers who had more exercise-focused sessions experienced greater reductions in relationship and physical strain (Menne et al., 2014).

As part of the randomized clinical trial, Care of Persons with Dementia in their Environments (COPE), caregivers who completed the biobehavioral intervention, which included occupational therapist-provided, home-based sessions, reported significant, positive changes in well-being and confidence at 4 months. At 9 months, COPE participants reported improved understanding of dementia, greater ability to provide care, improved quality of life for those receiving care, and greater ability of keeping these individuals at home (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010).

**Improving problem-solving skills.** Three interventions focused on building constructive problem-solving skills to improve family caregiver outcomes. In randomized clinical trials, all three were found to increase caregiver constructive problem-solving skills and reduce caregiver depression (Berry et al., 2012; Elliott, Berry, & Grant, 2009; Rivera, Elliott, Berry, & Grant, 2008). Family caregivers of older adults with TBI had fewer caregiver health complaints over the 12 months of the intervention (Rivera et al., 2008). Additionally, problem-solving interventions with caregivers of older adults were associated with reduced care recipient depression (Berry et al., 2012).

**Family-led trainings.** Three interventions focused on the role of “experienced” families in providing information and assistance to other families who needed information, planning assistance, and/or emotional support; one focused on aging family caregivers of adults with IDD and two on family caregivers of adults with mental illness. One year later, older family caregivers of adults with IDD who completed a five-session, peer-led intervention on future planning were significantly more likely than the control group to establish a special needs trust, initiate residential planning, develop a letter of intent, and experience reduced caregiver burden (Heller & Caldwell, 2006). Adults with IDD whose caregivers were in the intervention group completed a simultaneous peer-led intervention (with self-advocates from People First) and reported a significant increase in choice-making in their lives (Heller & Caldwell, 2006).

Both interventions for adults with mental illness used standardized curriculum facilitated by family caregivers for family caregivers. Caregivers who completed the intervention Journey of Hope had lower levels of depression, higher emotional role functioning and vitality, and reduced relationship problems with the family member with mental illness (Pickett-Schenk et al., 2006). Caregivers who completed NAMI’s Family to Family intervention had lower levels of depression and decreased worry and displeasure about the family member with mental illness 3 months after the intervention and these benefits were sustained at 9 months postintervention (Lucksted et al., 2013).

**Technological innovation.** Five interventions explored the potential to support family caregivers, at least in part, via technology, including the telephone and, for one study, a wearable distance monitoring device. Caregivers of older Veterans recovering from stroke favorably evaluated parts of a telehealth program aimed at caregivers and care recipients but expressed a desire for more in-home support in the initial weeks poststroke (Lutz, Chumblor, Lyles, Hoffman, & Kobb, 2009). Partners in Dementia Care, a telephone-delivered care coordination intervention for caregivers of older Veterans with dementia, was associated with reduced caregiver unmet need and depression, and increased support services utilization, as well as greater access to informal helpers,

specifically for caregivers who reported high levels of care recipient behavioral issues (Bass et al., 2013).

Significant decreases in caregiver depression, frustration and burden, reduced sleep problems, increases in social support, and improvements in health status were reported by caregivers of older adults with Alzheimer's disease in Alabama who completed Resources for Enhancing Alzheimer's Caregiver Health (REACH) II, a home-visit and telephone-based intervention (Burgio et al., 2009). A cognitive-behavioral therapy intervention with African American caregivers of older adults with progressive dementia showed moderate improvements in caregiver burden and access to caregiver assistance services for in-person and phone treatment delivery methods but moderate reductions in depression only for in-person treatment (Forducey, Glueckauf, Bergquist, Maheu, & Yutsis, 2012).

Caregivers of older adults expressed mixed emotions about wearable technology that monitors care recipient health from a distance. Although caregivers expressed interest in the potential to reduce burden and anxiety, they also worried about the impact technology would have on the quality of interactions, their relationship with care users, and the boundary issues raised by a technology described as intrusive by one half of the participants (Hall et al., 2014).

#### ***Question 4. Impact of family caregiving in late life on society***

The majority of articles in this review recognized the societal implications of family caregiving in late life in the background and to a lesser extent the conclusion sections. These articles addressed the size of the informal caregiving workforce, demographic trends (e.g., increased longevity and disability in old age, decreased fertility rates), and the labor and economic values of family caregivers. However, only two articles in the review directly examined the societal implications of family caregiving in late life.

Specifically for older Mexican women, larger family size (i.e., adult children) was associated with a decreased risk of institutionalization, highlighting the importance of fertility rates and family size in the familial and macroeconomics of caregiving. However, the opportunity cost experienced by the adult child caregiver was not mediated by family size, marital status of the care recipient, or living near the parent in need of care. Consequently, gendered experiences of caregiving (and the role of the state in supporting women caregivers) and labor force dynamics (reduced work of labor force exits) remain salient issues in understanding the societal costs of family caregiving (Brown et al., 2013).

The curvilinear distribution of asset poverty, wealth, and income by head of household age (as discussed in greater detail in Question 2) has significance for social policy discussions about the federal poverty guideline, financial and

employment support for family caregivers, and access to community living supports across the lifecourse. A socioeconomic approach to family caregiving highlights how individual and family experiences are patterned in ways that affect labor force participation and trajectories, national distribution of assets and wealth, and economic security in old age. Using multiple measures of socioeconomic status (such as ones that connect poverty to the median income) illustrates the relationship between family caregiving, disability, aging, and poverty at the national level (Parish et al., 2010).

## Discussion

Support for family members caring for older adults and care in old age has important public health, economic, and family/community implications. As previously discussed, the consequences and benefits of family caregiving in late life are unevenly distributed across populations by gender, race/ethnicity, and/or care recipient disability type. Additionally, access to informal and formal assistance for family caregivers is influenced by a number of issues at the individual, familial, community, cultural, and social policy levels. Despite the density of research on family caregiving in late life over the last decade, this review illustrates the unevenness of the research across types of disability, family relationship, and family caregiver support services. Future research should address the diversity of family caregivers (e.g., people of color, same-sex couples) and caregiver types (e.g., caregivers beyond parents and spouses, compound caregivers), caregiver changes across time and cohort (i.e., longitudinal research), the lived experience of caregivers (i.e., qualitative methods and analysis), and the similarities and differences between and across caregiver types (i.e., comparative studies).

### *Need for diverse samples*

Given the increasing racial and ethnic composition of the United States, broadly, and of older Americans, in particular, it is imperative that research reflects this diversity (Administration on Aging, 2015; Hayes-Bautista, Hsu, Perez, & Gamboa, 2002). However, nearly one-third of the studies sampled in the 61 studies with multiracial populations were at least 90% White. Across the studies in the review, Native Americans and Asian American/Native Hawaiian/Pacific Islanders were significantly under-represented, and though Latinos fared better, they were still absent from nearly 40% ( $n = 39$ ) of the more diverse samples. Furthermore, given the impact of acculturation on caregiving, it is notable that only four studies focused on the different experiences based on whether caregivers were born in the United States or abroad (Chow et al., 2010; Magaña et al., 2006; Scharlach et al., 2006, 2008). Another consideration for research with diverse populations is identifying an

appropriate comparison group, an issue addressed by Magaña and Smith (2006) in their work on Black and Latina caregiving mothers. Reflecting an intersectional approach, this work affirms the unique positionality of women of color, in their experiences as women, women of color, and caregiving women of color. Future research should include more diverse samples to more closely reflect the racial/ethnic breakdown of the United States and address the ethnic-specific cultural contexts of caregiving with single-group studies (e.g., J.-H. Kim & Knight, 2008).

In addition to racial/ethnic diversity, research on family caregiving in late life needs to acknowledge the lives of lesbian, gay, bisexual, and transgender (LGBT) older adults and their families. The research on spousal caregiving included in this review did not report same-sex couples. Some articles that focused on cohabiting in a broader sense (e.g., Noël-Miller, 2011) leaving open the possibility that some respondents were in same-sex couples, but this was not reflected in the description of the sample or the data analysis. Further, a frequency analysis for the words *gay*, *lesbian*, or *same-sex* of the works cited across all 97 articles included in this review yielded null ( $n = 0$ ) results. Additionally, if people identifying as transgender were present in the samples, they were unable to self-identify given the measures used, and if they were actively excluded, no justification was offered. Future research on caregiving in late life must include and identify LGBT individuals and families within study samples and address the growing literature on LGBT older adults in late life, the disparities they face, and their experiences as caregivers (Brown & Grossman, 2014; Croghan, Moone, & Olson, 2014; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013; The MetLife Mature Market Institute & The American Society on Aging, 2010).

### ***Need for research on new types of caregivers***

Family caregiving is a complex social phenomenon with many manifestations and a lifecourse dynamic that requires attention to caregiving transitions as care recipients age. Consequently, though caregiving work that focuses on mothers, wives, daughters, and daughters-in-law remains critically important, research on family caregiving in late life needs to also encompass other family relations, including men: siblings, aunts and uncles, grandparents, and compound caregivers. In this review, siblings and grandparents were the exclusive focus of one study each and a third study addressed a mixed sample of aunts and grandmothers (Burke et al., 2012; Minkler & Fuller-Thomson, 2005; Stokes, 2014, respectively). These relations are minorly present in a number of mixed caregiver studies (e.g., Berry et al., 2012), however their specific roles in caregiving are highly under-researched. Although research on sibling caregivers has been increasing, the low mean age of these studies made them ineligible for this review, highlighting the over-representation of certain ages and the missed

opportunity to learn about older siblings (Arnold, Heller, & Kramer, 2012; Heller & Kramer, 2009; Hodapp et al., 2010).

Given the important familial role of aunts (or uncles), especially for many ethnic groups, future caregiving research needs to include these family members as participants, addressing the current scarcity of knowledge in this area. And though Minkler and Fuller-Thomson's (2005) work on African American grandparents met the criteria for inclusion in the review, the work of other scholars (e.g., Ruiz, 2000, 2004; Smith-Ruiz, 2008) were not found through searches or reference lists, indicating researchers' limited engagement with this work.

Lastly, family caregiving research needs to more directly embrace and explore the notion of the compound caregiver (Perkins, 2010), an experience that qualitative and/or longitudinal research can easily document (Ghosh et al., 2012; Perkins & Haley, 2010). Future research should pay greater attention to the roles of these other family caregivers and, in particular, explore the complicated trajectories of compound caregivers.

### ***Need for continued longitudinal studies***

Research on aging and people who are aging benefits from longitudinal perspectives, following individuals as they grow, change, and sometimes die. Compared with cross-sectional approaches to family caregiving in late life that compare multiple age categories at one point in time (e.g., the Behavioral Risk Factor Surveillance System or many convenience samples), longitudinal data allows for an understanding of how the same individuals change over time. Research using the Wisconsin Longitudinal Study (e.g., Ghosh & Greenberg, 2009; Seltzer et al., 2011) illustrates the benefit of being able to explore outcomes for the same group of caregivers in mid- and late life. Similarly, the age composition and longitudinal design of the Caregiver Study of Osteoporotic Fractures (e.g., Fredman et al., 2006; Lyons et al., 2015) affords analysis of outcomes at regular intervals, even allowing for comparisons in mortality.

One of the under-recognized benefits of longitudinal research is the ability to chart the experience of cohorts, and potentially to compare across cohorts (e.g., the Greatest Generation, Boomers) as they experience caregiving in mid- and late life. Reimagining some of the cross-sectional studies in this review as longitudinal would provide for insightful comparative analyses, sensitive to particular changes in health and social policy ecologies. For example, as a longitudinal rather than cross-sectional study, Parish et al.'s (2010) research on income and asset poverty could provide not only an analysis of change over time but also differences in cohort experience based on differing policy realities (e.g., years since the Affordable Care Act). Future research should attend to both cohort longitudinal design and specificity, where possible following caregivers prospectively to monitor changes in outcomes.

### ***Need for qualitative research***

Qualitative research provides opportunities to explore the lived experience of aging, the influence of social programs on caregivers, and the daily rewards and hassles of care work. Qualitative research is an important exploratory tool, allowing for an initial engagement with unique perspectives (e.g., LGBT families, U.S. immigrants, siblings in old age). Only 13% of the studies in this review ( $n = 12$ ) employed qualitative methods. In the wake of significant changes in health and family caregiving policy arenas (e.g., National Family Caregivers Support Program, Medicaid home and community-based services Final Rule) over the last decade, there is a need to explore how these changes have affected family sociobehavioral and economic dynamics, as well as the individual experiences of caregivers and care recipients.

Scharlach et al. (2006) stands out as a skillful use of qualitative research methods to address many of the issues raised in this review, using focus groups to explore the differences in caregiving practices, beliefs, and use of caregiving assistance services by racial/ethnic/cultural group. Similarly, Calasanti and King (2007) and, by extension, Calasanti and Bowen, (2006) used interviews and thematic analysis to investigate the gendered differences in spousal caregiving for older adults with dementia and, in the process, identified a new form of care work: maintaining the gendered presentation of one's spouse. San Antonio et al.'s (2010) evaluation of self-directed services for older adults illustrates the utility of qualitative research for programmatic innovation and policy change. Coyle, Putman, Kramer, and Mutchler (2016) employed qualitative research to understand how the social world of care recipients and caregivers is constructed through program implementation of the Aging and Disability Resource Centers (ADRCs) but was not included in the review as respondents were exclusively staff members. Future research should engage qualitative ontologies and methodologies to attend to the experiences of caregivers as respond to social and health policy changes; provide care, services, and support during times of economic downturn; and navigate caregiving in culturally specific contexts and across the spectrum of acculturation.

### ***Need for comparative research***

The majority of studies in this review included multiple reasons for receiving care (i.e., impairment/disability types) and also multiple caregiver types (e.g., parents, spouses, and friends). However, very few of these studies engaged in comparisons across either disability or caregiver type. When data allows, comparisons of this sort have the potential to identify the uniqueness of caregiving trajectories and the need for programs that are responsive to these experiences (see Ghosh et al., 2012, regarding differences in the likelihood of

caregiver's spouses developing disability, and Heller et al., 2012, regarding caregiver satisfaction and mental health, as well as care recipient outcomes). Additionally, a limited number of studies included care recipients and caregivers—and when included, care recipients were approached in terms of outcomes rather than experiences. San Antonio et al. (2010) and Heller et al. (2012), both of which assessed consumer-directed programs, offer an alternate approach highlighting care recipient perspectives alongside those of caregivers.

### **Limitations**

Despite attempts to provide a comprehensive picture of the literature on aging, disability, and family caregiving, this review has limitations. First, the literature included in the review is constrained by the search terms used. In particular, the use of *disability/ies* as a broad search term, rather than terms for specific impairments (e.g., spinal cord injury) or chronic illnesses (e.g., diabetes) potentially excluded literature that might inform our understanding of family caregiving in late life. Limiting the review to research from the past decade means the review may have missed topics that have received more attention in the past, as well as classic intervention, policy, and behavioral research on these issues. Demonstrating familiarity with the multiple subfields within the disability, aging, and family caregiving services and policy research areas presented another challenge and may have limited the scope and presentation of this review. Additionally, balancing specificity (i.e., in terms of population) with the drive to generate meaningful synthesis in this review may have resulted in a less compact or integrated text. Lastly, space limitations left little room for discussion of theoretical frameworks, instrumentation, or operationalizing relevant caregiving concepts. We recommend future reviews address these issues in relation to specific caregiver types and in comparative discussions.

### **Summary**

In mid- and late life, family caregivers are an important source of informal support for older adults and adults with disabilities who are aging. Broadly speaking, family caregiving involves a variety of care, service, and support provision; encompasses many different relationship types; relates to multiple experiences of disability and impairment; and includes people of all races and ethnicities. In the United States, research on family caregiving remains conflicted about the ways in which caregiving can be helpful or harmful to caregivers' physical and mental health, whereas the economic impacts and need for supports are clearer. In this review, we explored the last decade of research on family caregiving in late life and identified areas for future

development, including research that: includes more diverse samples and caregiver types, engages longitudinal data to analyze changes over time, employs qualitative methods to illuminate lived experiences, and explores differences across caregiver types.

## Funding

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