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Title:

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Date:

2022-11-01

Citation:

Ervin, J., Taouk, Y., Fleitas Alfonzo, L., Peasgood, T. & King, T. (2022). Longitudinal association between informal unpaid caregiving and mental health amongst working age adults in high-income OECD countries: A systematic review. *Eclinicalmedicine*, 53, <https://doi.org/10.1016/j.eclinm.2022.101711>.

Persistent Link:

<https://hdl.handle.net/11343/321999>

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Longitudinal association between informal unpaid caregiving and mental health amongst working age adults in high-income OECD countries: A systematic review



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Summary

Background Informal unpaid caregivers provide most of the world's care needs, experiencing numerous health and wealth penalties as a result. As the COVID-19 pandemic has highlighted, informal care is highly gendered. Longitudinal evidence is needed to assess the causal effect of caregiving on mental health. This review addresses a gap by summarising and appraising the longitudinal evidence examining the association between unpaid caregiving and mental health among working age adults in high-income Organisation for Economic Co-operation and Development (OECD) countries and examining gender differences.

Methods Six databases were searched (Medline, PsycInfo, EMBASE, Scopus, Web of Science, Econlit) from Jan 1, 2000 to April 1, 2022. Population-based, peer-reviewed quantitative studies using any observational design were included. Population of interest was working age adults. Exposure was any unpaid caregiving, and studies must have had a non-caregiving comparator for inclusion. Mental health outcomes (depression, anxiety, psychological distress/wellbeing) were measurable by validated self-report tools or professional diagnosis. Screening, data extraction and quality assessment (ROBINS-E) were conducted by two reviewers. The study was prospectively registered with PROSPERO (CRD42022312401).

Findings Of the 4536 records screened; 13 eligible studies (133,426 participants) were included. Overall quality of evidence was moderate. Significant between-study heterogeneity precluded meta-analysis, so albatross and effect-direction plots complement the narrative synthesis. Results indicate a negative association between informal unpaid care and mental health in adults of working age. Importantly, all included studies were longitudinal in design. Where studies were stratified by gender, caregiving had a consistently negative impact on the mental health of women. Few studies examined men but revealed a negative effect where an association was found.

Interpretation Our review highlights the need to mitigate the mental health risks of caregiving in working age adults. Whilst men need to be included in further scholarship, reducing the disproportionate caregiving load on women is a crucial requirement for policy development.

Funding Melbourne School of Population and Global Health, Targeted Research Support Grant.

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Keywords: Informal unpaid care; Informal caregiving; Mental health; Gender; Systematic review; Longitudinal; HIC; OECD

Introduction

The vast majority of the world's care needs are met by informal unpaid caregivers.^{1,2} Estimated to equate to two billion people working 8 h per day with no remuneration, unpaid care is equal to 5% of global GDP.² Yet,

despite the substantial economic contribution of unpaid care, and the relief it delivers to the health system, informal caregiving remains largely unacknowledged.^{3,4} Importantly, unpaid caregiving is highly gendered, with women accounting for an estimated 80% of

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eClinicalMedicine
2022;53: 101711
Published Online XXX
<https://doi.org/10.1016/j.eclinm.2022.101711>

Research in context

Evidence before this study

This review examines the longitudinal association between unpaid caregiving and the mental health of working age adults in high-income Organisation for Economic Co-operation and Development (OECD) countries. Medline, PsycInfo, EMBASE, Scopus, Web of Science and Econlit were searched from Jan 1, 2000 to April 1, 2022 for terms (“informal unpaid car*” or “informal car*” or “unpaid car*” or “family car*” or carer or caregiv* or “unpaid childcar*”) and (“mental and health” or depress* or anxiety or “psychological stress” or “psychological distress” or psychological or mental health/or depression/or anxiety/), with search tiers 3&4 delineating countries and longitudinal study design. Of the 4536 records screened, 13 studies (totaling 133,426 participants) were deemed eligible for inclusion. The overall quality of the evidence was moderate.

Added value of this study

This review fills a remaining gap left by previous reviews. It was restricted to the longitudinal evidence to assess the

causal effect of caregiving on mental health, included caregiving for any persons requiring care, and synthesised the available literature from high-income OECD countries. It also focused on working age adults and explored the gender differences. The findings from this systematic review indicate informal unpaid care is negatively associated with mental health. Where studies were stratified by gender, caregiving was consistently negatively associated with mental health for women. Whilst few studies examined men, a negative effect was also reported where an association was found.

Implications of all the available evidence

Our finding that informal unpaid caregiving is negatively associated with the mental health of working age adults highlights the urgent need to mitigate the mental health risks of caregiving provision in this cohort. Whilst we identified that men need to be included in further scholarship, reducing the disproportionate caregiving load on working age women is a more pressing and urgent matter for policy consideration.

informal carers globally.⁵ Significantly, numerous penalties are experienced as a result of unpaid caregiving. Impacts in terms of economic and social inclusion are well documented,^{2,6} but caregiving can also negatively impact the physical and mental health of caregivers.^{2,7} Longitudinal evidence is needed to assess the causal effect of caregiving on mental health. As such, this review addresses a gap in the literature by examining the longitudinal association between unpaid caregiving and the mental health of working age adults in high-income Organisation for Economic Co-operation and Development (OECD) countries.

The COVID-19 pandemic has spotlighted informal care provision, highlighting the way in which care, particularly unpaid care, is under-recognised and undervalued across the globe.⁸ Unpaid caregiving/care work is variously defined. In some instances, unpaid care is all-encompassing, taken to include all unpaid services provided within a household for its members (such as care of persons and housework), as well as voluntary community work.^{2,9} In other cases, it is narrowly restricted to providing unpaid care only to persons requiring support due to illness or disability.¹⁰ Alternatively, an accepted extension of this limited version is the unpaid care of all persons with different grades of dependency, inclusive of healthy individuals such as dependent children or older parents.⁵ Given that the care of dependent children and elderly parents represents a significant component of the gendered unpaid care load, our approach aligns with the latter. Thus, for the purposes of this review, and following the

precedent of Friedemann-Sanchez & Griffin (2011), informal caregiving or unpaid care work is “the provision of unpaid personal services to meet the physical, mental, and emotional needs that allow a dependent person to function at a socially determined acceptable level of capability, comfort, and safety. We consider dependants to be all children (before they are legal adults), all those either temporarily or permanently ill or physically and/or mentally disabled, and the elderly”.¹¹

The caregiving stress process model (SPM),^{12,13} multiple role strain/overload,^{14,15} and time scarcity theories¹⁶ posit mechanisms through which caregiving is thought to impact mental health. Additionally, caregiving being emotionally laden, is intrinsically interconnected to the relationship characteristics between the caregiver and care-recipient.¹¹ To this end, whilst caregiving can negatively impact health and wellbeing, some studies have reported positive effects of caregiving, including reduced mortality and better self-rated quality of life.^{17,18} It is possible that these findings are due to the “healthy caregiver” hypothesis (akin to the healthy worker effect where healthier persons are more likely to be selected into caregiving (work)).¹⁹ However, it is also the case that the opposite may be true, whereby those with poorer health are more likely to become carers due to reduced labour market opportunities for example.²⁰ This potential for reverse causality (in either direction) highlights the need for robust longitudinal evidence in examining the associations between caregiving and health outcomes.

Three prior systematic reviews have examined the health impacts (including mental health) of caregiving for older adults only.^{21–23} They uniformly found evidence of a negative association between caregiving for older adults and the mental health of informal caregivers.^{21–23} Moreover, a 2020 systematic review and meta-analysis examined the health outcomes of unpaid caregivers in low- and middle-income countries.²⁴ Interestingly, this review revealed a mental health cost for caregivers of people in ill-health, but conversely a potential protective general health effect for those caring for healthy individuals (compared to non-caregivers).²⁴ Lastly, a number of prior reviews have focused on selected cohorts defined according to care recipient diagnosis,^{25–27} which, whilst providing valuable context specific information for these cohorts, cannot be extrapolated to the broader caregiving population.

Our review fills a remaining gap left by these reviews. Firstly, we examine the mental health impacts of caregiving for any persons requiring care (not restricting to older adults or specific disease categories and inclusive of both healthy and ill/disabled care recipients) and secondly, our review synthesises and summarises the available literature for unpaid care in high-income OECD countries. Moreover, our review focuses on working age adults, given the increased time pressures informal caregiving imposes on working adults. Lastly, acknowledging the considerable potential for reverse causation, we restrict our review to the longitudinal evidence to assess the causal effect of caregiving on mental health, a novel undertaking in this space.

The main aims of this review are:

- 1) To summarise the quantitative longitudinal evidence examining the association between informal unpaid caregiving and mental health amongst working age adults in high-income OECD countries
- 2) To assess the quality of the existing evidence
- 3) To examine gender differences in this association

Methods

Search strategy and selection criteria

This systematic review was prospectively registered in PROSPERO (CRD42022312401) and followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA)²⁸ guidelines (see [Supplementary 1](#) for PRISMA checklist). A four-tiered search strategy was developed in Medline (OVID) and subsequently employed across all databases. A complete list of search terms for each tier (including MeSH terms) and strategies for each database is available in [Supplementary 2](#). Literature searches were conducted on six electronic databases: Medline (OVID), PsycInfo (OVID), EMBASE (OVID), Scopus, Web of Science, and Econlit, with searches restricted to peer-reviewed material published between Jan 1, 2000, and April 1, 2022

(noting that main search was conducted on Nov 29, 2021 at which stage search alerts were set for each database and screening continued until April 1, 2022).

This systematic review was restricted to quantitative studies of longitudinal design examining associations between informal unpaid care and mental health. Only population-based studies from [high-income OECD countries](#) were included. Informal unpaid caring included caregiving for individuals either temporarily or permanently ill or physically and/or mentally disabled, and the elderly and children (before they are legal adults). Studies were only included if they had a non-caregiving comparator. This could be a comparison with non-caregiving individuals or within-person non-caregiving comparison. Restricting to longitudinal study design allowed this review to examine the relationship between informal caregiving and mental health in a way that maximised causal inference. Eligible studies had to measure common mental health outcomes (such as depression, anxiety, psychological distress) by either 1) using a validated measure of mental health symptomatology such as the MHI-5, Kessler, CES-D and GHQ-12 instruments,^{29,30} or 2) including a mental health diagnosis of depression or anxiety from a doctor as part of the study. Severe or psychotic mental illnesses, such as schizophrenia, were ineligible for inclusion.

Our population of interest was adults of working age (18–65 years). Where a study's population only partially overlapped with our defined population or extended beyond these parameters (e.g., whole population studies with an age range 16–100 years), the study was included only if: a) age disaggregated results were presented; or b) we could ascertain that most participants were of working age (18–65 years). Where the same dataset was used in multiple studies, we included the most relevant and/or recent study (with our exposure/outcomes of interest) covering the longest period. Observational studies that were cross-sectional in design were excluded, as were reviews and studies that were purely qualitative or descriptive. Studies analysing caregiving in a volunteer capacity (i.e., not kin/known to them) or paid care work (caring for the individual as part of their professional vocation) were excluded.

Records arising from search results were exported to [Covidence](#), a web-based tool to conduct systematic reviews. Two reviewers (JE and LFA) independently screened all articles (title/abstract and full text) for inclusion. Both reviewers were blinded to each other's decisions. Disagreements were solved by discussion, and a third reviewer (YT or TK) was consulted when a decision could not be reached.

Data analysis

Data extraction

A data extraction form was constructed to summarise the characteristics of included studies, including author, year of publication, location, study design,

population, sample size, characterisation of exposure, characterisation of the outcome, analytical approach, and measures of effect. Data extraction was conducted by one reviewer (JE) and cross-checked by a second reviewer (LFA).

Risk of bias (quality) assessment

The quality of included studies was assessed utilising the Risk of Bias tool for non-Randomised studies (ROBINS-E).³¹ This tool evaluates non-randomised evidence based on comparisons to the ideal target trial. ROBINS-E is specifically designed for assessing risk of bias (RoB) in observational studies on exposures, evaluates a larger range of domains of bias than other tools, and reports ratings for each RoB domain, in addition to an overall RoB study score.^{32,33} Studies were judged based on seven domains; bias due to 1) confounding, 2) selection of participants, 3) classification of exposure, 4) departures from intended exposures, 5) missing data, 6) outcome measurement and 7) selection of results. A study's overall RoB and each domain specific RoB could be assessed as low, moderate, serious, or critical. Item-level judgement for each of the seven domains was deduced from the most dominant RoB score within that domain. The overall RoB for each study was extrapolated from the highest RoB in any domain. Quality assessment was conducted independently by two reviewers (JE and LFA). Conflicts were solved through discussion. Greater detail pertaining to the application of this tool, and the specific risk assessments for each domain is described in detail elsewhere.³²

Our original intention was to conduct a meta-analysis. However, this was ultimately not possible due to significant variation between studies. Whilst all studies were longitudinal in design, there were marked differences in how different studies interrogated and categorised informal unpaid caregiving, the measures and scales through which the mental health outcome was assessed, as well as variation in statistical methods of analysis. Therefore, as per Cochrane recommendations,³⁴ findings were consequently synthesised and presented using alternative methods. These included an albatross plot,³⁵ Fisher's meta-analysis of combining p values,³⁴ an effect direction plot,³⁶ and a narrative synthesis.

Ethics

Ethics approval was not applicable for this systematic review because it is based exclusively on published literature.

Role of the funding source

The funder did not have any involvement in the design or conduct of any part of the study. JE, LFA, YT, and TK had access to the data and all authors were responsible

for the decision to submit the manuscript for publication.

Results

Study characteristics

The initial search identified a total of 6779 studies, from which 2756 duplicates were removed prior to screening. Title and abstract screening of 4023 records (and a further 513 records from search alerts monitored until April 1st, 2022) yielded a total of 140 papers to be assessed for eligibility through full-text screening. Of these, 127 were excluded for not meeting the eligibility criteria, resulting in a total of 13 studies (totaling 133,426 participants) for inclusion in the systematic review (see study selection (PRISMA) diagram Fig. 1). Studies excluded at full text review (with reasons for exclusion) are listed in [Supplementary 3](#). The most prominent reasons for exclusion included not having a non-caring comparator group or the sample population not being of working age.

In line with the review inclusion criteria, all thirteen included studies^{37–49} employed a longitudinal study design to examine the relationship between informal unpaid caring and mental health in working age adults, and all were from high-income OECD countries. Longitudinal methodology varied, with half of the studies employing fixed-effects regression methodology to assess within-person changes (changes in caregiving status for the same individual),^{38,40,44,46,47,49} whilst the remainder examined between-person effects, comparing caregivers with non-caring individuals,^{39,41–43,45,48} and one study interrogated both.³⁷ Geographically, there were two studies from Australia,^{43,46} the United Kingdom,^{39,45} and the United States,^{40,42} one from Canada,⁴¹ Sweden,⁴⁸ Germany,³⁸ the Netherlands,³⁷ Israel,⁴⁹ and Japan,⁴⁷ and one study utilised a European sample (including data from Austria, Germany, Sweden, Netherlands, Spain, Italy, France, Denmark, Switzerland, and Belgium).⁴⁴

Seven of the thirteen studies operationalised informal care as a binary variable (caregiving versus no caregiving),^{37,38,41–43,46,47} whilst six studies categorised caregiving in various ways. One study categorised the exposure by relationship with care recipient (no care versus biological parent care, parent-in-law care, spouse care, other kin care and non-kin care),⁴⁰ whilst another specifically examined “sandwich care” (no care versus sandwich caregiving [caregivers of both children and elders], caregivers of children only, and caregivers of elders only).⁴⁹ One study categorised caregiving by the limitation imposed by the caring role (no caregiving versus caregiving with no limitations, and caregiving with any degree or dimension of limitations in the caregiver's life).⁴⁸ Two studies categorised caregiving by load (no care versus caregiving <19 h/week, 10–19 h/week, or caregiving 20 h or more/week),⁴⁵ or frequency

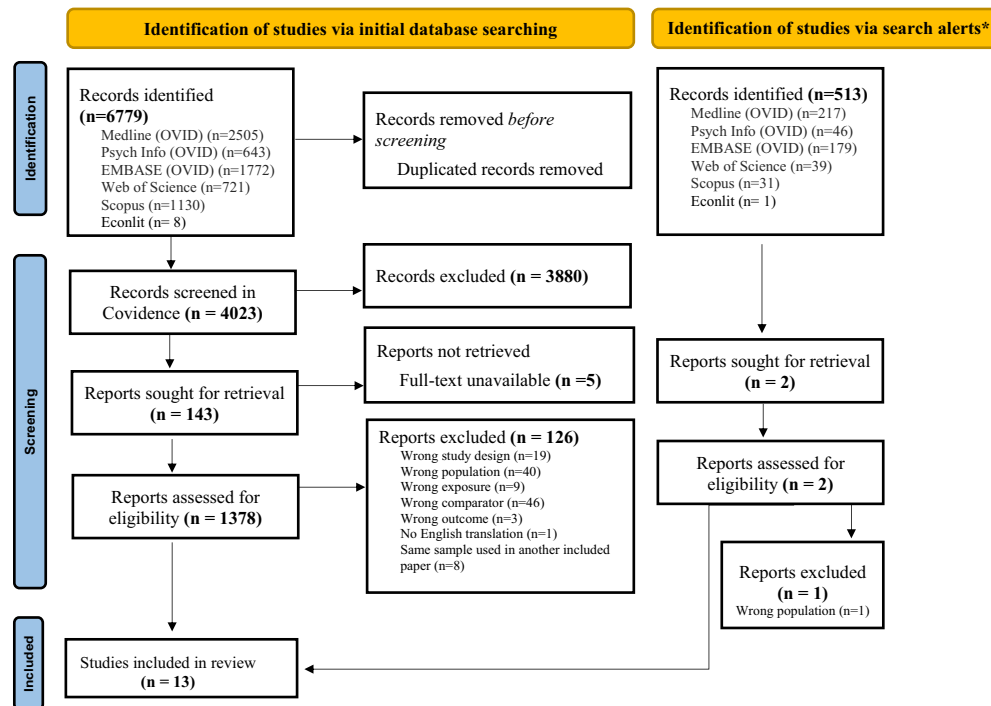


Fig. 1: Study selection (PRISMA) diagram. *513 additional abstracts were screened between December 2021 and April 1st, 2022, from search alerts set for all six databases after initial database searching.

(no caring versus daily, weekly, and any frequency of caregiving).⁴⁴ Finally, one study categorised caregiving by caregiving episodes and chronicity.³⁹

All included studies employed a validated self-reported survey-based measure of mental health. Five studies utilised validated depressive symptom measures of mental health (CES-D^{37,40,43} EURO-D⁴⁴ MDI⁴⁸ PHQ-9⁴⁹), five studies utilised a well-recognised psychological distress measure (K-6^{41,47} GHQ-12^{39,45}), whilst one study used a modified negative affect measure to assess psychological distress.⁴² Lastly, two studies employed the validated mental health inventory scale from the SF-36 (MHI-5⁴⁶ MCS³⁸) as their mental health measure. A descriptive summary and main findings of included studies (including effect estimates and confidence parameters where reported) can be found in Table 1.

Risk of bias assessment

Table 2 presents results for the risk of bias (RoB), quality assessment. In evaluating the longitudinal association between informal unpaid caregiving and mental health in working age adults, the overall quality of the extant evidence was moderate. Whilst none of the thirteen included studies was deemed at critical RoB overall, no study was assessed to be at the lowest RoB either. Three of the studies were judged as moderate RoB overall,^{37–39} and the remaining ten studies were rated at serious

RoB.^{40–49} Refer to Supplementary 4 for specific assessment of each RoB domain and pre-defined considerations for quality assessment process.

In examining all the quality assessment evidence together (Table 2), it is apparent that the item-level RoB for each domain is consistently low-moderate, with different sources of bias spread across the individual studies. Thus, despite the individual study-level RoB being mainly serious, we can have confidence that overall, each domain presents only a low-moderate risk of biasing our overall findings.

Data synthesis

Eight studies (comprising ten estimates) presented sufficient data to calculate a standardised mean difference (SMD), allowing comparison and construction of an albatross plot³⁵ (Fig. 2). Refer to Supplementary 5 for albatross plot explanation. All studies show a positive effect size; six estimates falling between the SMD contours of 0.05 and 0.15, and four below 0.05. We interpreted this as a small positive association between caregiving and poorer mental health, with no definitive subgroup differences. Utilising Fisher's method,³⁴ combining p-values for all included studies suggested there was strong evidence of unpaid caregiving being positively associated with poorer mental health ($p < 0.001$). Restricting this analysis to only those studies

| First author (year) country | Data source and study design | Analytical sample | Exposure/s and measurement | Mental health outcomes | Main findings |
|---|--|---|--|--|--|
| Bijnsdorp (2022) ³⁷ Netherlands | Study on Transitions in Employment, Ability and Motivation (STREAM) 3 waves (2015–17) Linear mixed effects regression (between- and within-person effects) | 12,447 (5797 women and 6650 men) | <i>Family caregiving</i> Respondents were labelled as family caregivers if they had spent time on family caregiving in the past 12 months (yes/no). Family caregiving was defined in the questionnaire as “providing unpaid care for a person in the close environment, excluding care for healthy children”. This could include family members, as well as friends or neighbours, but they use the term family caregiver throughout the manuscript as it covers the large majority of caregivers. Binary variable. | Depressive symptoms Measured with a short form (10-item) version of the Centre for Epidemiological Studies Depression (CES-D) index. | Family caregiving was associated with increased depressive symptoms between- and within-persons for both women [between-person (BP) $b = 0.80$, (95% confidence interval (CI) 0.52–1.08); within-person (WP) $b = 0.32$, (95% CI 0.08–0.56)], and men [BP $b = 0.75$, (95% CI 0.45–1.05); WP $b = 0.25$, (95% CI 0.01–0.48)] |
| Cameron (2008) ⁴¹ Canada | National Population Health Survey (NPHS) 3 waves (1994, 96, 98) Linear mixed effects regression | 1548 (800 caregivers, 748 non-carers) | <i>Family caregiving</i> Primary respondents were defined as family caregivers if they met the following criteria: 1) indicated that their primary daily activity was “caring for family” or “working and caring for family” or their reason for not being currently employed was “family responsibilities” and 2) have a household member with a disability limiting their ability to perform daily activities or necessitating assistance with an activity of daily living. Binary variable. | Psychological distress Measured with the Kessler Screening Scale for Psychological Distress (K6). | No significant differences in psychological distress between family caregivers and non-caregivers was reported [$b = 0.03$, SE 0.11, (95% CI –0.19, 0.25), $p = 0.82$] |
| Chesley (2006) ⁴² United States | Ecology of Careers Study (New York) 2 waves (1998, 2002) OLS regression | 3828 (1914 couples) | <i>Adult caregiving.</i> Respondents were asked, “Within the past year, have you provided regular special attention or care to any family members because they were elderly, disabled, have a chronic illness or are infirm in some way?” In cases of an affirmative response, a follow-up question asked the respondent to describe whether this person was a parent, an in-law, a grandparent, a spouse, a child, or some other relative. Binary variable. | Psychological distress Measured with a 4-item scale (abbreviated form of a 6-item scale) used in the Midlife in the United States Survey. | Transition into caregiving was associated with increased psychological distress in employed women [$b = 0.034$, SE 0.009, $p < 0.01$], but not for persistent care (no association). (There is an association for having a child younger than 12 in women). Not clear from the paper whether association was assessed for men (husbands) or not reported as no association. |
| Choi (2006) ⁴⁰ United States | National Survey of Families and Households (NSFH) 2 waves (1987/88 & 1992/93) Linear fixed effects regression | 1842 married adults (918 women and 924 men) | <i>Caregiving</i> For respondents who did not provide any type of caregiving at T1, the following inquiries were made at T2: Sometimes because of a physical or mental condition, illness, or disability, people require the assistance of friends or relatives. During the last 12 months, have you, yourself, given anyone not living with you at the time any help or assistance because of their health problem or disability? (i.e., out-of- household care) During the last 12 months, have you, yourself, given anyone who was living with you at the time any help with personal care because of their long-term physical or mental condition, illness, or disability? (i.e., in-household care) Categorized as; 1) no care, 2) biological parent care, 3) parent-in-law care, 4) spouse care, 5) other kin care, 6) non-kin care | Depressive symptoms Measured with a modified 12-item version of the Centre for Epidemiological Studies Depression index. | Transition into caregiving was associated with depressive symptoms for biological parent care [$b = 0.27$, SE 0.08, $p < 0.0001$] and spousal care [$b = 0.33$ (SE 0.13, $p < 0.01$)]. No association was found for parent-in law, other kin or non-kin care. |

(Table 1 continues on next page)

| First author (year) country | Data source and study design | Analytical sample | Exposure/s and measurement | Mental health outcomes | Main findings |
|--|--|---|--|---|---|
| (Continued from previous page) | | | | | |
| Ferreira (2017) ⁴³ Australia | Australian Longitudinal Study on Women's Health (ALSWH) 6 waves (1996, 1998, 2001, 2004, 2007, 2010) Logistic regression | 8453 (women only) | <i>Caregiving</i> At each survey, the women were asked "Do you regularly provide care or assistance (e.g. personal care, transport) to any other person because of their long-term illness, disability, or frailty?" Latent class analysis produced three trajectories (latent classes) which yielded probabilities describing: 'consistently highest', 'low then increasing', and 'consistently lowest' classes of caregiving. For this paper, the 'consistently highest' and 'low then increasing' classes were combined into one class reflecting 'caregiving' Binary variable. | 1. Depressive symptoms Measured using the Centre for Epidemiological Studies Depression scale (CESD-10) 2. Mental health Measured with the mental health subscale (MHI-5) from the Short Form-36 (SF-36) | Caregiving (compared to not caregiving) (in women not exposed to IPV) was associated with a 24% increase in the odds of depression [OR 1.24, (95% CI 1.06, 1.44)]. No association was observed for the SF-36 measure of MHI-5 [OR 1.08, (95% CI 0.89, 1.29)]. |
| Hajek (2018) ³⁸ Germany | Panel Study Labour Market and Social Security (PASS) 3 waves (2008/09, 2012, 2015) Linear fixed effects regression | 21,247 individuals (34,218 observations) | <i>Informal caregiving</i> Informal care was assessed using the question "And now we have a couple of questions regarding the care of other persons who are severely ill or have to be cared for due to reasons of age. Do you provide care, personally and on a regular basis, for relatives or friends in or outside your household? We are not referring to providing nursing care as an occupation." Binary variable. | Mental health Measured with the Mental health scale (MCS) from the modified version of the SF-12. | Onset of informal caregiving was not significantly associated with mental health [b = -0.50, SE 0.34]. |
| Heger (2017) ⁴⁴ Europe (Austria, Germany, Sweden, Netherlands, Spain, Italy, France, Denmark, Switzerland, Belgium.) | Survey of Health, Ageing and Retirement in Europe (SHARE) 4 waves (2004/05, 2006/07, 2011/12 & 2013) Linear fixed effects regression | 6421 (3669 women and 2752 men) | <i>Parental caregiving</i> Caregiving activities include help with personal care (e.g., dressing and bathing) and practical household help (e.g. help with home repairs, shopping and household chores) provided outside or inside the household. Categorised into no caring, daily, weekly, and any frequency of caregiving. | Depressive symptoms Measured with the EURO 12-item depression (EURO-D) scale. | Parental caregiving (any frequency) was negatively associated with mental health for both daughters [b = 0.145, SE = 0.058, p < 0.05], and sons [b = 0.112, SE = 0.056, p < 0.05]. |
| Hirst (2005) ⁴⁵ United Kingdom | British Household Panel Survey (BHPS) 10 waves (1991-2000) Logistic regression | 17,000 (3000 would-be carers, 2900 former carers, and 11,100 non-carers) (63,200 person-years) | <i>Caregiving</i> Caregiving is defined as looking after, giving special help or some regular service that is not provided in the course of paid employment. Categorised as; 1) non-carers, 2) caregiving under 19 h/week, 3) caregiving 10-19 h/week, 4) caregiving 20 h or more/week. | Psychological distress Measured with the 12-item version of the General Health Questionnaire (GHQ12). The scale was dichotomised to measure the proportion of respondents presenting high distress scores. | Compared to non-carers, providing 20 h or more care per week had increased odds of onset of psychological distress for both women [OR 2.86 (95% CI 2.09, 3.91)], and men [OR 2.06 (95% CI 1.31, 3.23)]. For 10-19 h care/week, there was an association in women [OR 1.70 (95% CI 1.21, 2.39)], but not in men [OR 1.34 (95% CI 0.83, 2.18)]. For those providing under 10 h care per week, the rate of onset of psychological distress was no different (for both women and men) from that of non-carers (p > 0.05). |

(Table 1 continues on next page)

| First author (year) country | Data source and study design | Analytical sample | Exposure/s and measurement | Mental health outcomes | Main findings |
|--|---|--|---|--|--|
| (Continued from previous page) | | | | | |
| Lacey (2019) ³⁹ United Kingdom | UK Household Longitudinal Study (UKHLS) 7 waves (2009–2016) Linear mixed effects regression | 9368 (5363 women and 4005 men) | <i>Informal caregivers</i> Informal caregivers were identified as participants who answered, 'yes' to either of the following questions in each of waves 1–7: 'Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example, a sick, disabled or elderly relative/husband/wife/friend etc.)?' 'Do you provide some regular service or help for any sick, disabled, or elderly person not living with you?' Categorized as: 1) 'not caregiving' comprised of participants who reported not caregiving in all six waves; 2) 'one episode 1–2 years' comprised of participants who reported informal caregiving either at only one wave or at two successive waves; 3) 'intermittent caregiver' comprised of participants who reported more than one episode of caregiving; and 4) '3+ years caregiver' comprised of participants who had at least one episode of caregiving for >3 successive years | Psychological distress Measured with the 12- item version of the General Health Questionnaire (GHQ12). | Women who engaged in long-term (>3 years) or intermittent caregiving had higher levels of psychological distress [b = 0.48, (95% CI 0.07–0.89) and b = 0.47, (95% CI 0.02–0.92) respectively] compared to non-caregivers. There was no association for one episode of caregiving in women [b = 0.07 (95% CI –0.35, 0.50). For men, informal caregiving was not associated with psychological distress for any category [1 episode b = 0.10 (95% CI –0.34, 0.54), intermittent caregiver b = 0.37(95% CI –0.17, 0.90), 3+ years caregiver b = 0.22 (95% CI –0.26, 0.71)]. |
| Mohanty (2019) ⁴⁶ Australia | Household Income and Labour Dynamics of Australia survey (HILDA) 10 waves (2005–2015) Linear fixed effects regression | 23,251 individuals (121,410 person-years of observation) | <i>Caregiving</i> Individuals who actively cared for a household member or non- resident individual due to a long-term health condition or elderly status (carers). Binary variable. | Mental health Measured with the mental health subscale (MHI-5) from the Short Form-36 (SF- 36) | Compared to non-caregiving, active caregiving was negatively associated with mental health [b = – 3.010, (95% CI –5.371, –0.648), p < 0.01]. |
| Oshio (2018) ⁴⁷ Japan | Longitudinal Survey of Middle-Aged and Older Adults 7 waves (2008–2014) Linear fixed effects regression | 21,788 women (3914 carers, 17,874 non-carers) | <i>Informal caregiving</i> Survey asks whether the respondents provide care to their immediate family (including father, mother, father-in-law, and mother-in-law), and if they do so, the family member(s) who receive care. We consider a respondent an informal caregiver if she cares for at least one of her parent(s) or parent (s)-in-law or both. Binary variable. | Psychological distress Measured with the Kessler Screening Scale for Psychological Distress (K6). | Informal caregiving was associated with increased psychological distress [b = 0.69, SE = 0.15, p < 0.001]. |
| Stratmann (2021) ⁴⁸ Sweden | Swedish Psykisk hälsa, Arbete och Relationer (PART) study 2 waves (1998–2000 & 2010) Logistic regression | 5108 | <i>Informal caregiving</i> The exposure was defined as informal caregiving to a family member and assessed according to a positive response to the question "Are you currently responsible for the care of a long-time sick or disabled family member?" In order to assess the perceived limitations that informal caregiving can have on the life of the caregiver, three follow up questions were asked regarding conflicts with work, leisure time, and family or friends due to informal caregiving. The exact questions asked were: Are your opportunities for work or leisure activities limited by this care responsibility? Are your opportunities for spending time with friends and family limited by | 1. Depressive symptoms Measured using the major depression inventory (MDI) self-reported instrument. 2. Anxious distress Measured using the DSM-5 criteria (five questions from three different scales) | Compared to non-caregiving, caregiving (that imposed any degree of limitation on caregivers' life) was associated with higher self-reported depression [OR = 1.44, (95% CI 1.06–1.96)], but not anxiety OR = 1.52, (95% CI 0.96–2.41)]. No significant associations were found in caregivers without limitations. Note – these results are for the 10-year follow up (longitudinal component of the study). |

(Table 1 continues on next page)

| First author (year) country | Data source and study design | Analytical sample | Exposure/s and measurement | Mental health outcomes | Main findings |
|--|---|-------------------|---|--|---|
| (Continued from previous page) | | | | | |
| Turgeman-Lupo (2020) ⁴⁹ Israel | Large cohort of Israeli employees 2 waves (2012/13 & 2014/16) Linear fixed effects regression | 1125 | <p><i>Sandwich caregiving</i></p> <p>In this study, sandwich caregivers were employees who work full time while living in the same household with at least one child 18 years of age or younger, and simultaneously providing unpaid assistance on a routine basis, such as help around the house, health care, or personal care, to an adult family member in need (e.g., parents, spouse, siblings). This status was based on participants' answers to the two following questions: (1) "Do you have children under the age of 18, living with you in the house?", (2) "Do you take care of a sick family member (parent, brother, spouse) (for example, escorting him/her to medical examinations, cooking, shopping, etc.)?"</p> <p>Categorised as; 1) sandwich (SG) caregiving (i.e., caregivers of both children and elders), 2) caregivers of children only, 3) 'caregivers of elders only, and 4) non-caregivers.</p> | Depressive symptoms Measured using the Personal Health Questionnaire (PHQ-9). | Non-carers were less likely to experience depressive symptoms than sandwich-caregivers. [b = -0.10, SE = 0.04, p < 0.01]. Sandwich carers were also more likely to have depressive symptoms than those caring for children [b = 0.08, SE = 0.03, p < 0.01], or elders only [b = 0.08, SE = 0.04, p < 0.05]. |

Table 1: Descriptive summary of included studies.

| First author (publication year) | Bias due to confounding | Bias in selection of participants into the study | Bias in classification of exposures | Bias due to departures from intended exposures | Bias due to missing data | Bias in measurement of outcomes | Bias in selection of the reported result | Study-level RoB judgement |
|------------------------------------|-------------------------|--|-------------------------------------|--|--------------------------|---------------------------------|--|---------------------------|
| Bijnsdorp (2022) ³⁷ | Moderate | Low | Moderate | Low | Low | Moderate | Low | Moderate |
| Cameron (2008) ⁴¹ | Serious | Low | Serious | Serious | Low | Moderate | Low | Serious |
| Chesley (2006) ⁴² | Serious | Low | Moderate | Low | Low | Moderate | Serious | Serious |
| Choi (2006) ⁴⁰ | Serious | Low | Moderate | Low | Low | Moderate | Low | Moderate |
| Ferrerira (2017) ⁴³ | Serious | Low | Moderate | Low | Moderate | Moderate | Low | Serious |
| Hajek (2018) ³⁸ | Moderate | Low | Moderate | Low | Low | Moderate | Low | Moderate |
| Heger (2017) ⁴⁴ | Moderate | Low | Moderate | Low | Serious | Moderate | Low | Serious |
| Hirst (2005) ⁴⁵ | Moderate | Moderate | Moderate | Low | Serious | Moderate | Low | Serious |
| Lacey (2019) ³⁹ | Moderate | Low | Moderate | Low | Moderate | Moderate | Low | Moderate |
| Mohanty (2019) ⁴⁶ | Serious | Low | Moderate | Low | Moderate | Moderate | Low | Serious |
| Oshio (2018) ⁴⁷ | Moderate | Low | Serious | Low | Low | Moderate | Low | Serious |
| Stratmann (2021) ⁴⁸ | Serious | Serious | Moderate | Serious | Serious | Low | Low | Serious |
| Turgeman-Lupo (2020) ⁴⁹ | Moderate | Serious | Moderate | Low | Low | Moderate | Low | Serious |
| Item-level judgement | Moderate | Low | Moderate | Low | Low | Moderate | Low | |

Table 2: Risk of bias/quality assessment.

presented in the albatross plot did not alter this finding ($p < 0.001$). Lastly, to complement the narrative synthesis, an effect direction plot is presented (Table 3) to enable visual synthesis of the effect direction of all included studies in the review.³⁶

As a quasi-sensitivity analysis, we considered whether our conclusions would be altered if only the results of the four studies^{37–40} at the lowest RoB overall (all those judged at moderate RoB overall) were included in the synthesis. Results were essentially unchanged. No study reported a positive effect of caring on mental health and the majority of studies, moderate risk of bias (66%) and serious risk of bias (81%) reported a negative effect. We are confident our synthesis (of the 13 eligible studies) is robust and aligns with the recommendation of synthesising studies.⁵⁰

Narrative synthesis

Of the thirteen studies comprising this review, only two studies reported no association between informal unpaid caregiving and mental health.^{38,41} Both of these studies examined caregiving as a binary variable across both genders (no sex stratified results), with one examining onset of caregiving,³⁸ whilst the other compared carers with non-carers.⁴¹ No studies included in this review reported a protective effect between informal caregiving and mental health.

The remaining eleven studies all reported a negative longitudinal association between informal unpaid care and mental health in at least one category or gender subgroup. Of the studies that were not stratified by sex, three examined their caregiving exposure categorically and reported that compared to non-caregiving, sandwich caregiving,⁴⁹ caring for biological parents and spousal caregiving,⁴⁰ and caregiving that imposes limitations on

carer’s life,⁴⁸ were all negatively associated with mental health. The remaining study not stratified by sex dichotomised caregiving (and non-caregiving) and also reported a negative association between caregiving and mental health.⁴⁶

Four studies examined women and men separately^{37,39,44,45} and a further three studies examined women only.^{42,43,47} All seven studies examining women reported a negative association between caregiving and mental health measures in women. The association was less uniform in men (in the 4 studies in which they were examined separately). Four of the seven studies examining women interrogated caregiving as a binary variable (vs no care) and all reported negative associations with mental health/depressive symptoms.^{37,42,43,47} One of these studies also examined men, reporting a negative association.³⁷ The three remaining studies examined both women and men through categorical caregiving exposures.^{39,44,45} For women, despite the significant heterogeneity between each individual study’s exposure categories, caregiving was uniformly associated with poorer mental health.^{39,44,45} The results for men were mixed. In one study, caregiving above 10 h per week (both in the 10–19 h/week and >20 h/week categories but not in the <10 h/week category) was associated with psychological distress in women, but for men, only above 20 h was associated with poorer mental health.⁴⁵ In another study, any frequency of parental caregiving (daily or weekly, compared to none) was positively associated with depression in both in daughters and sons.⁴⁴ Lastly, the third study reported higher levels of psychological distress in women who engaged in long-term (>3 years) or intermittent caregiving compared to non-caregivers (but no association for “one episode” of caregiving), but no association was reported for men in any category.³⁹

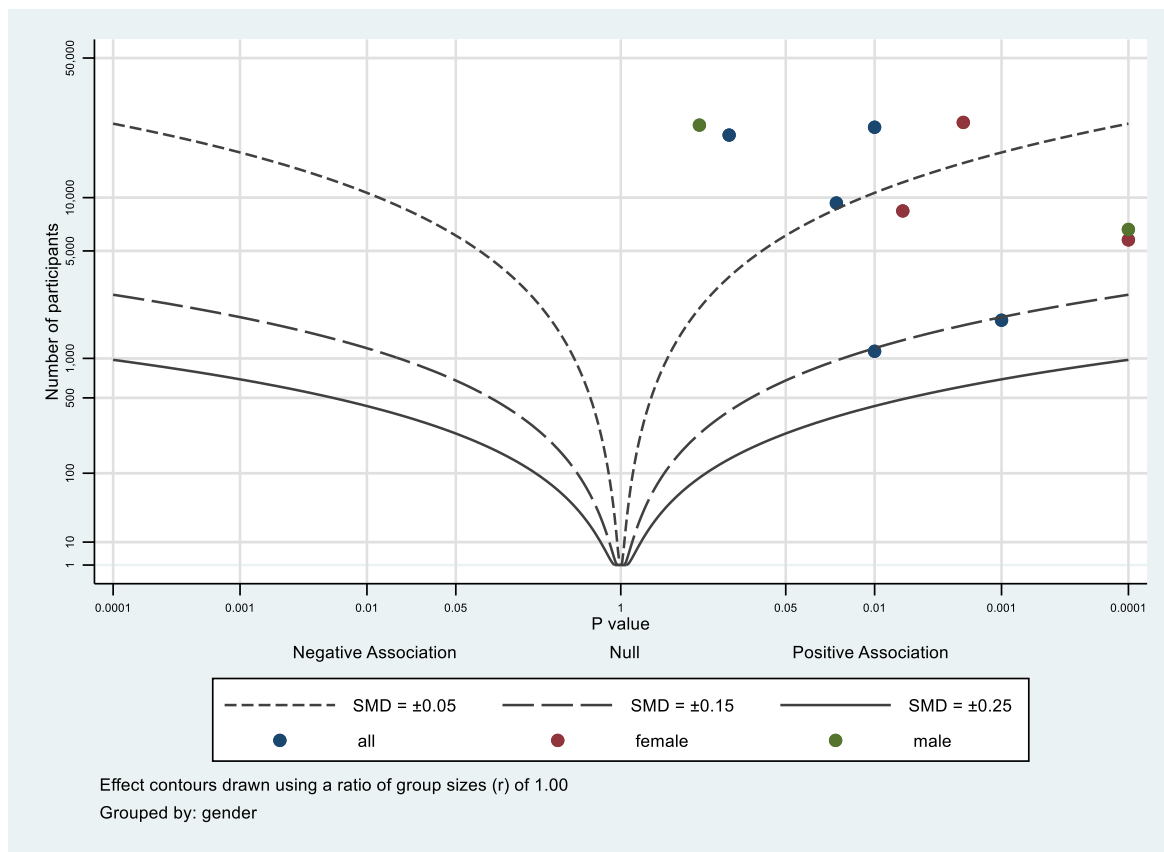


Fig. 2: Albatross plot. Containing 10 estimates (from 8 studies^{37,38,40,43,45,46,48,49}) where a standardised mean difference (SMD) or Cohen's d could be calculated. A positive association signifying that informal caregiving is positively associated with poorer mental health/depression. In studies where more than one estimate was reported, we chose the effect estimate for levels of exposure most comparable with the other included studies.

Discussion

Informal unpaid caregiving can significantly impact on the lives of those who provide it. This systematic review synthesised and assessed the quality of the quantitative longitudinal evidence examining the association between unpaid caregiving and mental health, amongst working age adults in high-income OECD countries. Where possible, we also interrogated gender differences in this association. Importantly, by imposing a non-caring comparator and restricting to studies with longitudinal design only, our review maximises causal inference in interrogating the relationship between informal caregiving and mental health. Overwhelmingly, this review suggests that unpaid caregiving is detrimental to the mental health of working age adults. Eleven of the thirteen included studies reported a significant negative association between care provision and mental health (either overall, or in at least one category when caregiving was interrogated as a categorical variable). No positive association was reported in any of the included studies. The overall quality of the evidence was moderate. Whilst no study was deemed at

critical risk of bias, all included studies were rated as either moderate or serious risk overall. Lastly, any observed gender differences were mild, but present. Men and women were analysed separately in only four included studies. Women were consistently negatively affected by unpaid caregiving in these four studies, whereas for men, results were less consistent.

Our finding that unpaid informal caregiving is detrimental to mental health aligns with the findings of previous systematic reviews that examined physical and mental health outcomes in caregivers of older adults.^{21,22} These reviews reported that higher levels of depression and lower mental health scores were associated with caregiving.^{21,22} Akin to our review, one also imposed a non-caring comparator,²² and another specifically examined the causal effect of informal caregiving on health.²¹ A third review that examined the subjective effects (emotional, psychosocial and physical) of caregiving (as opposed to caregiving status) also aligns with our findings, reporting a large positive association between these subjective caregiving effects and depressive symptoms.²³ Therefore, whilst acknowledging the

| Study | Risk of bias | Caregiving exposure (compared to no care) | Effect measure | All (non-sex stratified) | Women | Men |
|------------------------------------|--------------|---|----------------|--------------------------|-------|-----|
| Bijnsdorp (2022) ³⁷ | Moderate | Binary | B | | ▼ | ▼ |
| Lacey (2019) ³⁹ | Moderate | Categorical (long term 3+ yrs. and intermittent caring) | B | | ▼ | ◄► |
| Choi (2006) ⁴⁰ | Moderate | Categorical (biological parent and spousal care) | B | ▼ | | |
| Hajek (2018) ³⁸ | Moderate | Binary | B | ◄► | | |
| Cameron (2008) ⁴¹ | Serious | Binary | B | ◄► | | |
| Mohanty (2019) ⁴⁶ | Serious | Binary | B | ▼ | | |
| Stratmann (2021) ⁴⁸ | Serious | Categorical (caregiving that limits carers life) | OR | ▼ | | |
| Turgeman-Lupo (2020) ⁴⁹ | Serious | Categorical (sandwich carers; children and elders) | B | ▼ | | |
| Heger (2017) ⁴⁴ | Serious | Categorical (any frequency) | B | | ▼ | ▼ |
| Hirst (2005) ⁴⁵ | Serious | Categorical (caregiving for 10-19hrs per wk./>20 hrs per wk.) | OR | | ▼ | ◄► |
| Oshio (2018) ⁴⁷ | Serious | Binary | B | | ▼ | |
| Chesley (2006) ⁴² | Serious | Binary | B | | ▼ | |
| Ferreira (2017) ⁴³ | Serious | Binary | OR | | ▼ | |

Key Effect measure used: B = coefficient of linear regression; OR = odds ratio. Effect direction: upward arrow ▲= positive mental health impact; downward arrow ▼= negative mental health impact; sideways arrow ◄►= no change/mixed effects/conflicting findings.

Table 3: Effect direction plot.³⁶

differences in our sample population from these three prior reviews (ours of working age adults, and theirs weighted toward older (retired age) caregivers), our review contributes to mounting evidence that informal caregiving poses a significant threat to the mental health of unpaid caregivers.

Furthermore, our results generally align with a fourth review in the extant literature, reporting that unpaid caregivers of people with ill-health were more depressed than noncaregivers.²⁴ Yet, contrariwise they found that caregiving for healthy individuals may be protective for general health (however mental health was not examined, being limited by available studies).²⁴ Notably, this is the only prior review that, analogous to our review, had a mean working age sample population, and included childcare and care for other healthy individuals within their exposure. They noted however that studies examining care for healthy care-recipients were scarce (as was the case in our review), with only two studies identified: both of which examined grandparents as caregivers (caring for grandchildren) and general health status as the outcome. Given studies examining grandparents were largely excluded from our review (due to the working age restriction imposed), and that no studies examining caring for dependent children (compared to non-caregiving) were identified, our review was unfortunately delimited by the available literature with respect to the scope of care provision examined. Lastly, whilst this fourth review's sample age and definition of caregiving aligns most closely with ours, our review pertains exclusively to high-income OECD countries, where they examined low and middle-income countries.²⁴ Consequently, significant differences between geographical settings, contexts, and socio-cultural norms pertaining to caregiving and gender limits generalisability between the two reviews.

In addition to caregiving provision alone, it is recognised that care-recipient health status and other caregiving characteristics play important roles in the mechanisms through which caregiving impacts caregivers' health. For example, the affliction/illness experienced by the care-recipient can influence caregivers' health. In comparison to other diseases/conditions, caregiving for a loved one with dementia (or Alzheimer's disease) has been repeatedly reported to be especially impactful on caregivers' mental health.^{23,24} Moreover, caregiving features, such as the intensity of care provision is also an established contributor, with a prior review reporting larger effect sizes when more intensive care was provided.²¹ This was also evidenced in our review, where one study reported that caregivers' providing >20 h/week were twice as likely (as non-carers) to move above the GHQ threshold for high distress scores.⁴⁵ It is also likely that some nuance exists between the mental health effects associated with onset of caregiving compared to persistent caregiving. Whilst our review provides insufficient data to draw any conclusions, we note that one study reported transition into caregiving was associated with increased psychological distress in employed women, but no association was found for persistent care.⁴² In contrast, another study reported higher levels of psychological distress for women who engaged in long-term (>3 years) caregiving but not for those with "one episode" of caregiving.³⁹

Furthermore, whilst the caregiving stress process model (SPM)^{12,13} outlines possible mechanisms through which caregiving is posited to impact mental health, it is also recognised that unpaid caregivers experience both financial and time costs due to the demands of caregiving, both of which can negatively impact mental health. In addition, prioritising the care recipient over oneself can prevent carers from effectively practicing

self-care or other positive health behaviours. Moreover, carer's mental health can also be affected by the sheer worry and stress of someone they love and care about being unwell. This is known as the family effect.⁵¹ Whilst not relevant for caregiving for healthy individuals, the family effect has the potential to bias (over-estimate) the relationship between caregiving for ill kin and mental health.⁵² However, despite being an important consideration, disentangling the family effect from the impact of care provision is not commonplace.⁵¹ A prior review assessed whether included studies accounted for the family effect, with only two out of fifteen studies doing so.²¹ One study (also included in our review) did address this, through inclusion of an additional variable pertaining to "poor health of parent", in examining the effect of parental care on daughters and sons.⁴⁴ They concluded that the family effect was small.⁴⁴ Another study in our review, whilst not explicitly intending to interrogate the family effect, examined caregiving via category of care-recipient (biological parent care, parent-in-law care, spouse care, other kin care, non-kin care).⁴⁰ It is theorised that the family effect is smaller (or absent) for an ill parent-in-law compared to one's own parent,⁵³ and in reporting a significant association with depression for biological parental care compared to a null association for parent-in-law care, this study potentially substantiates a considerable family effect in this association.⁴⁰ Despite the contradictory results pertaining to the possible influence of a family effect in these two studies in our review, it is important to acknowledge that none of the other eleven studies in our review accounted for the family effect, thereby potentially mis-estimating the effect of caregiving on mental health.

Shifting the gaze to gender differences, caregiving in women was uniformly associated with poorer mental health across all seven studies that examined women. However, given only four of these studies also looked at men, any conclusions pertaining to gender differences are limited to these four studies solely. The results of which suggesting that men are affected, albeit less uniformly than women. This finding only somewhat aligns with prior reviews, with one reporting that in the minority of studies presenting sex-stratified estimates health effects were larger or solely present for females,²¹ another reporting that carer sex did not change their overall effect estimate for depression,²³ and a third reporting mixed results with worse health outcomes for women in two studies, one reporting the opposite effect, and three finding no gender differences.²⁴ Ultimately, the mild gender differences revealed in our review are likely driven considerably by differential exposure to caring. We know that women perform more informal care provision, especially in working age cohorts, where the juggle of paid work with unpaid caring commitments is an especially gendered phenomenon. Ultimately, time is a resource for health.⁵⁴ In general, when women are with faced high caregiving loads, other

commitments are not easily re-distributed,⁵⁵ but rather all these elements are piled together, driving time poverty and contributing to mental health tradeoffs.⁵⁶

Overall, our findings highlight the need to help alleviate the mental health risks of caregiving in working age adults. This is especially pertinent given informal care needs are increasing worldwide, both with the ageing global population as well as the ongoing demands of the COVID-19 pandemic. Such interventions exist and have been the focus of numerous reviews.⁵⁷⁻⁶¹ Measures include improving both services and support for caregivers, programs to enhance coping skills for caregivers, and various interventions such as subsidised professional home care, assistive technology and carer's leave policies.⁵⁷⁻⁶¹

Our review reveals several avenues for future research. These include a need for baseline data and stratification by gender, the inclusion of men in further scholarship, and consideration of the family effect when examining the mental health of caregivers. We also identified a dearth of studies examining caregiving for "healthy" care-recipients such as children and healthy adults/elders. Additionally, future directions should include exploring the nuance that may exist between types, intensity and duration (onset vs persistent) of caregiving and mental health. More recently there has been some suggestion that low-intensity caregiving is associated with decreased mortality.⁵² Given most studies in our review utilised a binary measure of caregiving, our caregiving cohorts are largely blended together; this not only oversimplifies caregiving but may also mask any potential protective effect that lower levels of care provision may have on mental health.

This review has some limitations. Firstly, misclassification is a concern for both the exposure and outcome measures in this review given they were ubiquitously self-reported through self-administered questionnaires. However, given this is likely non-differential, it is expected to bias results towards to the null, potentially leading to under-estimation of the true effect of caring. Additionally, estimates may be vulnerable to common method bias resulting in spurious or inflated associations between the exposure and outcome. Some individuals may systematically overstate both their unpaid caring status and mental health problems due to negative affectivity or other propensity for overly pessimistic evaluation, rather than an objective representation of the actual environment. We also acknowledge both the healthy carer effect (which could bias towards the null) and the family effect (which could bias results away from the null), neither of which could be adequately accounted for. Moreover, we acknowledge that the association between caregiving and mental health may be modified by gender, but we were unable to assess this due to insufficient number of studies presenting gender-stratified results. Lastly, we were limited by a lack of studies examining childcare (that is, studies on childcare that imposed a non-

caring comparator) and thus could not assess the effect of caregiving for children on mental health.

Noteworthy strengths of this review include restricting our review to studies of longitudinal design (maximising causal inference), imposing a non-caring comparator, reporting according to strict PRISMA guidelines (registered PROSPERO), and conducting the quality assessment of RoB using a rigorously validated scoring tool (ROBINS E).

This systematic review examined the quantitative longitudinal evidence of the association between informal unpaid caregiving and mental health of working age adults in high-income OECD countries. Overall, the results show a negative association between informal unpaid care and mental health for adults of working age. Importantly, all included studies were longitudinal in design, giving greater confidence in the results. Where studies were stratified by gender, caregiving had a consistently negative impact on the mental health of women. Very few studies examined men, but also revealed a negative effect where an association was found. The overall quality of studies was moderate, with no one domain of bias particularly problematic across all included studies. Our review highlights the urgent need for interventions to help mitigate the mental health risks of caregiving in working age adults. Whilst men need to be included in any further scholarship in this area, reducing the disproportionate caregiving load on women (given their differential exposure) is an additional crucial requirement for policy development.

Contributors

TK, JE, YT, and TP conceived the study and formulated the study design and literature search. JE conducted the literature search. JE and LFA conducted the screening, extracted and analysed the data, and conducted the quality assessment. YT and TK contributed to data verification, analysis and interpretation. YT and JE conducted the data synthesis. JE wrote the manuscript and prepared the figures and tables. All authors contributed to drafts of the manuscript and approved the final version.

Data sharing statement

The data used in this systematic review are publicly available. The data extraction form and data used for the risk of bias assessment are available upon reasonable request to the authors.

Declaration of interests

The authors have no competing interests to declare.

Acknowledgments

This research was supported by an ARC Linkage Project (LP180100035), and a Melbourne School of Population and Global Health Targeted Research Support Grant. JE and LFA acknowledge support from University of Melbourne Research Training Scholarships. TK is supported by an Australian Research Council (ARC) Discovery Early Career Award (DE200100607). YT is supported by a Victorian Health and Medical Research Fellowship.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.eclinm.2022.101711>.

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