



CARE AND CARING: An Interdependent Relationship

The Health Impact of Caring
Evidence Brief

January 2023



International Alliance
of Carer Organizations

Building a global understanding and respect for the vital role of carers

About the International Alliance of Carer Organizations

The International Alliance of Carer Organizations (IACO) is a global network of carer organizations dedicated to providing strategic leadership to establish a global understanding and recognition of the essential role of carers. Through partnerships, advocacy, and knowledge translation we strengthen and honour the voice of carers. www.internationalcarers.org

IACO MEMBERS

[Association Française des Aidants \(France\)](#) (formed in 2003) advocates for the recognition of the role of caregivers, address caregiver-related issues and directly support caregivers.

[Care Alliance Ireland](#) (established in 1995) is a national network of 95 voluntary organisations supporting family carers by providing information, developing research and policy and sharing resources.

[Caregivers Israel](#) (established in 2014) is a non-profit organization that is committed to raising public awareness to the caregiving issue; to recognising and supporting Israel's family caregivers.

[Carers Australia](#) (established in 1993) is the national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a national level.

[Carers Canada](#) (established in 2000) is a national coalition dedicated to increasing awareness, recognition, and support for caregivers. Carers Canada is a priority program of the Canadian Home Care Association (CHCA).

[Carers Denmark](#) (established in 2014) works to improve the conditions of life for carers themselves, irrespective of the diagnoses or handicaps of those for whom they care through collaborates with others working on health policy—nationally and internationally.

[Carers Finland](#) (established in 1991) is an advocacy and support association for carers with a mission to improve the social status of families in informal care situations by influencing legislation and public opinion.

[Carers Hong Kong](#) (established in 2018) is advised by caregivers and patients' groups, cross-sectoral professional bodies and NGOs to promote better policies and quality services for caregivers' selfless.

[Carers Japan](#) (established in 2010) aims to raise public awareness of family carer issues and solve problems faced by carers through advocacy, research, policy recommendations, enlightenment and provision of information and advice to carers.

[Carers New Zealand](#) (established in 1995) is the country's peak body supporting family, whānau and aiga carers. It assists a direct network of 50,000+ carers and partner organisations. .

[Carers UK](#) (established in 1965) supports carers and provides information and advice about caring, influences policy through research based on carers' real-life experiences, and campaigns to make life better for carers.

[Carers Worldwide](#) (established in 2012) works with family carers in low- and middle-income countries. It aims to improve support, services, and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, or disabled, or who has mental health problems.

[Swedish Family Care Competence Centre](#) (established in 2008) is commissioned by the Ministry of Health and Social Affairs via the National Board of Health and Welfare Sweden is a centre of excellence for family care.

[Taiwan Association of Family Caregivers](#) (established in 1996) is dedicated to advocating for family caregivers' rights in Taiwan.

[The National Alliance for Caregiving \(NAC\)](#) (founded in 1996) envisions a society that values, supports and empowers family caregivers in the United States to thrive at home, work and life.

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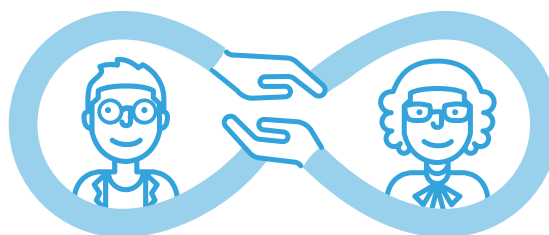
EXECUTIVE SUMMARY

The International Alliance of Carer Organizations (IACO) is a global coalition dedicated to providing strategic leadership and advocacy to increase awareness, recognition and supports for carers. Through our international engagement and knowledge translation, IACO brings visibility to the unique needs of carers and leading practices in carer specific policies and programming.

In every country around the world, individuals with disabilities, chronic health issues or frailty rely on unpaid care from family and friends. Referred to as carers, family carers or caregivers, these individuals take on a range of caring roles including helping with daily activities, providing emotional support, providing complex medical care, being an advocate and navigating health and social care service systems. With the population ageing faster than ever before, carers are the greatest source of ongoing care for older people. Their ongoing dedication and care can have a significant impact on the health, well-being and involvement of older adults within their communities.

While care recipients are more often the focus of health and social care delivery providers, effective programmes require an equal emphasis on ensuring the unique vulnerabilities of carers are considered and supported. In the absence of appropriate supports to ensure carers' well-being, there is a high potential for serious negative health outcomes with unintended consequence such as inappropriate hospitalizations, acute exacerbations, worsening quality of life and unplanned sickness for both care recipients and carers.

To achieve positive health outcomes and quality of life for both carers and care recipients, a better understanding of their interdependent relationship and key well-being variables is required.



A core element in IACO's five-year strategic plan is to increase understanding of the impact and influence carers have on care recipients' health outcomes, health and social care systems and economies. This evidence brief was commissioned to advance this goal and gain a greater insight into the impact of caring on caregivers. To delve deeper into the dynamics of care and caring, members of the IACO identified a broader need to specifically understand the impact of caring on the health of both carers and care recipients. To this end, two parallel literature searches were conducted to explore key research questions:

- What is the impact of caring on the health of carers?
- What is the impact of caring on the health of care recipients?

As a first step in understanding this dynamic, this evidence brief presents the results of a scan of online databases addressing the research questions. Using a rigorous screening process, the search yielded 22 papers that address the impact of caring on the health of carers and only one paper on the impact of caring on the health of care recipients. This paper discusses the key themes and conclusions of both topics. The main findings of the scan include the following:

1. The physical and mental health impact of caring on carers can be negative or positive depending on many factors related to carers and care recipients.

- Methods to measure the impact were mixed, with some studies relying on biomarkers, while others used objective measures and predictive indicators (e.g., increased risk for depression among carers).

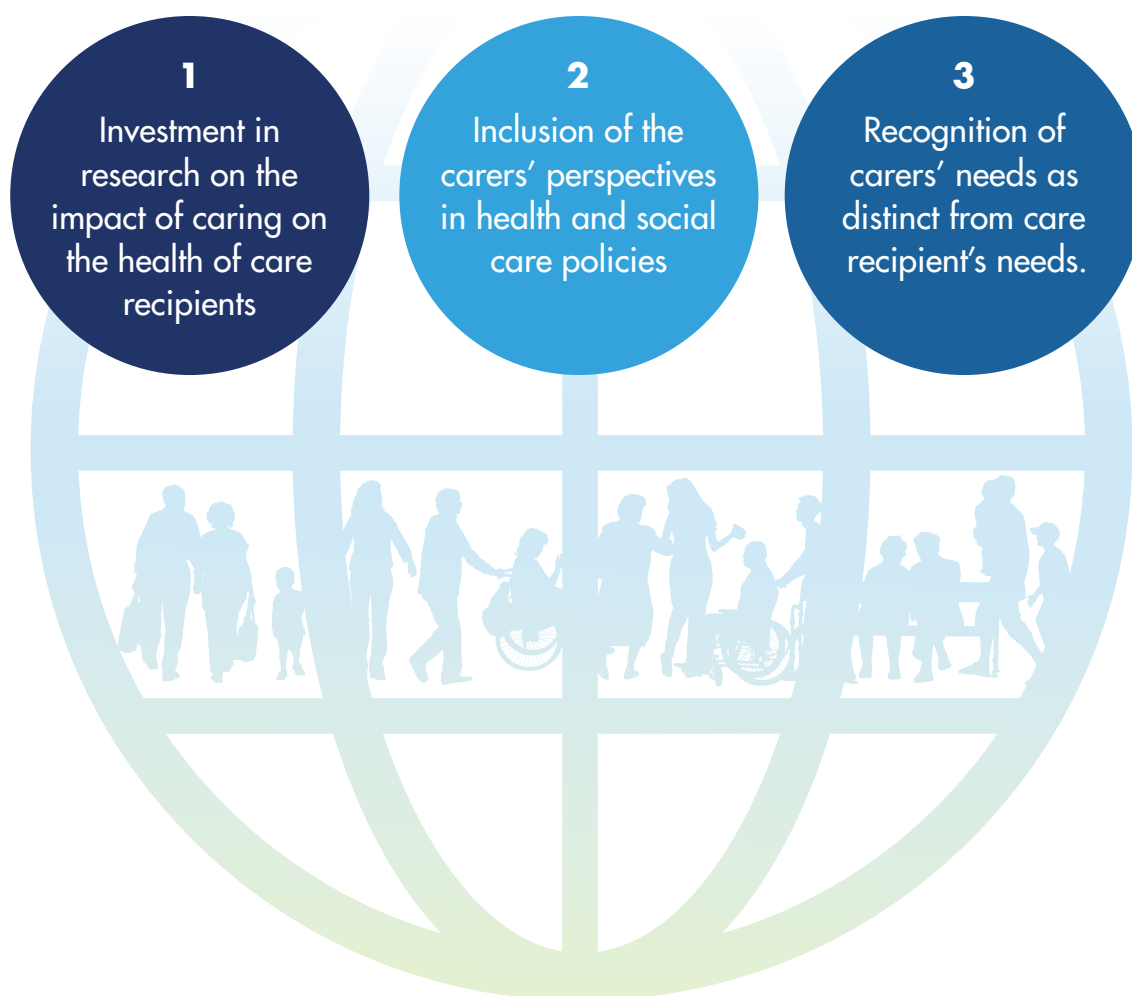
2. Varies by:

- Carer traits
 - GENDER: female carers experience more mental health difficulties, while male carers experience more physical health difficulties.
 - AGE: Older carers and millennial carers report the greatest declines in health.
 - ETHNICITY AND INCOME: Minority populations and low-income populations experience worse declines in self-rated health.
- The care provided
 - Increases in duration and intensity of care are associated with increases in negative physical and mental health effects for carers.
- The diagnosis of care recipients
 - Carers of individuals with dementia, Alzheimer's disease and cancer are at higher risk for negative health impacts.

3. There is a scarcity of research examining the impact of caring on the health of care recipients.

Creating policies and programming that support the well-being of care recipients and carers requires understanding that their journeys are linked across time. The interdependent nature of the caring relationship influences their needs as individuals who receive care and individuals who provide practical help, encouragement and support. Effective policies and programming must achieve a balance of dependence and independence in addressing the needs of care recipients and caregivers.

This evidence brief provides initial insights into key well-being variables and will be used as an evidence-based foundation for actions to address the universal needs of carers around the globe. It will be used to inform decision makers about the role and impact of caring; and a call-to-action in achieving the vision of a global understanding and recognition of the essential role of carers with respect to care recipients, health and social care systems and society:





INTRODUCTION

To delve deeper into the dynamics of care and caring, members of the IACO identified a broader need to understand the impact of caring on the health of both carers and care recipients. The concept of health is characterised as the measurable physical and mental health of carers, whether it be changes in biomarkers or symptoms of depression.

This evidence brief examines the health impact of caring and how it has been measured in the literature. The two questions explored are:

What is the the impact of caring?



	On the health of carers	On the health of care recipients
Population	Carers of all ages	Carer recipients of all ages
Intervention	Caring	Receiving care
Outcome	Positive, negative and neutral health impacts on carers	Positive, negative and neutral health impacts on care recipients

For the purposes of this brief, a carer is defined as an unpaid individual, such as a family member, neighbour, friend or other significant individual, who takes on a caring role to support someone with a physical disability, a debilitating cognitive condition or a chronic life-limiting illness. The terms caregiver, family caregiver and carer are used interchangeably by IACO members.

RESEARCH QUESTION # 1

What is the impact of caring on the health of carers?

SEARCH STRATEGY AND RESULTS

Under the guidance of the IACO Advocacy and Policy Standing Committee, P Moores Consulting conducted a literature search and analysis in late 2020. The search included the following databases: PubMed, Cochrane Review, Health Systems Evidence, Social Systems Evidence and Google. Only sources published from 2015 to 2020 were included in order to focus on the most recent and relevant evidence. Table 1 displays the search terms used.

Table 1: Search Terms – Carers

Research Question Term	MeSH Headings	Keywords and Synonyms
Home Care	Home nursing (MeSH) Entry terms: non-professional home care, nonprofessional home care	Homecare (home, homes) Domiciliary (domicile) Residential Out-of-hospital Community*
Carer	Caregivers (MeSH) Entry terms: care givers, carers, family caregivers, spouse caregivers	Caretak* Custodian Home help
Health Outcomes	Health status (MeSH) Entry terms: level of health	Health effect* Health impact* Health change*

Sources were included if they:

- examined carers of any age caring for care recipients of any age;
- focussed on direct measures of physical health and/or mental health;
- examined positive, negative and neutral health impacts; and
- objectively measured health or self-rated health.

Sources were excluded if they:

- focussed on programmes directed toward educating or training carers;
- examined carers' experiences with the health care system;
- measured changes in carers' health behaviours (e.g., healthy eating, smoking);
- examined caregiver burden or strain without measuring the health impact; or
- examined caregiver quality of life without including specific health measures.

A total of 22 sources passed the screening and are included in this review:

- 3 synthesized sources (e.g., systematic reviews)
- 12 peer-reviewed single studies (e.g., academic journal articles)
- 7 grey literature sources (e.g., reports, book chapters)

The sources included in the review¹ involved sources or study samples from the United States (10), worldwide (5), Europe (5), Japan (4), Germany (3), Canada (2), Republic of Korea (2), Netherlands (1), United Kingdom (1), Sweden (1), Belgium (1) and Australia (1). See Appendix A for an overview of each source. Table 2 displays the number of titles screened, the number of titles that passed abstract review and the number of titles that passed the full text screening to be included in this paper.

Table 2: Search Results – Carers

Search	Titles Screened	Abstract Review	Full Text Screen
PubMed	833	99	11
Cochrane Reviews	90	0	0
Health Systems Evidence & Social Systems Evidence	172	31	1
Google	113	24	15
IACO Recommended	9	4	4
Total			31
Failed Full-Text Screen			9
Passed Full-Text Screen – Included in Brief			22

In addition, this evidence brief was guided by the IACO Policy and Stakeholder Relations Committee, consisting of Carers UK, Carers Canada, Carers Japan, Carers Hong Kong and Carers Denmark. The Committee provided input on the research questions, literature search strategy, sources to be included and analysis.

¹ Totals reflect studies included within synthesised sources.

FINDINGS

Findings from the sources are divided into two major categories:

1 Impact of caring on the health of carers: physical health, mental health and mortality

2 Factors that influence the health impact of carers: carer subpopulations, intensity and duration of care, care recipients' health conditions

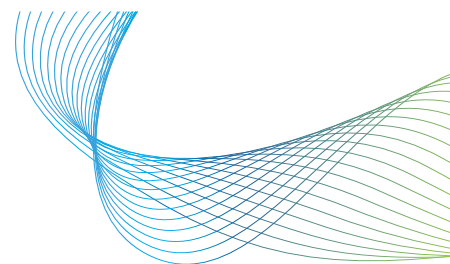
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The physical and mental health impact of caring can be negative or positive depending on many factors related to carers and care recipients.


Overall, results were mixed in terms of the general impact of caring on carers' health. For example, a systematic review found that no clear conclusion could be drawn regarding the longer-term effects of informal caring on carers' health (Bom et al., 2019a). However, many other sources reported on the general negative impact of caring on carer health. Carers show higher levels of depression and physical health issues when compared to non-carers, and also have lower scores on health indexes such as the BlueCross BlueShield Health Index (BlueCross BlueShield Association, 2020). Carers also self-rate their health as poorer compared to non-carers (Committee on Family Caregiving for Older Adults et al., 2016). A recent study found that carers' health declines over time no matter how many hours of care they provide, their income-level, their marital status and whether or not they have a choice in assuming the carer role (National Alliance for Caregiving, 2020). That being said, other studies report mental and physical health benefits to carers because of their caring experience (American Psychological Association, 2015).

Specific to the impact of caring on physical health, studies have attempted to measure differences in specific health measures. A report from the American Psychological Association described biomarker studies comparing carers to non-carers. These studies reported abnormalities in measures of endocrine and immune system function, but were limited by small samples or because they focussed on specific carers (e.g., carers of people with dementia) (American Psychological Association, 2015).

What is the impact of caring?




In terms of the impact of caring on mental health, peer-reviewed studies often report the negative impact of informal caring on mental health based on the strong foundation of academic literature that indicates carers are more likely than non-carers to report symptoms of depression and other indicators of psychological distress (Roth et al., 2015; Committee on Family Caregiving for Older Adults et al., 2016).

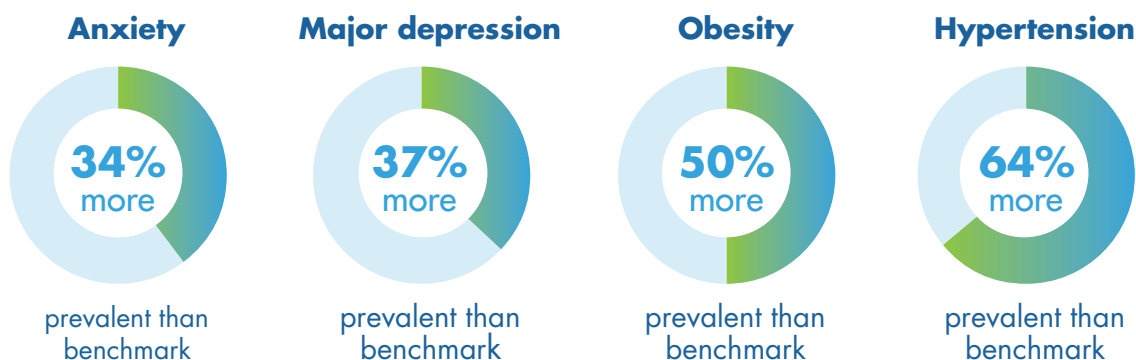
 A study from the Netherlands examined the mental and physical health impact of providing informal care. Using the Mental Components Summary Scale (MCS), the results indicated that there is only a negative impact on mental health, but that the effect is small compared to the mean MCS score. However, this study also found that a severe illness occurring in a family member causes a “family effect” and decreases the MCS score to one similar to carers. As a result, it is difficult to uncouple the impact of caring from the impact of having a family member with a severe illness. A similar result was found for spousal caring (Bom et al: 2019b). Statistically significant but small negative mental health effects were also found using longitudinal data from the elderly population in Europe (Heger, 2017).


Carers who cease care after the care recipient has died experience more depressive symptoms than those who cease their caregiving role after the recipient no longer has functional limitations or continues to have functional limitations. Those with more depressive symptoms at baseline also have more depressive symptoms at follow-up. Care recipients entering a nursing home during care also results in more depressive symptoms for carers, which is further exacerbated by the number of instrumental activities of daily living (IADL) limitations and the number of health conditions of care recipients (Perone et al., 2019).

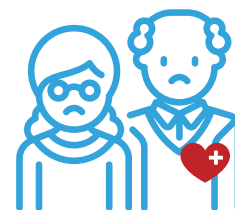


Increases in duration and intensity of care are associated with increases in negative physical and mental health effects for carers.

 A national study of carers in the United States observed an increase in stress-related physical and behavioural health conditions in addition to depression, which are 37 percent more prevalent in carers (BlueCross BlueShield Association, 2020). The findings include the following:



 A study from Sweden comparing the life situation after a stroke in patient–informal caregiver relationships. During the first post-stroke year the study found that increases in anxiety in either the carer or the care recipient impacts the other (Olai et al., 2019).



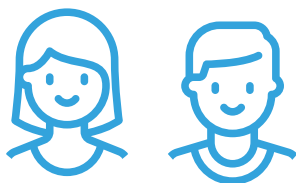
A limited number of sources have examined the impact of informal care on the mortality of carers. The results are mixed, but are generally positive. A literature review found increased mortality among older spousal carers, but only if they reported emotional strain because of caring. The same review, however, included many sources that reported the opposite effect—that carers have lower mortality rates (Committee on Family Caregiving for Older Adults et al., 2016). A positive impact on the mortality of carers was also found in recent population-based studies (American Psychological Association, 2015). Another study reported an 18 percent survival advantage for carers over a six-year period (Roth et al., 2015). Regardless, other studies have found no significant difference in the mortality of carers versus non-carers (Miyawaki et al., 2019; Roth et al., 2015).

CARER TRAITS

In an effort to make sense of the mixed higher-level results about the health impact of caring, many studies have focussed on specific subpopulations of carers such as males and females, and carers of different ages, ethnicities and household incomes. For instance, studies have found the impact of caring impacts males and females differently. A systematic review of studies aimed at estimating the causal effect of informal caregiving on the health of various subgroups of caregivers found that health effects are larger for or only found in females (Bom et al., 2019a). Another study found that the caregiving effect and the family effect only impact the mental health of females, whereas males experience a physical health decline in response to informal caring (Bom et al., 2019b). A study examining self-rated health also found more positive mental health scores in male carers and more positive physical health scores in female carers (Penning & Wu, 2016).

Research shows that the age of carers influences the health impact of providing care. Older adults providing care to their spouses are more likely to present with frailty and use antidepressants than carers of younger ages (Potier et al., 2018). Another review noted how older adults in caring roles are especially at risk of health issues as the role taxes their health, leading to compromised immune response systems and exacerbation of existing chronic conditions (American Psychological Association, 2018).

Studies also show that the health impact of caring is stronger among millennial carers. American carers from this age group were found to have 60 percent more anxiety than the benchmark, 64 percent more major depression, 74 percent more obesity and 82 percent more hypertension (BlueCross BlueShield Association, 2020). Another U.S. study found a similar impact on millennial carers: 22 percent rated their health as fair or poor in 2020, versus 14 percent in 2015 (National Alliance for Caregiving, 2020).



Female carers experience more mental health difficulties, while male carers experience more physical health difficulties.

These two studies from the United States also examined the health impact of caring according to ethnicity. One study found that the health impact is much larger in communities with a majority Black population and to a lesser extent Hispanic population as compared to majority white communities (BlueCross BlueShield Association, 2020). The other study found that Hispanic and Asian American carers had significant declines in self-rated health from 2015 to 2020 (National Alliance for Caregiving, 2020).

Only one study has examined the health impact of carers' household income. The results indicated that household income is associated with only small differences in the health of carers (BlueCross BlueShield Association, 2020).

TYPE OF CARE

A worldwide review of the association between caring and depression found that caring is associated with higher rates of depression. This impact is more prevalent among middle-aged carers and carers with a larger number of caregiving activities (Koyanagi et al., 2018). Caring is also associated with the consumption of antidepressants (Potier et al., 2018) and experiencing more mentally unhealthy days (National Association of Chronic Disease Directors, 2018).

The research studies included in this brief indicates the health impact of two additional factors: caring intensity and duration. A systematic review of studies aimed at estimating the causal effect of informal caregiving on the health of various subgroups of caregivers found larger health effects when more intensive care (e.g., wound care vs. housecleaning) is provided. However, it also noted that the overall findings in the literature are mixed (Bom et al, 2019a). Results from an American study of carers found that carers in more intense care situations had the greatest declines in self-rated health between 2015 and 2020. These include carers who have no help at all and carers who live with their care recipient (National Alliance for Caregiving, 2020).

The duration of care also impacts the health of carers. A study of the mental and physical health impact of providing care found that providing at least eight hours of care per week has a considerably larger negative health impact on carers than providing less than eight hours of care per week (Bom et al., 2019b). Results from the American Cancer Society National Quality of Life Survey for Caregivers found that carers of a person with a cancer diagnosis have larger increases in depressive symptoms after five years of caring as opposed to those caring for an individual in remission or who has passed away (Committee on Family Caregiving for Older Adults et al., 2016).

CARE RECIPIENT'S DIAGNOSIS

Many research studies have examined the health impact of care recipients' medical conditions on carers. The most common condition found to negatively impact the health of carers is dementia. Carers of individuals with dementia report more stress, poorer health and higher rates of depression than other carers (American Psychological Association, 2015; Bauer & Sousa-Poza, 2016; Committee on Family Caregiving for Older Adults et al., 2016; Roth et al., 2015). Care recipient behavioural problems associated with dementia (e.g., disruptive and aggressive behaviour), physical and cognitive impairment and time spent caring increase depressive symptoms in carers (Bauer & Sousa-Poza, 2016). A study of carers of those with Alzheimer's disease or dementia in Japan showed similar outcomes, with carers reporting lower physical and mental health scores and more frequent anxiety, hypertension and diabetes (Goren et al., 2016).

Carers of cancer patients have also been found to have higher rates of depression, with factors such as carers' health, economic situation and duration of care exaggerating this impact (Geng et al., 2018). Caring for a child with a developmental disability is also associated with greater ill health, with the largest association for mixed developmental disabilities and the smallest for Down syndrome (Masfield et al., 2020).

A study assessing family caregivers of patients with Alzheimer's disease or dementia in Japan found that caregivers experience greater depression, whether through greater severity, greater frequency of major depressive disorder or greater likelihood of self-reported depression diagnosis in comparison to non-caregivers (Goren et al., 2016). These findings are echoed by other studies, which have found high proportions of negative mental health impacts among carers. For example, a Canadian longitudinal cohort study examined changes in carers' health at three, six and 12 months of caring. The study found that more than half of the carers were at risk for clinical depression at the beginning of the study, and over time the percentage of carers at risk for depression continued to be higher than the lifetime prevalence of depression in the Canadian population. The study also found that reporting a positive effect from caring is related to carers' feelings of success or access to support (Grigorovich et al., 2017).



Carers of individuals with dementia, Alzheimer's disease and cancer are at higher risk for negative health impacts.

RESEARCH QUESTION # 2

What is the impact of caring on the health of care recipients?

SEARCH STRATEGY AND RESULTS

During the development of this evidence brief, a parallel literature search was conducted to examine the health impact on care recipients of receiving informal care. A literature search was conducted of the following databases: PubMed, Cochrane Review, Health Systems Evidence, Social Systems Evidence and Google. Table 3 displays the search terms used.

Table 3: Search Terms – Care Recipients

Research Question Term	Medical Subject (MeSH) Headings	Keywords and Synonyms
Home Care	Home Nursing (MeSH) Entry terms: non-professional home care, nonprofessional home care	Homecare (home, homes) Domiciliary (domicile) Residential Out-of-hospital Community*
Carer	Patients (MeSH) – Entry terms: clients Outpatients (MeSH) – Entry terms: out-patients	N/A – no other keywords
Health Outcomes	Health status (MeSH) Entry terms: level of health	Health effect* Health impact* Health change*

Originally, only sources published from 2015 to 2020 were included, but a lack of results required extending the time period to 2010. Table 4 displays the number of titles screened, the number of titles that passed abstract review and the number that passed the full-text screening to be included in this paper. Only a single source passed the screening to be included in this review. This source involves a synthesized literature review that includes studies predominantly from North America (44.4 percent) and Europe (39.5 percent).

Studies were excluded from this search if they focussed on:

- interventions to improve caregiver health; or
- the impact of home care versus other care venues.

Table 4: Search Results – Care Recipients

Search	Titles Screened	Abstract Review	Full Text Screen
PubMed	94	4	1
From Carers Search	N/A	1	1
Cochrane Reviews	90	0	0
HSE/SSE	11	1	0
Grey Literature	90	28	6
Total			8
Failed Full-Text Screen			7
Passed Full-Text Screen – Included in Brief			1

FINDINGS

The one study that passed full-text screening is a systematic review that aimed to synthesize the evidence on the impact of informal caregiver distress on the health outcomes of community-dwelling dementia care recipients. The review found that caregiver distress from caring for someone with dementia is associated with the end of home care and the institutionalisation of the dementia care recipient. Caregiver distress is also associated with increases in the care recipient's behavioural and psychological symptoms of dementia (Stall et al., 2019).

There are a few possible explanations for the lack of literature in this area. First, many of the sources that passed the abstract review focus on comparing outcomes of home-based care with care at other health care settings. While these findings provide a glimpse of the health impact of caring on care recipients, the studies do not separate the effect on carers from that on professional home care staff. Second, many studies on home care recipient health outcomes focus on measures of quality of life as opposed to specific health measures.

Limitation of findings

This evidence brief is limited by the language of publication as it is biased toward American publications. The measurement of health status is not always important in many caring situations, especially palliative care, thus there are fewer studies looking at this issue than in other areas (e.g., carer burden and strain).

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- Stall, N.M., Kim, S.J., Hardacre, K.A., Shah, P.S., Straus, S.E., Bronskill, S.E., Lix, L.M., Bell, C.M. & Rochon, P.A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *Journal of the American Geriatrics Society*, 67(3), 609-617.

APPENDIX A: DATA EXTRACTION TABLES

CITATION
American Psychological Association. (2015). Mental and physical health effects of family caregiving. Retrieved from www.apa.org/pi/about/publications/caregivers/faq/health-effects .
YEAR
2015
JURISDICTION
United States
FOCUS OF SOURCE
Provides an overview of the mental and physical health effects of caring.
RESEARCH SUMMARY
<p>Meta-analyses of the physical and mental health effects of caregiving show higher levels of depression and physical health problems in caregivers when compared with non-caregivers.</p> <p>In Pinquart and Sörensen's review, effect sizes (differences between caregivers and non-caregivers) for all studies were .58 standard deviation units (SDUs) for measures of depression and .18 SDUs for measures of physical health, with caregivers having higher depression and worse health.</p> <p>A widely-cited, landmark population-based study of caregiving (Schulz & Beach, 1999) indicated that spouse caregivers who report strain are at risk for premature mortality. This study has been cited incorrectly by many scholars, policy groups and caregiver websites to suggest that all caregivers are at risk of heightened mortality (Brown & Brown, 2014; Roth et al., in press). Five more recent population-based studies of caregiving and mortality, all with larger sample sizes than Schulz & Beach (2009), report the opposite effect, with caregivers living longer than non-caregivers (See Roth et al. in press for a review).</p> <p>Biomarker studies comparing caregivers and non-caregivers (see Lovell & Wetherell, 2011 for a review) often report that caregivers have abnormalities in measures of endocrine and immune system function, but nearly all of these studies use small convenience samples and focus on dementia caregivers (Roth et al., in press). Thus evidence is currently mixed as to whether caregiving has generally negative effects on objective indicators of health.</p> <p>Older adults in caregiver roles may be particularly vulnerable because caregiving demands may tax their health and physical abilities and compromise their immune response systems. In addition, the stress associated with caregiving can exacerbate existing chronic health conditions (Navaie-Waliser et al., 2002).</p> <p>Older caregivers may also be at increased risk for unintentional injuries such as falls, cuts, scrapes and bruises that can range from minor to serious. Furthermore, there is evidence that women take on more caregiving tasks, report more care recipient problems and experience more distress due to caregiving than male caregivers.</p> <p>Due to the demands on their time, caregivers may be less likely to engage in preventive health behaviours than non-caregivers and thus neglect their own health (Schulz, 1997) and may be at increased risk for medication use (Vitaliano et al., 2003). Dementia caregivers report more stress and depression than other caregivers (Ory et al., 1999).</p> <p>In summary, population-based studies show that many caregivers do not report high levels of strain, cope successfully with caregiving, report many psychological benefits from caregiving, and may even experience improved health and reduced mortality because of their caregiving experience. However, subgroups of caregivers clearly report higher levels of strain, experience heightened depression, and may show negative health effects from caregiving.</p>

CITATION

Bauer, J.M. & Sousa-Poza, A. (2015). Impacts of informal caregiving and caregiver employment, health, and family. IZA Discussion Paper No. 8851. Retrieved from <http://ftp.iza.org/dp8851.pdf>

YEAR

2015

JURISDICTION

Worldwide

FOCUS OF SOURCE

Examines the impact of caregiving on the caregiver.

RESEARCH SUMMARY

Several meta-analyses that pay particular attention to the psychological implications (e.g., Schulz et al., 1990, 1995; Pinquart & Sörensen 2003a, 2003b, 2006; Savage & Bailey 2004) indicate that the majority of studies have found a negative association between caregiving and psychological measures.

In a subsequent review, Schulz et al. (1995) focussed on 41 papers, published between 1989 and 1995, that examine the well-being effects of caring for dementia patients, a form of care that places a high burden on the caregiver. Their general conclusion is that providing care for dementia patients leads to higher levels of depressive symptoms (see also Etters et al., 2008).

They found overall evidence that behavioural problems (e.g., disruptive and aggressive behaviour), physical and cognitive impairment, and the time spent on caregiving place a burden on caregivers and increase symptoms of depression. Behavioural problems are particularly important when caring for care recipients with dementia.

This finding is supported by Black and Almeida's (2004) review of associations between behavioural and psychological symptoms of dementia and the burden on caregivers. They found a strong link with caregiver burden but, based on the weak correlation with depression, suggest that the concept of burden might be too broad to identify clinically relevant caregiving outcomes.

An overview by Savage and Bailey (2004) likewise examined the impact of caring on caregivers' mental health, but clusters relevant papers according to different factors associated with caregiver burden. They found that the care relationship is an important factor for mental health outcomes, with closer relationships inducing more positive outcomes for caregivers. They also found evidence that mental impairment among care recipients negatively affects caregivers' well-being. The amount of informal care provision increases the probability of feeling burdened and directly decreases well-being.

This literature shows, however, that physical health outcomes can be linked to informal caregiving through the following dynamics: (a) caregiving often requires physically demanding work over a longer duration, which might cause musculoskeletal injuries and aggravation of arthritis and other chronic illnesses; (b) caregivers tend to neglect a healthy lifestyle (e.g., diet and exercise); and (c) caregiving increases stress and lowers psychological health, which is likely to manifest in such physical outcomes as hypertension and cardiovascular disease (Pinquart & Sörensen 2007).

The most severe physical impairments can be found among caregivers who are older, male or in charge of patients with dementia. This risk group is slightly different from those identified in the psychological health research, where women in particular perceive a higher cost of caring (Raschick & Ingersoll-Dayton, 2004).

The general association between informal care and worse health is demonstrated by Legg et al. (2013), who employed U.K. census data to reveal a significant negative association between care and health that becomes stronger with care hours provided (see also Ugreninov, 2013). Mentzakis et al. (2009) used 14 waves of the British Household Panel (BHPS) to explore the determinants of caregiving. They identified a significant correlation between worse health and the probability that caregivers are providing residential care.

Dementia caregiving, in particular, is associated with a high burden and overall downturns in health, as demonstrated by Schoenmakers et al.'s (2010) meta-analysis of its impact. This supports most of Pinquart and Sörensen's (2007) observations.

In contrast to these mostly negative associations, other studies draw a more ambivalent picture on the impact of caregiving. One possible explanation is that caregiving can also induce a psychological uplift that may increase physical health by enhancing well-being. Another explanation may be self-selection out of the caregiver role when the severity of the physical impairment makes care impossible. In such cases, public support could provide different options for selecting out of the caregiver role when the adverse health effects become too severe or at least reduce the care intensity. Empirical evidence for this notion is provided by Dujardin et al. (2011), who show in a country comparison that a heavy care burden, although more prevalent in Britain than in Belgium, has a less adverse health effect for British caregivers, probably because of the better public support.

O'Reilly et al. (2008) therefore conclude that previous literature underestimates the positive health outcomes associated with caregiving.

CITATION
BlueCross BlueShield Association. (2020). The impact of caregiving on mental and physical health. Retrieved from https://www.bcbs.com/sites/default/files/file-attachments/health-of-america-report/HOA-Caregivers_3.pdf
YEAR
2020
JURISDICTION
United States
FOCUS OF SOURCE
Examines the health impact associated with caregiving among the Blue Cross and Blue Shield (BCBS) commercially insured population.
RESEARCH SUMMARY
<p>As measured by the BCBS Health Index, caregivers had an average Health Index of 89.6 in 2018. This score is 2.2 points lower than the benchmark population, which translates to a 26 percent greater impact of physical and behavioural health conditions that could lower their overall health.</p> <p>In addition to lower overall health, caregivers suffer from more stress-related physical and behavioural health conditions. For example:</p> <ul style="list-style-type: none"> - Anxiety – 34 percent more than benchmark - Major depression – 37 percent more than benchmark - Obesity – 50 percent more than benchmark - Hypertension – 64 percent more than benchmark <p>Compared to the benchmark population, millennial caregivers are more likely to experience stress-related conditions. For example, adjustment disorder and hypertension are 82 percent more prevalent among millennials who are caregivers. They are also much more likely to have adverse health events, including ER visits and hospitalizations. In addition, the increased rates of health</p> <p>conditions among millennial caregivers are more prominent when compared to Gen X and baby boomer caregivers. For example:</p> <ul style="list-style-type: none"> - Anxiety – 60 percent more than benchmark - Major depression – 64 percent more than benchmark - Obesity – 74 percent more than benchmark - Hypertension – 82 percent more than benchmark <p>Demographic factors like race, ethnicity and income are also associated with caregivers' health. As measured by the BCBS Health Index, the health impact of caregiving is much larger in communities with a majority Black population and, to a lesser degree, in communities with a majority Hispanic population when compared to communities with a majority white population.</p> <p>Household income is associated with smaller differences in the health of caregivers. The BCBS Health Index difference between caregivers in low-income communities and the benchmark population in the same communities is only slightly higher than that of middle- and high-income communities.</p>

CITATION
Cohut, M. (2020). How the pandemic is influencing the mental health of caregivers. <i>Medical News Today</i> , MediLexicon International. Retrieved from www.medicalnewstoday.com/articles/heightened-challenges-how-the-pandemic-impacts-caregivers .
YEAR
2020
JURISDICTION
United Kingdom
FOCUS OF SOURCE
Examines the impact of the COVID-19 pandemic on caregivers.
RESEARCH SUMMARY
<p>Each care provider faces different challenges from the outset, depending on the specifics of the condition with which their loved one lives: "The mental health challenges for the carer can [include] lack of sleep because of 24-hour care and the toll that [fatigue] takes on the ability to function, which, in turn, can affect the ability to help with the physical needs of the patient and the effect that can have on the mental well-being of the carer."</p> <p>In addition, "Feelings of failure at not being able to ease the pain and anxiety of the patient can impact on the carer's own self-esteem and sow seeds of doubt that they are not good enough for the job, leading to feelings of guilt and then low mood when depression could take hold."</p> <p>This impact becomes even more serious in the context of a public health emergency, such as the current COVID-19 pandemic. A recent paper in the <i>Journal of Pain and Symptom Management</i> explains how the pandemic is likely to raise the stress levels of family caregivers and affect their mental health. Some of the factors contributing to poorer mental health among caregivers in this period include:</p> <ul style="list-style-type: none"> - an increased sense of isolation and reduced access to official sources of support due to physical distancing measures; - increased financial strain; and - delays or cancellations in formal primary care services for themselves and their loved ones.

CITATION
Bom, J., Bakx, P., Schut, F. & van Doorslaer, E. (2019). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. <i>The Gerontologist</i> , 59(5), e629–e642. NOTE: appraised 4/9 with AMSTAR by McMaster Health Forum
YEAR
2019
JURISDICTION
Australia (1), Europe (4), Germany (2), Japan (2), Korea (Republic of) (2), United States (4)
FOCUS OF REVIEW
Provides an overview of studies aimed at estimating the causal effect of informal caregiving on the health of various subgroups of caregivers.
KEY FINDINGS
<p>All studies reviewed found a short-term negative effect for certain subgroups of caregivers, except for the study by Fukahori and colleagues (2015).</p> <p>The studies estimating mental health effects all found that caregiving might result in a higher prevalence of depressive feelings and lowered mental health scores.</p> <p>Estimates of the physical health impact of informal care were less stable and differed in sign. Many studies found negative physical health effects of caregiving (Coe & Van Houtven, 2009; Do et al., 2015; Goren et al., 2016; Hong et al., 2016; Stroka, 2014; Trivedi et al., 2014; de Zwart et al., 2017). These effects relate to a wide variety of physical health outcomes such as increased drug intake (Stroka, 2014; de Zwart et al., 2017) and pain affecting daily activities (Do et al., 2015).</p> <p>In contrast with these negative effects, Di Novi and colleagues (2015), Trivedi and colleagues (2014), and Coe and Van Houtven (2009) found positive effects of informal caregiving on physical health for some specific subgroups.</p> <p>Studies that separately estimated health effects for males and females have often found that health effects are larger or solely present for females (Heger, 2017; Stroka, 2014; de Zwart et al., 2017).</p> <p>The intensity of provided care appears to be another source of heterogeneity in the health effects of caregiving. Various studies compare average or moderate caregivers with intensive caregivers based on the hours of care provision. These studies (Brenna & Di Novi, 2016; Heger, 2017; Stroka, 2014) found larger health effects when more intensive care is provided.</p> <p>A clear conclusion regarding the longer-term effects of informal caregiving cannot yet be drawn. As all studies used survey data, many were unable to estimate longer-term caregiving effects. Only five studies estimated effects over a longer period (Coe & Van Houtven, 2009; Kenny et al., 2014; Rosso et al., 2015; Schmitz & Westphal 2015; de Zwart et al., 2017). Both Schmitz and Westphal (2015) and de Zwart and colleagues (2017) did not find any longer-term effects of informal caregiving on health.</p> <p>Kenny and colleagues (2014) found negative health effects two years after the start of caregiving for working female caregivers and positive effects for nonworking caregiving males.</p> <p>The study by Coe and Van Houtven (2009) is the only one that compared persons who stopped providing care to persons who continued caregiving for two more years. They found negative mental health effects for females and negative physical health effects for males who continue caregiving.</p> <p>The studies included in this review indicate that there is a causal negative effect of caregiving on health. This caregiving effect can manifest itself both in mental and physical health effects. Interestingly, the presence and intensity of these health effects differ strongly by subgroup of caregivers. Female and married caregivers, along with those providing intensive care, appear to experience more negative health effects from caregiving. These groups might have several other responsibilities on top of caregiving duties, thereby being more strongly affected by the caregiving tasks.</p>

CITATION
American Psychological Association. (2015). Mental and physical health effects of family caregiving. Retrieved from www.apa.org/pi/about/publications/caregivers/faq/health-effects .
YEAR
2015
JURISDICTION
United States
FOCUS OF SOURCE
Provides an overview of the mental and physical health effects of caring.
RESEARCH SUMMARY
<p>Meta-analyses of the physical and mental health effects of caregiving show higher levels of depression and physical health problems in caregivers when compared with non-caregivers.</p> <p>In Pinquart and Sörensen's review, effect sizes (differences between caregivers and non-caregivers) for all studies were .58 standard deviation units (SDUs) for measures of depression and .18 SDUs for measures of physical health, with caregivers having higher depression and worse health.</p> <p>A widely-cited, landmark population-based study of caregiving (Schulz & Beach, 1999) indicated that spouse caregivers who report strain are at risk for premature mortality. This study has been cited incorrectly by many scholars, policy groups and caregiver websites to suggest that all caregivers are at risk of heightened mortality (Brown & Brown, 2014; Roth et al., in press). Five more recent population-based studies of caregiving and mortality, all with larger sample sizes than Schulz & Beach (2009), report the opposite effect, with caregivers living longer than non-caregivers (See Roth et al. in press for a review).</p> <p>Biomarker studies comparing caregivers and non-caregivers (see Lovell & Wetherell, 2011 for a review) often report that caregivers have abnormalities in measures of endocrine and immune system function, but nearly all of these studies use small convenience samples and focus on dementia caregivers (Roth et al., in press). Thus evidence is currently mixed as to whether caregiving has generally negative effects on objective indicators of health.</p> <p>Older adults in caregiver roles may be particularly vulnerable because caregiving demands may tax their health and physical abilities and compromise their immune response systems. In addition, the stress associated with caregiving can exacerbate existing chronic health conditions (Navaie-Waliser et al., 2002).</p> <p>Older caregivers may also be at increased risk for unintentional injuries such as falls, cuts, scrapes and bruises that can range from minor to serious. Furthermore, there is evidence that women take on more caregiving tasks, report more care recipient problems and experience more distress due to caregiving than male caregivers.</p> <p>Due to the demands on their time, caregivers may be less likely to engage in preventive health behaviours than non-caregivers and thus neglect their own health (Schulz, 1997) and may be at increased risk for medication use (Vitaliano et al., 2003). Dementia caregivers report more stress and depression than other caregivers (Ory et al., 1999).</p> <p>In summary, population-based studies show that many caregivers do not report high levels of strain, cope successfully with caregiving, report many psychological benefits from caregiving, and may even experience improved health and reduced mortality because of their caregiving experience. However, subgroups of caregivers clearly report higher levels of strain, experience heightened depression, and may show negative health effects from caregiving.</p>

CITATION
Bauer, J.M. & Sousa-Poza, A. (2015). Impacts of informal caregiving and caregiver employment, health, and family. IZA Discussion Paper No. 8851. Retrieved from http://ftp.iza.org/dp8851.pdf
YEAR
2015
JURISDICTION
Worldwide
FOCUS OF SOURCE
Examines the impact of caregiving on the caregiver.
RESEARCH SUMMARY
<p>Several meta-analyses that pay particular attention to the psychological implications (e.g., Schulz et al., 1990, 1995; Pinquart & Sörensen 2003a, 2003b, 2006; Savage & Bailey 2004) indicate that the majority of studies have found a negative association between caregiving and psychological measures.</p> <p>In a subsequent review, Schulz et al. (1995) focussed on 41 papers, published between 1989 and 1995, that examine the well-being effects of caring for dementia patients, a form of care that places a high burden on the caregiver. Their general conclusion is that providing care for dementia patients leads to higher levels of depressive symptoms (see also Etters et al., 2008).</p> <p>They found overall evidence that behavioural problems (e.g., disruptive and aggressive behaviour), physical and cognitive impairment, and the time spent on caregiving place a burden on caregivers and increase symptoms of depression. Behavioural problems are particularly important when caring for care recipients with dementia.</p> <p>This finding is supported by Black and Almeida's (2004) review of associations between behavioural and psychological symptoms of dementia and the burden on caregivers. They found a strong link with caregiver burden but, based on the weak correlation with depression, suggest that the concept of burden might be too broad to identify clinically relevant caregiving outcomes.</p> <p>An overview by Savage and Bailey (2004) likewise examined the impact of caring on caregivers' mental health, but clusters relevant papers according to different factors associated with caregiver burden. They found that the care relationship is an important factor for mental health outcomes, with closer relationships inducing more positive outcomes for caregivers. They also found evidence that mental impairment among care recipients negatively affects caregivers' well-being. The amount of informal care provision increases the probability of feeling burdened and directly decreases well-being.</p> <p>This literature shows, however, that physical health outcomes can be linked to informal caregiving through the following dynamics: (a) caregiving often requires physically demanding work over a longer duration, which might cause musculoskeletal injuries and aggravation of arthritis and other chronic illnesses; (b) caregivers tend to neglect a healthy lifestyle (e.g., diet and exercise); and (c) caregiving increases stress and lowers psychological health, which is likely to manifest in such physical outcomes as hypertension and cardiovascular disease (Pinquart & Sörensen 2007).</p> <p>The most severe physical impairments can be found among caregivers who are older, male or in charge of patients with dementia. This risk group is slightly different from those identified in the psychological health research, where women in particular perceive a higher cost of caring (Raschick & Ingersoll-Dayton, 2004).</p> <p>The general association between informal care and worse health is demonstrated by Legg et al. (2013), who employed U.K. census data to reveal a significant negative association between care and health that becomes stronger with care hours provided (see also Ugreninov, 2013). Mentzakis et al. (2009) used 14 waves of the British Household Panel (BHPS) to explore the determinants of caregiving. They identified a significant correlation between worse health and the probability that caregivers are providing residential care.</p> <p>Dementia caregiving, in particular, is associated with a high burden and overall downturns in health, as demonstrated by Schoenmakers et al.'s (2010) meta-analysis of its impact. This supports most of Pinquart and Sörensen's (2007) observations.</p> <p>In contrast to these mostly negative associations, other studies draw a more ambivalent picture on the impact of caregiving. One possible explanation is that caregiving can also induce a psychological uplift that may increase physical health by enhancing well-being. Another explanation may be self-selection out of the caregiver role when the severity of the physical impairment makes care impossible. In such cases, public support could provide different options for selecting out of the caregiver role when the adverse health effects become too severe or at least reduce the care intensity. Empirical evidence for this notion is provided by Dujardin et al. (2011), who show in a country comparison that a heavy care burden, although more prevalent in Britain than in Belgium, has a less adverse health effect for British caregivers, probably because of the better public support.</p> <p>O'Reilly et al. (2008) therefore conclude that previous literature underestimates the positive health outcomes associated with caregiving.</p>

CITATION

Bom, J., Bakx, P., Schut, F. & van Doorslaer, E. (2019). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *The Gerontologist*, 59(5), e629–e642.

NOTE: appraised 4/9 with AMSTAR by McMaster Health Forum

YEAR

2019

JURISDICTION

Australia (1), Europe (4), Germany (2), Japan (2), Korea (Republic of) (2), United States (4)

FOCUS OF REVIEW

Provides an overview of studies aimed at estimating the causal effect of informal caregiving on the health of various subgroups of caregivers.

KEY FINDINGS

All studies reviewed found a short-term negative effect for certain subgroups of caregivers, except for the study by Fukahori and colleagues (2015).

The studies estimating mental health effects all found that caregiving might result in a higher prevalence of depressive feelings and lowered mental health scores.

Estimates of the physical health impact of informal care were less stable and differed in sign. Many studies found negative physical health effects of caregiving (Coe & Van Houtven, 2009; Do et al., 2015; Goren et al., 2016; Hong et al., 2016; Stroka, 2014; Trivedi et al., 2014; de Zwart et al., 2017). These effects relate to a wide variety of physical health outcomes such as increased drug intake (Stroka, 2014; de Zwart et al., 2017) and pain affecting daily activities (Do et al., 2015).

In contrast with these negative effects, Di Novi and colleagues (2015), Trivedi and colleagues (2014), and Coe and Van Houtven (2009) found positive effects of informal caregiving on physical health for some specific subgroups.

Studies that separately estimated health effects for males and females have often found that health effects are larger or solely present for females (Heger, 2017; Stroka, 2014; de Zwart et al., 2017).

The intensity of provided care appears to be another source of heterogeneity in the health effects of caregiving. Various studies compare average or moderate caregivers with intensive caregivers based on the hours of care provision. These studies (Brenna & Di Novi, 2016; Heger, 2017; Stroka, 2014) found larger health effects when more intensive care is provided.

A clear conclusion regarding the longer-term effects of informal caregiving cannot yet be drawn. As all studies used survey data, many were unable to estimate longer-term caregiving effects. Only five studies estimated effects over a longer period (Coe & Van Houtven, 2009; Kenny et al., 2014; Rosso et al., 2015; Schmitz & Westphal 2015; de Zwart et al., 2017). Both Schmitz and Westphal (2015) and de Zwart and colleagues (2017) did not find any longer-term effects of informal caregiving on health.

Kenny and colleagues (2014) found negative health effects two years after the start of caregiving for working female caregivers and positive effects for nonworking caregiving males.

The study by Coe and Van Houtven (2009) is the only one that compared persons who stopped providing care to persons who continued caregiving for two more years. They found negative mental health effects for females and negative physical health effects for males who continue caregiving.

The studies included in this review indicate that there is a causal negative effect of caregiving on health. This caregiving effect can manifest itself both in mental and physical health effects. Interestingly, the presence and intensity of these health effects differ strongly by subgroup of caregivers. Female and married caregivers, along with those providing intensive care, appear to experience more negative health effects from caregiving. These groups might have several other responsibilities on top of caregiving duties, thereby being more strongly affected by the caregiving tasks.

CITATION
Bom, J., Bakx, P., Schut, F. & van Doorslaer, E. (2019). Health effects of caring for and about parents and spouses. <i>The Journal of Economics and Ageing</i> , 14(C).
YEAR
2019
JURISDICTION
Netherlands
FOCUS OF REVIEW
Examines the mental and physical health impact of providing informal care and disentangles the caregiving effect—the effect of caring <i>for</i> someone in need—from the family effect—the effect of caring <i>about</i> someone in need.
RESEARCH SUMMARY
<p>The researchers used the Dutch <i>Study on Transitions in Employment, Ability and Motivation</i> (STREAM) panel survey, which includes four annual waves of data from 2010 to 2013. It collects extensive information on determinants of transitions into and out of employment and of work productivity among persons aged 45–64 years. This is also the age group providing most informal care in the Netherlands (Gezondheidsmonitor, 2016). The STREAM sample is stratified at baseline on age and work status and is drawn from an existing Internet panel (Ybema et al., 2014). The sample at baseline consisted of 4,400 males and 3,528 females; across all waves, there were 17,055 male and 13,693 female observations.</p> <p>SF-12 Health Survey, which includes questions regarding health during the past four weeks, was used to derive two subscales: the Physical Component Summary Scale (PCS) and the Mental Component Summary Scale (MCS). Both scales range from 0 to 100, where a higher score equals a better health status (Ware et al., 1995). The researchers also captured two specific aspects of health that are particularly likely to be affected by caregiving: fatigue and depression. They measured fatigue using the SF-36 vitality subscale (0–100) based on responses to four items, where a higher score indicates lower fatigue/higher vitality (Ware et al., 1993). To measure depression, they used the CES-D-10 scale (0–30). A higher score indicates increased presence of depressive symptoms (Andresen et al., 1994).</p> <p>The estimation results suggest that informal caregiving only has a negative effect on mental health as measured by the MCS. The effect is small compared to the mean MCS score (only about 1 percent). The researchers also observed significant family effects on mental health: a severe illness occurring to a family member leads to a significant decrease in the mental health score of about the same size as the caregiving effect and to a significant increase in depressed feelings. Only changes in a few other covariates (i.e., having financial difficulties, being employed and having mother alive) were associated with health changes.</p> <p>The family effect and the caregiving effect differ by gender; both the caregiving effect and the family effect only affect the mental health of females. Males, by contrast, experience a physical health decline in response to informal caregiving. This difference does not seem to be driven by hours spent caring, since male and female caregivers in the sample devoted roughly the same amount of time to care.</p> <p>The impact of informal care on mental health and vitality is considerably larger for individuals who provide at least eight hours of care per week (31 percent of the caregivers provide at least this amount) than for those providing less than eight hours of care per week.</p> <p>The caregiving effect is larger when caring for a spouse rather than someone else. Spousal caregiving especially affects vitality and depression scores. These effects are substantial; this type of caregiving relates to a change of more than 10 percent in the average CES-D-10 score. There is also a difference in terms of the family effect; a severe illness of a spouse has a negative effect on mental health and vitality scores and increases depression scores, but these effects are absent when a parent or other close family member falls ill.</p>

CITATION

Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine, Schultz, R. & Eden, J. (Eds.). (2016). Family caregiving roles and impacts. In *Families Caring for an Ageing America*. Washington, DC: National Academies Press. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK396398/>

YEAR

2016

JURISDICTION

United States

FOCUS OF SOURCE

Explores the health impacts of family caregiving.

RESEARCH SUMMARY

The negative psychological effects of caregiving span a continuum ranging from the perception that caregiving is stressful or burdensome, to symptoms of depression and/or anxiety, to clinical depression diagnosed by a health professional, to impaired quality of life (Schulz & Sherwood, 2008; Zarit et al., 1980).

A large and robust literature documents higher rates of psychological distress among caregivers compared with non-caregiver comparison groups. Evidence has been steadily accumulating since one of the earliest reviews by Schulz and colleagues (1995), and now includes individual clinical studies, multiple systematic reviews (e.g., Cuijpers, 2005; Pinquart & Sörensen, 2003), and a number of population-based epidemiological studies (Capistrant, 2016; Wolff et al., 2016).

The prevalence of negative psychological effects among caregivers indicates that large segments of the caregiving population experience adverse effects. For example, 26 percent of all caregivers and 29 percent of those caring for the most disabled older adults report substantial emotional difficulties in NSOC (Spillman et al., 2014). In addition, 13 percent of all caregivers and 15 percent of those caring for the most disabled older adults report symptoms of anxiety and depression. In a study of caregivers of individuals who experienced a stroke, Haley and colleagues (2009) found that 14 percent of stroke caregivers report clinically significant levels of depression. Even higher rates of depression are found in those caring for the dementia population. In a systematic review of 10 studies in this population, the prevalence rate for depressive disorders is 22.3 percent using standardised diagnostic criteria (Cuijpers, 2005). Among cancer caregivers, 25 percent report clinically meaningful levels of depressive symptoms two years after the care recipient's diagnosis (Girgis et al., 2013; Kim et al., 2014).

A meta-analysis of 84 studies found that caregivers experience more depression and stress and less general subjective well-being than non-caregivers (Pinquart & Sörensen, 2003). Although differences in psychological well-being between whites and racial and ethnic subgroups are generally small, several systematic reviews report that African-American caregivers tend to report lower levels of caregiver burden and depression than white, non-Hispanic caregivers, while Hispanic and Asian-American caregivers report more depression than white caregivers (Nápoles et al., 2010; Pinquart & Sörensen, 2005). In a systematic review, Cuijpers (2005) found that the relative risk for clinical depression among dementia caregivers compared with non-caregivers in six studies ranged from 2.80 to 38.68. In an analysis of data from the prospective Nurses' Health Study, women who provide 36 or more hours of care per week to a disabled spouse are nearly six times more likely than non-caregivers to experience depressive or anxious symptoms (Cannuscio et al., 2002).

However, caregiving over a long period of time may also have negative psychological effects. The American Cancer Society National Quality of Life Survey for Caregivers, which includes follow-up assessments two and five years after cancer diagnosis, found that those who are still caregiving at five years have the largest increase in depressive symptoms and the poorest quality of life when compared to caregivers for recipients now in remission or bereaved caregivers of recipients who have died (Kim et al., 2014). Among the group that was still caregiving, the level of clinically meaningful depressive symptoms rises from 28 percent at two years to 42 percent at five years (Kim et al., 2014).

A different longitudinal pattern was found in the stroke population, suggesting that the impact of caregiving over time may vary across clinical populations. In the Caring for Adults Recovering from the Effects of Stroke (CARES) study, caregivers at nine months after a stroke have significantly higher depressive symptoms than non-caregiving controls. However, this difference decreases over time, suggesting that caregivers are able to adapt to caregiving demands that remain relatively stable over time (Haley et al., 2015).

Positive psychological effects may mitigate some of the negative effects of caregiving, as several studies have found that positive effects are associated with lower levels of burden and depression and better overall mental health. For example, van der Lee and colleagues (2014) found that a sense of competence or self-efficacy is associated with less caregiver burden and greater mental health, while Kim and colleagues (2007) found that caregivers' esteem from caregiving is associated with lower psychological distress and better mental functioning.

Caregivers tend to rate their health as poorer than non-caregivers. Caregivers for older care recipients consistently report poorer subjective health status than non-caregivers (Berglund et al., 2015; Pinquart & Sörensen, 2003). Poorer caregiver physical health is closely associated with greater caregiver burden and depressive symptoms and is associated to a lesser degree with hours of care provided, the number of caregiving tasks, months in the caregiver role, as well as the physical, cognitive and behavioural impairments and problems of the care recipient (Pinquart and Sörensen, 2007).

Family caregivers in England responding to a national survey of users of primary care services also report poorer health and a worse primary care individual experience compared with non-caregiver individuals with similar demographics, including age, gender, ethnicity and level of social deprivation (Persson et al., 2015). In NSOC, 20 percent of all caregivers and 39 percent of caregivers of high-need older adults reported that they experience a substantial level of physical difficulty. Sleep problems affect more than 40 percent of caregivers and are highly correlated with reports of substantial negative effects of caregiving (Spillman et al., 2014).

Using the Health and Retirement Study (HRS), a large representative sample of U.S. adults, Capistrant and colleagues (2012) found that being a spousal caregiver independently predicts incident cardiovascular disease. Longer-term caregivers have twice the risk of short-term caregivers. However, this effect was observed only among white caregivers, not among non-white caregivers. Ji and colleagues (2012) reported similar results for spousal caregivers of persons with cancer. After cancer diagnosis in their spouse, the risk of coronary heart disease (CHD) and stroke are higher in both male spouse and female spouse caregivers when compared to males and females without an affected spouse. These effects are more pronounced when the type of cancer has a high mortality rate, such as pancreatic and lung cancers. These findings suggest that psychological distress associated with the diagnosis may play a role in the risk of CHD and stroke.

Also based on data from the HRS collected between 1998 and 2010, Dassel and Carr (2014) showed that spousal caregivers of persons with dementia are significantly more likely to experience increased frailty (i.e., unintentional weight loss, self-reported exhaustion, weakness, slow walking speed and low physical activity [as defined by Fried et al., 2001]) over time when compared to non-dementia spousal caregivers. Similarly, a systematic review of 192 articles focussed on cancer caregiving (1990–2008) found that the most prevalent problems for caregivers include sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite and weight loss (Stenberg et al., 2010).

One of the consistent themes in the caregiver health-effects literature concerns the role of caregiver strain in predicting negative health effects (Schulz et al., 1997), including mortality. Schulz and Beach (1999) found increased risk of mortality (63 percent) among older spousal caregivers, but only if they reported emotional strain in the caregiving role. Perkins and colleagues (2013) reported similar results showing that caregivers who report high levels of caregiving strain have an excess 55 percent mortality risk when compared with those reporting no stress. Living with a person with Parkinson's disease five years after first Parkinson hospitalization is associated with higher risk of all-cause mortality for both male and female spouses in a study by Nielsen and colleagues (2014).

In contrast to these studies, several recent population-based studies suggest the opposite—that caregiving is associated with lower mortality risk (Brown et al., 2009). Fredman and colleagues (2015) found a 26 percent lower mortality risk among older adult caregivers when compared to non-caregivers, and several U.S. census-based studies show lower mortality rates among caregivers (O'Reilly et al., 2008; O'Reilly et al., 2015; Ramsay et al., 2013). These opposing perspectives on caregiving and mortality may be explained by the fact that negative impact studies are typically based on vulnerable, older, strained caregiving spouses providing intense levels of care, while studies reporting positive effects focus on all caregivers regardless of age of caregiver, relationship to the care recipient, or type and amount of care provided.

In a meta-analysis of the literature in this area, Vitaliano and colleagues (2003) found moderately sized statistically significant differences between dementia caregivers and controls, indicating more adverse effects among dementia caregivers. Subsequent studies have shown an increased risk of cardiometabolic changes and increased Framingham Coronary Heart Disease Risk Scores in dementia caregivers as well as proinflammatory changes and accelerated ageing of the immune system (i.e., telomere erosion) (Damjanovic et al., 2007; Haley et al., 2010; Kiecolt-Glaser et al., 2003; Mausbach et al., 2007; von Känel et al., 2008).

CITATION
Geng, H.-M., Chuang, D.-M., Yang, F., Yang, Y., Liu, W.-M., Liu, L.-H. & Tian, H.-M. (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. <i>Medicine (Baltimore)</i> , 97(39), e11863.
YEAR
2018
JURISDICTION OF INCLUDED STUDIES
30 studies – country not reported – labelled as “worldwide”
FOCUS OF REVIEW
Estimates the prevalence rate of depression in cancer patient caregivers and identifies factors affecting depression and quality of life of cancer caregivers.
RESEARCH SUMMARY
<p>21,149 caregivers were appraised in these studies. Age of the caregivers was 52.65 years and 31.14 percent were men.</p> <p>The prevalence of depression in cancer caregivers is 42.30 percent. The weighted average depression scores measured with any psychometric tool are also above depression threshold for each of the tools used. The prevalence of anxiety in this population is 46.56%.</p> <p>Factors associated positively with depressive symptoms include patient’s condition; caregiver’s sleep quality; caregiver’s avoidance; caregiving burden; duration of caregiving; spouse caregiver; caregiver being unemployed; caregiver with chronic disease; caregiver’s financial problems; and caregiver’s female sex. Factors associated negatively with depressive symptoms include overall quality of life of caregiver; pre-loss grief; caregiver’s education level; caregiver’s age; caregiver’s sense of coherence; caregiver’s bondage with patient; and caregiver’s social support.</p> <p>The study found that the prevalence of anxiety and depression in cancer patient caregivers is high and quality of life of caregivers is low. Whereas the presence of cancer itself has been found to be a dominant source of depression and anxiety in caregivers, several other factors may exaggerate the symptoms, including the relationship and communication between caregiver and patient; caregiver’s social, economic and psychological attributes; caregiver’s health; and caregiving duration.</p>

CITATION
Goren, A., Montgomery, W., Kahle-Wroblewski, K., Nakamura, T. & Ueda, K. (2016). Impact of caring for persons with Alzheimer’s disease or dementia on caregivers’ health outcomes: findings from a community based survey in Japan. <i>BMC Geriatrics</i> , 16, 122.
YEAR
2016
JURISDICTION
Japan
FOCUS OF STUDY
Assesses how family caregivers for patients with Alzheimer’s disease (AD) or dementia in Japan differ from non-caregivers in characteristics and health outcomes (i.e., comorbidities, health-related quality of life [HRQoL], productivity and resource use).
RESEARCH SUMMARY
<p>A total of 1,302 unique (i.e., non-duplicated) caregivers for an adult relative with AD or dementia were compared with 53,758 non-caregivers (i.e., those not currently caring for an adult relative with any condition) from the 2012 and 2013 National Health and Wellness Survey in Japan, for a total $n=55,060$. Comparisons were made on: comorbidities (including Patient Health Questionnaire (PHQ-9) cut-off scores suggesting presence/absence of major depressive disorder (MDD)); Work Productivity and Activity Impairment (WPAI), SF-36v2-based HRQoL; and use of healthcare resources. Sociodemographic characteristics, health characteristics and behaviours, and Charlson comorbidity index (CCI) scores were compared across groups. Propensity matching, based on scores generated from a logistic regression predicting caregiving, was used to match caregivers with non-caregivers with similar likelihood of being caregivers. Bivariate comparisons across matched groups served to estimate outcome differences due to caregiving.</p> <p>With respect to baseline characteristics, compared to non-caregivers, caregivers were on average older, female, married/partnered, frequent alcohol drinkers, current smokers and exercisers, had higher average CCI scores and were less likely to be employed. Caregivers were also more likely to have health insurance, greater education, higher income and fewer children in the household.</p> <p>Compared to non-caregivers, caregivers experience greater depression, whether demonstrated in higher PHQ-9 scores (indicating greater severity, greater frequency of MDD), or by a greater likelihood of a self-reported diagnosis with depression. Caregivers also report more frequent insomnia, anxiety, hypertension, pain and diabetes.</p> <p>Caregivers experience significantly lower health utilities, reaching the MID for meaningfully poorer HRQoL. Caregivers also have significantly lower PCS and MCS scores, indicating poorer physical and mental health status, respectively.</p> <p>The study also found that across a majority of health outcome measures, caregivers experience significantly greater burden than non-caregivers, even after matching them with non-caregivers with very similar baseline characteristics. Caregivers also experience greater frequency of comorbidities, including depression, insomnia, anxiety and pain, compared with non-caregivers.</p>

CITATION
Grigorovich A., Lee, A., Ross, H., Woodend, A., Forde, S. & Camerin, J.I. (2017). A longitudinal view of factors that influence the emotional well-being of family caregivers to individuals with heart failure. <i>Aging & Mental Health</i> , 21(8), 844-850.
YEAR
2017
JURISDICTION
Canada
FOCUS OF STUDY
Examines changes in caregivers' well-being over time and identifies patient and caregiver factors associated with positive and negative outcomes.
RESEARCH SUMMARY
<p>Using a longitudinal reported measures design, this study focused on PHF (person with heart failure) who were admitted to hospital and participated in a pharmaceutical management intervention ("Seamless pharmaceutical care for patients with heart failure"), and their family caregivers from one urban hospital in Ontario.</p> <p>At baseline, caregivers had cared for the PHF an average of 18 months. Over half of the sample (27 caregivers, 54 percent) reported symptoms of depression above the clinical cutoff (Patten et al., 2006) and over half of the sample (34 caregivers, 68 percent) reported levels of positive affect equal to or above the population mean (>31.1) (Crawford & Henry, 2004). A comparison between the characteristics of PHF in the study sample and PHF in the pharmaceutical trial revealed that participants recruited for the caregiver study were representative of the larger patient population in terms of their demographics and health-related quality of life; however a smaller percentage of them had comorbidity.</p> <p>The unconditional growth model showed that caregivers' level of depression symptoms remained stable over the year of follow-up. The full model indicated that caregivers' depression symptoms were significantly associated with more caregiver participation restriction. No patient-reported factors were associated with caregivers' depression symptoms.</p> <p>The unconditional means model provided an estimate of caregivers' mean level of positive affect across all four time points. The unconditional growth model showed that caregivers' level of positive affect remained stable over the year of follow-up. The full model showed that positive affect was significantly associated with caregivers experiencing greater feelings of personal gain and having more social support available.</p> <p>The study indicated that caregivers' negative and positive emotional outcomes remain stable over time and are associated with different caregiver factors. In terms of negative outcomes, over half of caregivers were at risk for clinical depression at the start of the study, and the percentage of caregivers at risk continued to be higher than the lifetime prevalence (12 percent) of depression in the Canadian adult population (Patten et al., 2006) across all time points. Caregivers' depression symptoms were associated with caregivers experiencing difficulties maintaining participation in valued activities. In addition, despite being at risk for clinical depression, a significant proportion of caregivers reported levels of positive affect that were comparable to the general population (Crawford & Henry, 2004). Caregivers' positive affect was associated with their feelings of personal gain and their access to social support.</p> <p>The study suggests that the chronic nature of heart failure may negatively impact the ability of caregivers to cope with their role and maintain emotional well-being, alongside their other life roles. In particular, the findings underscore the importance of screening for depression in caregivers of people with heart failure across the caregiving trajectory to identify caregivers who may not be able to adapt to their role without additional supports and intervention.</p>

CITATION
Hajek, A., Bock, J.-O. & Konig, H.-H. (2017). Association of informal caregiving with body mass index and frequency of sporting activities: evidence of a population-based study in Germany. <i>BMC Public Health</i> , 17, 755.
YEAR
2017
JURISDICTION
Germany
FOCUS OF STUDY
Examines whether informal caregiving time and type of caregiving activities are associated with body mass index (BMI) and the frequency of sporting activities among informal caregivers.
RESEARCH SUMMARY
<p>DEAS is an ongoing longitudinal, population-based study of the German community-dwelling population in the second half of life (40 years and over). It started in 1996. For this study, the sample was drawn using national probability sampling and was systematically stratified by region (West and East Germany), age and gender.</p> <p>Among the caregivers, 65.1 percent provided help around the house, 83.2 percent looked after their relative, 27.9 percent provided nursing care services and 67.9 percent provided any other type of help. The mean age of all informal caregivers was 63.4 years, with a range from 40 to 91 years. Most (60 percent) were female.</p> <p>There was a statistical significant difference between caregivers who provide nursing care services as compared to those who only provide other types of informal care. The BMI of the group providing nursing care services was about 0.7 kg/m² higher than the BMI of the group not providing nursing care services. In addition, BMI was significantly higher in the group that provided more than five hours of care per week.</p> <p>The provision of nursing care services was associated with an increased BMI of about 0.6 kg/m². For example, for an individual of 1.70 m height performing nursing care services, this increase in BMI equals an increase in weight of about 1.68 kg. Spending more time on providing informal care was associated with an increased BMI; each additional hour per week was associated with a higher BMI of about 0.01 kg/m².</p> <p>With respect to the control variables, female gender, the number of illnesses and net equivalent income per capita were positively associated with BMI, whereas a higher age was negatively associated with BMI.</p> <p>The results show that BMI increases with caregiving time and performing nursing care services, whereas it is not associated with other caregiving activities (e.g., helping around house, looking after someone or any other help).</p>

CITATION
Masefield, S.C., Prady, S.L., Sheldon, T.A., Small, N., Jarvis, S. & Pickett, K.E. (2020). The caregiver health effects of caring for young children with developmental disabilities: a meta-analysis. <i>Maternal and Child Health Journal</i> , 24, 561-574.
YEAR
2020
JURISDICTION
Worldwide
FOCUS OF REVIEW
Assesses the evidence for the effect of caring for young children with developmental disabilities on mothers' health, and the influence of different disability diagnoses and socioeconomic status.
RESEARCH SUMMARY
<p>The meta-analysis included 23 estimates of association from 14 retrospective studies for the outcomes of stress (n=11), depressive symptoms (n=9), general health (n=2) and fatigue (n=1). Caring for a child with a developmental disability was associated with greater ill health. The largest association was for mixed developmental disabilities and smallest for Down syndrome. There was insufficient socioeconomic information to perform subgroup analysis. The small number of studies and data heterogeneity limits the precision of the estimates of association and generalizability of the findings.</p>

CITATION
Heger, D. (2017). The mental health of children providing care to their elderly parent. <i>Health Economics</i> , 26(12), 1617-1629.
YEAR
2017
JURISDICTION
Europe
FOCUS OF STUDY
Estimates the effect of caregiving and the decline of a parent's health on adult children's mental health.
RESEARCH SUMMARY
<p>The researchers uses data from waves 1, 2, 4 and 5 of the SHARE collected in 2004/2005, 2006/2007, 2011/2012 and 2013 covering the population of adults over the age of 50 in Europe. SHARE is the first data set to include a wide variety of health and sociodemographic information of older adults at a pan-European level.</p> <p>The sample was limited to sons and daughters aged 50 to 70 who participated in two or more interviews and who had at least one living parent at the time of their first interview. Countries participating in all four waves are Austria, Germany, Sweden, the Netherlands, Spain, Italy, France, Denmark, Switzerland and Belgium. Greece participated in waves 1 and 2; the Czech Republic participated in waves 2 to 5; and Poland was part of SHARE for wave 2 and 4.</p> <p>The researchers found significant but small negative effects of caregiving for the two outcome measures of mental health for daughters, but no clear pattern with respect to the frequency of care. Caregiving increases daughters' EURO-D score by 0.13 symptoms for weekly caregiving and 0.15 symptoms for any frequency of caregiving. Because more frequent caregiving is less common, the estimated effect becomes statistically insignificant for daily caregiving. The probability of suffering from four or more depressive symptoms increases by approximately 3 percentage points. Again, for daily caregiving, the effect is no longer statistically significant.</p> <p>Sons who provide caregiving experience a slightly smaller increase in the number of depressive symptoms but a similar increase in the probability of suffering from clinical depression for any frequency of care.</p> <p>There are statistically significant but small negative effects of caregiving on mental health for caregiving in general. However, the effect size increases considerably for daughters if caregiving is triggered by the parent's need for care as indicated by only having a single parent. While both sons and daughters respond to their parent's need for care, the additional stress of providing care to a single parent leads to reduced mental health for only daughters.</p>

CITATION
Koyanagi, A., Devylger, J.E., Stubbs, B., Carvalho, A.F., Veronese, N., Haro, J.M. & Santini, Z.I. (2017). Depression, sleep problems, and perceived stress among informal caregivers in 58 low-, middle-, and high-income countries: A cross-sectional analysis of community-based surveys. <i>Journal of Psychiatric Research</i> , 96(2).
YEAR
2018
JURISDICTION
Worldwide
FOCUS OF STUDY
Examines the association of caregiving with depression, sleep problems and perceived stress worldwide.
RESEARCH SUMMARY
<p>The study included 258,793 adults aged 18 or more from predominantly nationally representative samples from 10 high-income countries, 27 middle-income countries and 21 low-income countries that participated in the World Health Survey (WHS).</p> <p>Over all samples, caregiving was associated with significant 1.54 times higher odds for depression and 1.37 times higher odds for sleep problems, while the mean stress score was 3.15 points higher.</p> <p>The strongest association was observed in the middle-aged for depression, and in the youngest for sleep problems and perceived stress.</p> <p>An increasing number of caregiving activities are associated with significantly increased odds for depression and sleep problems as well as higher mean perceived stress scores.</p>

CITATION

National Alliance for Caregiving. (2020). Caregiving in the U.S. 2020 report. Retrieved from https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf

YEAR

2020

JURISDICTION

United States

FOCUS OF SOURCE

Presents a portrait of unpaid family caregivers today. The core areas examined include:

- The prevalence of caregivers in the United States
- Demographic characteristics of caregivers and care recipients
- Caregivers' situations in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of care recipients, and other unpaid and paid help provided
- How caregiving affects caregiver stress, strain and health
- Financial impact on caregivers
- Impacts on and supports provided to working caregivers
- Information needs and resources
- Technology and role of online supports

RESEARCH SUMMARY

Caregiver self-rated health seems to have declined during the past five years; alarmingly, the stress associated with caregiving may exacerbate declines in health that occur with age. Four in 10 caregivers (41 percent) consider their health to be excellent or very good, down significantly from 2015 (48 percent). One in five caregivers say their health is fair or poor (21 percent), up significantly from 2015 (17 percent) and comparable to other research. By comparison, using the same self-rated health measure, the general U.S. population has not seen a comparable decline in self-reported health over the past five years,

The drop-off in caregiver self-rated health since 2015 is happening across most subgroups of caregivers. Caregivers report significantly worse health across all hours of care and ages of recipients; among both low- and high-income caregivers; among all marital statuses; and among both those who had a choice and those who had no choice in providing care.

Some groups of caregivers stand out as having significant declines in self-rated health, while their peers have not. The youngest caregivers—those ages 18 to 49—are less likely to say they are in excellent or very good health (40 percent in 2020 vs. 52 percent in 2015) and are more likely to report having fair or poor health (21 percent in 2020 vs. 15 percent in 2015). The decline seems to be concentrated among millennials, who say they are in worse health now than they were in 2015 (40 percent rating excellent or very good in 2020 vs. 56 percent in 2015, and 22 percent rating their health as fair or poor in 2020 vs. 14 percent in 2015). Other research suggests that generally, as a whole, millennials are experiencing health declines at earlier ages than generations before them, so perhaps millennial caregiver health declines are reflective of overall population health declines among their generation.

Alarmingly, caregivers in the more “demanding” or “intense” care situations have had the greatest slides in self-rated health in the past five years:

- Fewer than four in 10 caregivers who have no other help at all (either paid or unpaid) report having excellent or very good health (36 percent), down from 50 percent in 2015.
- The highest-intensity care situations are experiencing health declines: 35 percent report being in excellent or very good health (down from 42 percent in 2015), while 27 percent report being in fair or poor health (up from 21 percent in 2015).
- Caregivers who live with their care recipient are experiencing health declines (35 percent in excellent or very good health, down from 45 percent in 2015), while those who do not live together are down in health status only slightly.
- Primary caregivers' health is also declining, with just 39 percent reporting excellent or very good health compared to 49 percent in 2015.

Other groups showing significant declines in self-rated health include the following:

- Hispanic caregivers (35 percent rate their own health as excellent or very good vs. 51 percent in 2015)
- Asian-American caregivers (41 percent vs. 60 percent in 2015)
- Women caregivers (40 percent, down from 48 percent in 2015)
- Working caregivers generally (46 percent vs. 53 percent in 2015), and “full-time” working caregivers specifically (47 percent of those working 30 hours or more vs. 54 percent in 2015)
- Caregivers with a high school diploma or less education (31 percent vs. 43 percent in 2015)
- Caregivers who do not live in a rural area (42 percent vs. 50 percent in 2015)
- Those caring for a spouse/partner (32 percent excellent or very good vs. 45 percent in 2015) and caring for a relative other than a parent (40 percent vs. 53 percent in 2015)

Groups that rate themselves in better health include the following:

- White caregivers (45 percent rate their own health as excellent or very good), compared to African-American (34 percent) or Hispanic (35 percent) caregivers
- Caregivers who feel they had a choice in taking on their role (45 percent rating excellent or very good vs. 38 percent had no choice)
- Higher-income caregivers (47 percent in excellent or very good health vs. 31 percent of those with less than \$50,000 in household income)
- More educated caregivers (51 percent of those with a college degree or higher vs. 41 percent of those with some college vs. 31 percent of those with a high school diploma or less)

At the other end of the health spectrum, caregivers who more often self-rate as being in fair or poor health include:

- Those who feel alone (30 percent vs. 16 percent of those who do not feel alone)
- Caregivers who live with their care recipient (27 percent vs. 16 percent of those not living together)
- Those in high-intensity caregiving situations (27 percent vs. 16 percent in medium- to low-intensity situations)
- Primary caregivers (23 percent vs. 16 percent non-primary)

While seven out of 10 caregivers feel that providing care has not affected their own health (72 percent), nearly one out of four feel that caregiving has made their health worse (23 percent).

Half of those who feel alone feel that caregiving has made their health worse (50 percent), compared to just 13 percent of those who do not feel alone.

Caregivers who report lesser or lower health status are the same caregivers reporting that their role has made their health worse, including:

- Those in high-intensity caregiving situations (32 percent say it has made their health worse vs. 16 percent in medium- to low-intensity situations)
- High-hour caregivers (33 percent when providing 21 or more hours of care weekly vs. 18 percent of lower-hour caregivers)
- Caregivers who live with their care recipient (29 percent vs. 18 percent not living together)
- Those who feel they had no choice in taking on their role (32 percent vs. 12 percent had a choice)
- Primary caregivers (25 percent vs. 18 percent non-primary)

White (24 percent) and Asian-American (27 percent) caregivers more often report that caregiving has made their health worse, as compared to Hispanic caregivers (17 percent); and while Asian-American caregivers are older than Hispanic caregivers, caregiver age has no effect on the health impact of caregiving.

One out of three caregivers of a spouse/partner report caregiving has made their health worse (33 percent), compared to 21 percent of those caring for all others.

As the length of caregiving rises, so too does the reported impact on caregiver health, for the worse: 27 percent of those who have provided care for a year or longer report caregiving is making their health worse vs. just 17 percent of those who have cared for less than a year

CITATION

Miyawaki, A., Tanaka, H., Kobayashi, Y. & Kawachi, I. (2019). Informal caregiving and mortality – Who is protected and who is not? A prospective cohort study from Japan. *Social Science & Medicine*, 223, 24-30.

YEAR

2019

JURISDICTION

Japan

FOCUS OF STUDY

Tests the association between caregiving and survival in the *Komo-Ise* study, a prospective cohort of community-dwelling residents aged 44–77 years living in two areas in Gunma prefecture, Japan.

KEY FINDINGS

In this community-based cohort of informal caregivers in Japan, the researchers found no overall association between informal caregiving and all-cause mortality.

These findings are in contrast to previous studies that suggested protective effects of caregiving on mortality as a whole and among most subgroups in the United Kingdom (O'Reilly et al., 2015, 2008; Ramsay et al., 2013) or the United States (Brown et al., 2009; Fredman et al., 2010; Roth et al., 2013).

Compared with non-caregivers, informal caregivers tended to be younger, were more likely to be female, were more educated, were more likely to be employed and were less likely to have a history of stroke.

Data are drawn from the *Komo-Ise* study, a prospective cohort established in 1993 among all the inhabitants in *Komochi* village (rural area: population density around 300/km², 0 hospital beds/1000 residents and 12 nursing home beds per 1,000 residents aged 65 or older in 2000, n = 4,875) and the downtown of *Iseaki* city (urban area: population density around 2,000/km², 13 hospital beds/1,000 residents and 23 nursing home beds per 1,000 residents aged 65 or older in 2000, n = 7,755), both located in Gunma prefecture, Japan (Iwasaki et al., 2002; Konishi et al., 2015).

CITATION	
National Association of Chronic Disease Directors. (2018). Caregiving for family and friends – A public health issue. Retrieved from https://www.cdc.gov/aging/agingdata/docs/caregiver-brief-508.pdf	
YEAR	
2018	
JURISDICTION	
United States	
FOCUS OF SOURCE	
Examines the characteristics of caregivers and the caregiving situation, the health status of caregivers and the percentage of adults who are not current caregivers who think they will be caregivers in the future.	
RESEARCH SUMMARY	
14.5 percent of caregivers reported experiencing 14 or more mentally unhealthy days in the past month.	17.6 percent of men caregivers 45 years of age and older reported CHD and/or stroke compared to 11.8 percent of women.
17.6 percent of caregivers reported experiencing 14 or more physically unhealthy days in the past month.	The prevalence of these conditions varied by racial/ethnic groups: 14.4 percent of white caregivers, 13.3 percent of Black/African American caregivers, 12.3 percent of Hispanic caregivers and 7.6 percent of Asians/Pacific Islanders caregivers reported CHD and/or stroke.
Caregivers are at increased risk for having multiple chronic diseases as they may neglect their own personal health needs while providing care to others:	Caregivers were also asked they anticipate becoming caregivers in the future:
40.7 percent of caregivers reported having two or more chronic diseases.	17.2 percent of middle-aged and older adults who are not currently caregivers expect to provide care within the next two years.
53.4 percent of caregivers aged 65 years and older have two or more chronic diseases compared to 34.8 percent caregivers aged 45 to 64 years.	20.0 percent of adults aged 45–65 expect to provide care in the future.
14.1 percent of caregivers reported coronary heart disease (CHD) and/or stroke.	12.8 percent of adults aged 65 and older expect to provide care in the future.
22.2 percent of caregivers aged 65 years and older reported CHD and/or stroke compared to 10.3 percent of caregivers aged 45 to 64 years.	

CITATION	
Olai, L., Borgquist, L. & Svardsudd, K. (2015). Life situations and the care burden for stroke patients and their informal caregivers in a prospective cohort study. <i>Uppsala Journal of Medical Sciences</i> , 120(4), 290-298.	
YEAR	
2015	
JURISDICTION	
Sweden	
FOCUS OF STUDY	
Compares the life situation after stroke in patient–informal caregiver relationships during the first post-stroke year.	
RESEARCH SUMMARY	
This longitudinal cohort study examined subjects admitted to hospital because of stroke, with a planned follow-up at one week after discharge and three and 12 months from the day of admission. It used patient interviews and mailed questionnaires to informal caregivers to obtain data.	
The inclusion criteria were individuals 65 years of age or older, living in their own home and with no dementia diagnosis prior to the initial hospital admission, discharged from the Department of Internal Medicine (stroke unit or general ward) during the period between September 1, 1999 and May 31, 2001 after an acute stroke. Out of 432 potential participants, 42 died while at the Department of Internal Medicine and 13 died at the Department of Geriatrics. The 377 survivors constitute the study population of this report.	
On average, caregivers had higher HAD (hospital anxiety and depression) anxiety scores than patients (6.0 versus 3.5), higher depression scores (13.9 versus 4.1) and higher GQL (Gothenburg Quality of Life) activity scores (20.8 versus 13.7). Patients had higher levels in all NHP (Nottingham Health Profile) dimensions (17.4 versus 7.4).	
There was a statistically significant positive relationship between patients' and informal caregivers' HAD anxiety scores, NHP scores and activity score.	
Significant associations between informal caregiver and patient responses (relationship responses) were found for HAD anxiety, total NHP and GQL activity scale.	

CITATION
Penning, M.J. & Wu, Z. Caregiver stress and mental health: Impact of caregiving relationship and gender. <i>The Gerontologist</i> , 56(6), 1102-1113.
YEAR
2016
JURISDICTION
Canada
FOCUS OF STUDY
Examines the stress and mental health implications of caregiving for a spouse, children, parents, siblings, other family members and nonfamily (friends, neighbours, coworkers) among middle-aged and older male and female caregivers. Two research questions were examined: (a) What impact does the relationship of the caregiver to the care receiver have on the stress and mental health outcomes of caregivers? (b) Does this impact vary depending on the gender of the caregivers?
RESEARCH SUMMARY
<p>This study drew on the 2007 Canadian General Social Survey, Cycle 21 (GSS-21), conducted by Statistics Canada, to examine the stress and overall mental health implications of spousal caregiving compared with providing care for children, parents, siblings, other family members and nonfamily (friends, neighbours, coworkers). The study sample included all respondents who had provided assistance to an individual because of a long-term health condition or physical limitation in the past 12 months ($n = 6,140$). It excluded paid assistance to clients or patients.</p> <p>Although the mean level of self-rated stress is somewhat higher among female than male caregivers, no significant difference is evident in terms of self-rated mental health. A comparison of mean levels of stress and mental health by both gender and relationship of the caregiver to the care receiver indicates that women report higher levels of stress than men across all caregiving relationships. In addition, stress is highest among those caring for a spouse, followed by children and parents. With regard to self-rated mental health, in contrast, the findings suggest considerable disparity associated with both gender and relationship to the care recipient: whereas male caregivers report better mental health than female caregivers when comparing caregivers to a spouse, children, parents, and other family members, female caregivers report better mental health among those caring for siblings and nonfamily members.</p> <p>The findings also revealed that among women, compared with those caring for a spouse, those caring for parents, siblings, other family members or nonfamily members report significantly better mental health. However, no differences are evident when comparing the mental health of caregivers to a spouse to that of caregivers to children. This was evident in both models. The findings differ considerably among men. Although caregivers to parents and to other family members also report significantly better mental health than spousal caregivers prior to the introduction of control variables, these relationships are no longer significant following the introduction of control variables. Instead, no significant differences were found when comparing the self-rated mental health of spousal caregivers to those caring for those in other familial or nonfamilial relationships.</p> <p>Among both female and male caregivers, higher levels of mental health are evident among those who have higher levels of education, those who are employed or retired rather than engaged in other work-related activities (e.g., working inside the home, looking for work), those with moderate or higher levels of household income, caregivers reporting no personal activity limitations or chronic illness, and caregivers not providing care to individuals with both physical and mental health needs. Among female caregivers, better mental health is also reported by those who are older. Among male caregivers, never-married individuals report poorer mental health, whereas those providing care for older adults have better mental health. Those who see their care recipients at least once a week also report better mental health than those in the reference category (i.e., daily contact).</p> <p>The mean levels of self-rated stress reported by the middle-aged and older caregivers in the study are moderate, while overall self-rated mental health was fairly high. Thus, notwithstanding the greater stress and poorer mental health that caregivers tend to report when compared with non-caregivers, their overall mental health appears to be fairly good.</p> <p>Secondly, as suggested by previous literature, stress levels are somewhat greater among female than male caregivers. However, in contrast with frequently reported findings (including those based on the same measure as used here—e.g., Mawani & Gilmour, 2010) suggesting that women also tend to report poorer mental health than men, female and male caregivers in the study appear to have similar levels of self-rated mental health.</p>

CITATION

Perone, A.K., Dunkle, R.E., Feld, S., Shen, H.-W., Kim, M.H. & Pace, G.T. (2019). Depressive symptoms among former spousal caregivers: Comparing stressors, resources, and circumstances of caregiving cessation among older husbands and wives. *Journal of Gerontological Social Work*, 62(6), 682-700.

YEAR

2019

JURISDICTION

United States

FOCUS OF STUDY

Addresses the depressive symptoms of former spousal caregivers after caregiving ceased under varying circumstances. Specifically, the researchers addressed depressive symptoms of spouses who were the primary caregivers to their partners and stopped providing care over a two-year follow-up period under three circumstances: when the care receiver (1) no longer had functional problems; (2) continued having functional problems; or (3) died. They also investigated whether the effect of care-related stressors and resources during and after caregiving cessation on depressive symptoms differ for male and female spouses who were former caregivers, given evidence that caregiving women have more depressive symptoms than caregiving men (Mausbach et al., 2013).

RESEARCH SUMMARY

The researchers used data from the 2000–2014 Health and Retirement Study (HRS), an ongoing, longitudinal panel study that surveys a nationally representative sample of Americans 50 years and older and their spouses or partners approximately every two years. The final CG sample included 945 male spouses and 1,425 female spouses for a total of 2,370 caregivers.

The study found that all caregivers who ceased care after the care recipient died (reference group) had significantly more depressive symptoms than caregivers who stopped after the care recipient no longer had functional limitations or continued having functional limitations. Gender differences were not detected in these relationships.

Some background and context factors were significantly associated with depressive symptoms of caregivers. All caregivers with more depressive symptoms at baseline had more depressive symptoms at follow-up. Older caregivers and older female spouse caregivers had fewer depressive symptoms at follow-up.

Some care-related stressors related to care recipient and caregiver health during caregiving were significantly associated with follow-up depressive symptoms for female spouse caregivers. During caregiving, female spouses whose care recipients had a nursing home stay between baseline and follow-up had more depressive symptoms at follow-up. However, only male spouse caregivers who provided more baseline hours of monthly care had fewer depressive symptoms at follow-up.

When considering care-related stressors after cessation, the number of instrumental activities of daily living (IADL) limitations, number of health conditions and any follow-up paid work were significantly associated with more depressive symptoms at follow-up for all groups. Female spouse caregivers with more IADLs at follow-up had more follow-up depressive symptoms after caregiving had ended, whereas male spouses showed no such association.

CITATION
Potier, F., Degryse, J.-M., Aubouy, G., Henrard, S., Bihin, B., Debaq-Chainiaux, F., Martens, Hl. & de Saint-Hubert, M. (2018). Spousal caregiving is associated with an increased risk of frailty: A case-control study. <i>Journal of Frailty and Aging</i> , 7, 170-175.
YEAR
2018
JURISDICTION
Belgium
FOCUS OF STUDY
Explores if older spousal caregivers are at greater risk for frailty compared to older people without a load of care.
RESEARCH SUMMARY
<p>The study used a cross-sectional analysis of the baseline data from a cohort study of older spousal caregivers supporting those with cognitive deficits (score of more than 2/7 on the Global Deterioration Scale) or functional impairment (a minimum dependence of one activity in daily living) who were still living at home. All participants had to be 70 years of age or older.</p> <p>A total of 79 community-dwelling spousal caregivers of older patients were recruited. The median age was 79.0 years, and the sample was almost equivalent in gender (53 percent of women). Care receivers' median age was 81 years. A large majority (82 percent) of the care receivers had cognitive impairment and 68 percent had cognitive impairment with behavioural disorders. Their functional status was variable with a median of 3 notes of 6 on the Katz ADL scale.</p> <p>The researchers' model showed that for the same age, gender and comorbidities, caregiving is associated with a risk of frailty, the consumption of antidepressants, shorter nights of sleep and more difficulties maintaining a social network.</p> <p>The study identified that older spousal caregivers are more likely to present with frailty, disturbed sleep, difficulties maintaining a social network and use of anti-depressive drugs than people without this load of care.</p> <p>After the multivariable analysis, caregivers showed a six times greater risk of being frail compared with non-caregiver controls. The researchers screened frailty with the definition of L. Fried and focussed on physical indicators including muscle strength, endurance or weight loss. More precisely, caregivers were more likely to be in a pre-frail stage (one or two present criteria), which is identified as a high risk of progressing to frailty.</p>

CITATION
Stall, N.M., Kim, S.J., Hardacre, K.A., Shah, P.S., Straus, S.E., Bronskill, S.E., Lix, L.M., Bell, C.M. & Rochon, P.A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. <i>Journal of the American Geriatrics Society</i> , 67(3), 609-617.
YEAR
2019
JURISDICTION OF INCLUDED STUDIES
Most studies were conducted in North America (44.4 percent) or Europe (39.5 percent).
FOCUS OF REVIEW
Synthesizes the available evidence on the impact of informal caregiver distress on the health outcomes of community-dwelling dementia care recipients.
RESEARCH SUMMARY
<p>By far, admission to a nursing home of the person with dementia is the most frequently reported outcome; this was investigated in 36 study populations of which 17 were assessed as high quality. Overall, nearly two-thirds of these studies (61.1 percent of all studies and 70.6 percent of high-quality studies) reported that caregiver distress is associated with significant increases in the institutionalization of the dementia care recipient.</p> <p>The next most frequently reported outcomes were care recipient behavioural and psychological symptoms of dementia (BPSD) and elder abuse.</p> <p>A total of 10 study populations (five were good quality) examined the association between caregiver distress and BPSD, with most (90 percent of all studies and 100 percent of high-quality studies) reporting that caregiver distress is associated with worsening BPSD in care recipients. A total of 10 studies (four were good quality) reported the impact of caregiver distress on elder abuse (all 10 studies measured physical abuse and verbal abuse, with six of the studies also measuring neglect), and all reported that dementia care recipients with distressed caregivers are at a significantly increased risk of experiencing elder abuse.</p>

CITATION
Roth, D., Fredman, L. & Haley, W.E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. <i>The Gerontologist</i> , 55(2), 309-319.
YEAR
2015
JURISDICTION
Worldwide
FOCUS OF STUDY
Aims to re-examine some of the existing evidence on the health effects of caregiving, focussing in particular on one commonly cited claim that family caregiving is associated with an increased risk for mortality.
RESEARCH SUMMARY
<p>There is a large literature indicating that caregivers, as a general group, are more likely to report symptoms of depression and other indicators of psychological distress than non-caregivers (Pinquart & Sörensen, 2003; Roth et al., 2009; Schulz & Sherwood, 2008). Many studies also suggest that caregivers have poorer physical health when compared with various samples of non-caregivers (Pinquart & Sörensen, 2003; Vitaliano et al., 2003). Several investigations specifically restricted to dementia caregivers have reported higher inflammatory burden and other biomarkers of poorer health in these caregivers compared with various non-caregiving comparison groups (Gouin et al. 2012; Kiecolt-Glaser et al., 2003; Lovell & Wetherell, 2011; von Känel et al., 2006).</p> <p>However, there is very little evidence from well-controlled population-based studies that family caregivers, as a general group, have poorer objective physical health than suitable non-caregiving comparison groups. There is considerable evidence that caregivers experience symptoms of emotional distress, but some of this may be a result of observing a family member struggling with a serious or disabling medical condition (Amirkhanyan & Wolf, 2003; Monin & Schulz, 2009) rather than because of any stress involved in providing care to that person.</p> <p>When the mortality data for spouse caregivers with and without caregiving strain were combined and compared with the spouses of nondisabled participants, the overall caregiving mortality effect was not statistically significant.</p> <p>The five subsequent population-based mortality studies vary in their details, such as the specific caregiving questions used, who comprised the non-caregiving comparison group, the different caregiving subgroups examined, the covariates included in the analytic models and the length of the follow-up period (4–8 years). There is, however, one consistent finding across all five subsequent population-based studies: <i>Caregivers, as a general group, have significantly reduced mortality rates compared to their respective non-caregiving reference groups.</i></p> <p>The results indicate that caregivers have an 18 percent survival advantage over a six-year period compared to the propensity-matched non-caregivers.</p> <p>Additional analyses of large datasets thought to represent the entire population of Northern Ireland (O'Reilly et al., 2008) and England and Wales (Ramsay et al., 2013) have yielded similar survival benefits for caregivers compared to corresponding non-caregivers.</p> <p>Two of the subsequent studies have further examined the effect of caregiving stress or strain on mortality, and neither has confirmed an increased mortality risk even for caregivers under high stress. Specifically, Fredman and colleagues (2010) found that caregivers reporting high caregiving-related stress do not show differences in mortality compared to non-caregiving women, whereas caregivers with low levels of caregiving-related stress have a significantly reduced risk of mortality compared to their non-caregiving counterparts. Similarly, Roth and colleagues (2013) found that caregivers reporting high caregiving strain do not differ in mortality when compared to their propensity-matched non-caregiving controls.</p>

CITATION
Stall, N.M., Kim, S.J., Hardacre, K.A., Shah, P.S., Straus, S.E., Bronskill, S.E., Lix, L.M., Bell, C.M. & Rochon, P.A. (2019). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. <i>Journal of the American Geriatrics Society</i> , 67(3), 609-617.
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