

The mental and physical health of young carers: a systematic review



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The health of those who care for someone with a health condition or advanced age is poorer, on average, than non-carers. However, the health of young carers (<18 years of age) has been under-researched, especially in quantitative studies. This systematic review aimed to summarise studies assessing the mental and physical health of young carers. 1162 unique studies were screened and 14 associations between being a young carer and health were identified (two studies were treated as a single unit of analysis as they had information from the same sample). Most of the included studies were done in the UK, with the remaining studies done in the USA, Canada, Australia, and Austria. A cross-European study of 21 countries was also included. Five of the included studies investigated both mental and physical health outcomes, seven studies investigated only mental health outcomes, and one study investigated only physical health outcomes of being a young carer. All of the included studies, except one, were cross-sectional in design. Most studies found that young carers had poorer physical and mental health, on average, than their non-caregiving peers. However, the evidence is relatively weak and more quantitative research is needed, particularly research that is longitudinal in design and assesses physical health outcomes.

Introduction

Informal caregiving is typically defined as the provision of unpaid care for a friend or relative who requires additional support because of an illness, disability, or advanced age.¹ Caring tasks vary and often encompass practical support (eg, shopping or housework), emotional support, and physical or personal care. Informal caregiving is becoming increasingly important; an ageing population alongside an increase in years spent living in poor health has led to a larger need for care in many countries.² When this larger need is combined with rising age at parenthood, decreasing family size, and an increase in single-parent families, the responsibility of unpaid care is increasingly shared by children and young people. Although it is difficult to capture the true prevalence of young carers, the England and Wales Census 2011 reported almost 178 000 carers younger than 18 years.³ Estimates of the prevalence of young carers vary slightly but are typically between 2% and 8% of young people in high-income countries.⁴ However, the COVID-19 pandemic is likely to have increased this prevalence.⁵

Systematic reviews have previously been done to summarise studies of the physical and mental health of adult caregivers,^{6–8} including the health effects of providing care to people with specific conditions.^{9,10} These reviews show that there is, on average, a negative effect of providing care on both mental and physical health, especially for female caregivers and caregivers providing intense care (eg, living in the household with the care recipient or providing many hours of care).⁶ One of the most comprehensive reviews of the health of adult caregivers found that caregiving had the largest effect on depression compared with other health outcomes, although the authors note that this could be the result of an over-reliance on non-representative samples (eg, including convenience samples of

caregivers providing intense care).⁸ Furthermore, there was evidence of publication bias and of insufficient control for confounders (eg, socioeconomic circumstances).⁸

To our knowledge, no systematic reviews have considered the mental and physical health of young carers from quantitative studies, showing a strong under-recognition of young carers in research, particularly in quantitative studies.¹¹ Although previous systematic reviews on the health of adult carers provide a convincing basis for an adult carer health penalty (if caring can be assumed to be causal), we cannot assume that the same applies to young carers. Childhood is considered to be a protected phase of the life course in which activities like caring should be avoided.¹² Adult carers are likely to have more control over their care responsibilities than young carers because of increased human capital, legal, financial, and age advantages, and a better position to seek external social support.¹³ Consequently, young carers are recognised in social policy in the UK, Australia, Sweden, and Norway as particularly vulnerable carers. However, young carers are not recognised in social policies in most other countries.⁴ Hence, there is an urgent need to assess the unique needs of young carers and to inform appropriate social policies to better support these needs. In this systematic review, we aim to summarise quantitative studies assessing associations between being a young carer and both physical and mental health.

Methods

This systematic review was done in accordance with the Cochrane Handbook for Systematic Reviews.¹⁴ The protocol was registered on the International Prospective Register of Systematic Reviews (CRD42020189688) and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (appendix pp 2–3).

See Online for appendix

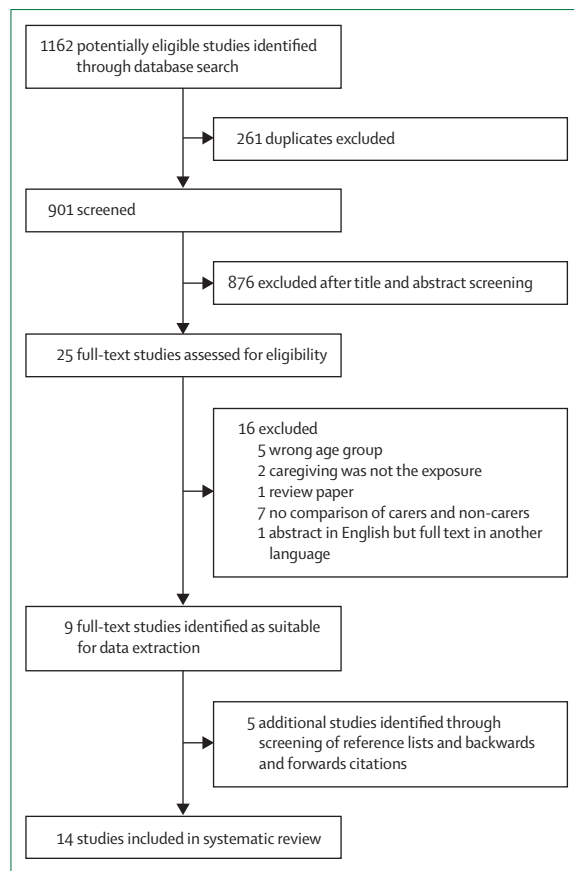


Figure: Study selection

Search strategy and selection criteria

A systematic search of peer-reviewed and non-peer-reviewed studies (including grey literature) was done between April 14 and April 19, 2021, and checking of backwards and forwards citations was done until Jan 23, 2022. Six electronic databases were searched (Applied Social Sciences Index and Abstracts, Cumulative Index to Nursing and Allied Health Literature, MEDLINE, PsycINFO, Scopus, and Google Scholar) with free-text and heading search terms (appendix p 4). Search terms were broad to ensure that all studies that included any health outcome—for which there would be too many search terms to be exhaustive—were found.

The identified studies were stored and deduplicated in EndNote, then imported into Rayyan Qatar Computing Research Institute.¹⁵ Two reviewers (REL and AM) independently screened all titles and abstracts to identify eligible studies. Studies were eligible for inclusion if they were quantitative (cross-sectional, case-control, or cohort study), published in English, assessed caregiving up to age 18 years (consistent with national and international definitions of young caring, such as the UK Children and Families Act 2014),¹⁶ and quantified at least one association between being a young carer (compared with being a non-carer) and any measure of physical or mental health.

We excluded studies that were not published in English, used samples of people older than 18 years, were reviews or opinion pieces, or did not include non-carers as a comparator group. The full texts of studies eligible for inclusion were then screened by both reviewers independently, according to the previously listed criteria. Reasons for exclusion were recorded at the full-text screening stage. Google Scholar search alerts were set up, reference lists were searched manually, and backwards and forwards citations of eligible full texts were done to ensure all relevant studies were captured.

Data collection and analysis

The quality of the included studies was assessed with an amended version of the Newcastle-Ottawa Scale (appendix pp 5–6). This measure was used to assess variability in quality across studies and potential bias, and was not used to guide the inclusion of studies. Any disagreements between the two reviewers were resolved through discussion. A third reviewer (BX) was available for unresolved disagreements, if necessary. Data from the included studies were extracted into a form, including citation details (first author surname and year of publication), study details (country, study design, sample size, and name of dataset used), participant characteristics (age range), details of health outcomes (measures used), and measures and strength of associations (eg, effect estimates).

Most studies presented several associations, often for both mental and physical health. As per the study protocol, any subgroup analyses (eg, by age group or gender) that emerged as important findings were also reported. Finally, a table of effect directions¹⁷ was produced to summarise the findings of all included studies.

Results

The database searches returned 1162 studies; once duplicates were removed, 901 studies remained. After title and abstract screening, 25 studies were eligible for full-text review. Of these 25, nine were eligible for inclusion in this systematic review (figure). The most common reasons for exclusion were the study not including a non-carer comparison group or not including people younger than 18 years. Searching the reference lists of included studies and checking backwards and forwards citations resulted in an additional five studies being included in this systematic review. Two included studies had information on the same sample,^{18,19} and so were treated as a single unit of analysis. Therefore, this systematic review includes 13 unique studies.

Characteristics of included studies

All studies were published between 2005 and 2022, and all studies, except two,^{20,21} were published in the past 10 years. Most of the included studies were done in the UK,^{18–20,22–26} and the rest were done in the USA,^{21,27}

Location	Dataset	Study design	Participants, n	Age range of sample	Health outcome	Definition of caregiver used	Quality assessment*
Buckner et al (2010) ³⁰ West Midlands, UK	England and Wales Census 2011	Cross-sectional	773 422	5–15 years	Self-report of general health over the past 12 months	Young person provides help or support to someone because they have long-term physical or mental health conditions, illnesses, or problems related to advanced age; reported by parent or head of household†	6 stars
Cheesbrough et al (2017) ³² England	Kantar Taylor Nelson Sofres Face to Face Omnibus	Cross-sectional	904	5–17 years	Self-report of general health over the past 12 months; mental health (measure not specified)	Child or young person provides help or support to a person or people who have physical or mental health conditions, are disabled, are misusing substances, or have problems related to advanced age; reported by parent or head of household	2 stars
Cohen et al (2012) ³⁷ Florida, USA	NA	Cross-sectional	1281	10–14 years	Behaviour Problems Index	Young person provides assistance to a family member who needs special care because of a medical condition, advanced age, or a disability; reported by the young person	6 stars
Collins and Bayless (2013) ³³ UK	NA	Cross-sectional	40	11–18 years	Strengths and Difficulties Questionnaire; Visual Analogue Self-Esteem Scale	Young person was recruited from a carers charity; reported by the young person	3 stars
Gallagher et al (2022) ³¹ Austria, Belgium, Switzerland, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, UK, Ireland, Israel, Lithuania, Netherlands, Norway, Poland, Portugal, Slovenia, Spain, and Sweden	European Social Survey wave 7	Cross-sectional	2279	14–18 years	Center for Epidemiological Studies Depression Scale	Young person looks after or provides help to family members, friends, neighbours, or others because of long-term physical or mental health conditions, a disability, or problems related to advanced age; reported by the young person	7 stars
Hunt et al (2005) ³¹ USA	NA	Cross-sectional	463	8–18 years	Behaviour Problems Index	Anyone aged 8–18 years in the household who provides unpaid help or care to any person; the care recipient does not necessarily live with the young person and the care can include help with personal needs, meals, household chores, shopping, paperwork, medication, transport, or regular visits to see how the care recipient is doing; reported by parent or head of household	6 stars
King et al (2021) ³⁹ Australia	Longitudinal study of Australian children	Longitudinal	3341	14 or 15 years when caregiver status established; 18 or 19 years when health outcome assessed	Kessler Psychological Distress Scale	Young person helps someone who has a long-term health condition, a disability, or problems with advanced age; reported by the young person	8 stars
Lakman and Chalmers (2019) ³⁸ Southern Ontario, Canada	NA	Cross-sectional	248	8–18 years	Center for Epidemiological Studies Depression Scale; Rosenberg Self-Esteem Scale; an adapted social anxiety scale	Not provided	5 stars

(Table 1 continues on next page)

Location	Dataset	Study design	Participants, n	Age range of sample	Health outcome	Definition of caregiver used	Quality assessment*
(Continued from previous page)							
Lloyd (2013) ³⁴ Northern Ireland	Kids' Life and Times survey	Cross-sectional	4192	10–11 years	Health-related quality of life; KIDSCREEN-10; self-rated health	Young person helps look after someone who has an illness, is disabled, or has problems due to advanced age; reported by the young person	6 stars
Nagl-Cupal et al (2014) ³⁵ Austria	NA	Cross-sectional	7403	10–14 years	Physical health (measures included quality of sleep, frequency of headaches, and frequency of back pain); mental health (measures included frequency of worry, sadness, and good mood)	Young person has a family member with a long-term illness or disability and provides a substantial amount of support with personal care, emotional care, or household activities; reported by the young person	5 stars
Robison and Egan (2017), ¹⁸ Robison et al (2020) ¹⁹ Glasgow, Scotland	National Health Service Greater Glasgow and Clyde secondary schools health survey	Cross-sectional	11 215	11–18 years	Physical health (measures included illness or disability that affected function, self-rated health, physical health conditions, and hours of sleep); mental health (measures included Strengths and Difficulties Questionnaire; frequency of worry about school, personal issues, family issues, appearance or the future; and mental health conditions)	Young person provides help or support to someone in their household who has long-term physical or mental health conditions, illnesses, or who are misusing substances; reported by the young person	7 stars
Sharpe et al (2021) ³⁵ Cornwall, England	Wellbeing Measurement Framework survey	Cross-sectional	7477	12–14 years	Strengths and Difficulties Questionnaire	Person aged <18 years provides regular or ongoing care to a family member who has an illness, a disability, a mental health condition, or who is misusing substances; reported by the young person	8 stars
Tseliou et al (2018) ³⁶ Northern Ireland	Northern Ireland census 2011	Cross-sectional [‡]	433 328	5–17 years [§]	Chronic mobility problems and chronic mental health issues	Young person provides help or support to someone because they have long-term physical or mental health conditions, illnesses, or problems related to advanced age; reported by parent or head of household [†]	8 stars

NA=not available. *From the Newcastle-Ottawa Quality Assessment tool. †The census form does not specify who should complete it. The form is addressed to the household, joint householders, or members of the household aged ≥16 years. Therefore, answers are listed as reported by a parent or the head of household. ‡This study has both longitudinal and cross-sectional components. However, the analysis of young carers aged 5–17 years is cross-sectional. §This study includes individuals aged 5–24 years but disaggregates to those aged 5–17 years and those aged 18–24 years for the analyses. Only the analysis for those aged 5–17 years was considered.

Table 1. Characteristics and quality assessment of included studies

	Study design	Age range of sample	Mental health outcome	Findings
Cheesbrough et al (2017) ²²	Cross-sectional	11–17 years	Self-reported emotions in the past week (measure not specified)	No differences in reports of emotions between young carers and their peers
Cohen et al (2012) ²⁷	Cross-sectional	10–14 years	Behaviour Problems Index	Young carers had higher amounts of anxiety and depressive symptoms than their peers; associations were strongest for young carers living with a care recipient
Collins and Bayless (2013) ²³	Cross-sectional	11–18 years	Strengths and Difficulties Questionnaire; Visual Analogue Self-Esteem Scale	Young carers had lower self-esteem than their peers; young carers had higher Strengths and Difficulties Questionnaire scores (total and on emotional symptoms, conduct problems, and peer problems subscales) than their peers; there were no differences in prosocial behaviours between young carers and their peers
Gallagher et al (2022) ³¹	Cross-sectional	14–18 years	Center for Epidemiological Studies Depression Scale	Young carers reported more depressive symptoms than their peers
Hunt et al (2005) ²¹	Cross-sectional	8–18 years	Behaviour Problems Index	Young carers aged 8–11 years reported more anxiety and depressive symptoms than their peers; associations were stronger for boys and when young carers lived with a care recipient; young carers aged 12–18 years reported more anxiety, depressive symptoms, and antisocial behaviours than their peers; there were no gender differences for this age group
King et al (2021) ²⁹	Longitudinal	14 years or 15 years when caregiver status established; 18 years or 19 years when health outcome assessed	Kessler Psychological Distress Scale	Young carers had poorer mental health 4 years after caregiver status was established than their peers; associations were strongest for young carers providing daily care
Lakman and Chalmers (2019) ²⁸	Cross-sectional	8–18 years	Center for Epidemiological Studies Depression Scale; Rosenberg Self-Esteem Scale; an adapted social anxiety scale	Young carers reported more depressive symptoms and poorer self-esteem than their peers; there were no differences in adapted social anxiety scale scores between young carers and their peers
Lloyd (2013) ²⁴	Cross-sectional	10–11 years	Health-related quality of life; KIDSCREEN-10	Young carers had lower health-related quality of life scores than their peers
Nagl-Cupal et al (2014) ³⁰	Cross-sectional	10–14 years	Self-reported emotions (measure not specified)	Young carers were more likely to worry and feel sad than their peers; young carers were less likely to be in a good mood than their peers
Robison and Egan (2017), ¹⁸ Robison et al (2020) ²⁹	Cross-sectional	11–18 years	Strengths and Difficulties Questionnaire; frequency of worry about school, personal issues, family issues, appearance, or the future; mental health conditions	Young carers had higher total Strengths and Difficulties Questionnaire scores than their peers; young carers were more likely to report worrying about school, appearance, personal issues, or family issues than their peers; young carers were more likely to report emotional or mental illness than their peers
Sharpe et al (2021) ²⁵	Cross-sectional	12–14 years	Strengths and Difficulties Questionnaire	Young carers had higher Strengths and Difficulties Questionnaire scores than their peers (total and on emotional symptoms, conduct problems, and peer problems subscales); there were no differences in prosocial subscale scores between young carers and their peers
Tseliou et al (2018) ²⁶	Cross-sectional	5–17 years	Chronic mental health issues	Young carers aged 5–17 years were more likely to report chronic mental health conditions than their peers; association was strongest for young carers providing more than 20 h a week of care

Table 2: Studies comparing the mental health of young carers with non-caregiving peers

Canada,²⁸ Australia,²⁹ and Austria.³⁰ One study was a cross-European analysis of 21 countries.³¹ All studies, except one,²⁹ were cross-sectional in design. Sample sizes varied from 40 to 773 422. Five studies considered both mental and physical health outcomes,^{18,19,22,24,26,30} seven studies considered only mental health outcomes,^{21,23,25,27–29,31} and one study considered only physical health outcomes.²⁰ The definition of the term young carer varied between studies (table 1). Most frequently, being a young carer was reported by the young person themselves. Ten studies mentioned potential reasons why someone might need care but only three studies included substance misuse as a reason.^{19,22,25} One study recruited young carers directly from a carer charity²³ and one study did not state how young carers were identified.²⁸

Most included studies were rated as being high quality (six or more stars; table 1, appendix p 7). Most studies had samples that were either truly or somewhat representative of young carers in society and had non-caregiving peers from the same source. Only seven of the 13 studies included controls for important confounders of the relationship between caregiving and health.

Mental health of young carers

12 of the included studies considered any mental health outcome (table 2). Nine of these studies applied at least one widely used, validated measure, such as the Strengths and Difficulties Questionnaire,^{18,19,23,25} the Behaviour Problems Index,^{21,27} the Center for Epidemiological Studies Depression Scale,^{28,31} the Visual Analogue

	Study design	Age range of sample	Physical health outcome	Findings
Buckner et al (2010) ²⁰	Cross-sectional	5–15 years	Self-rated health	Young carers were more likely to report poor health than their peers, particularly those providing >20 h a week of care
Cheesbrough et al (2017) ²²	Cross-sectional	5–17 years	Self-rated health	Young carers aged 11–17 years were less likely to report their own health as very bad than their peers; if young carer (age 5–17 years) health was reported by a parent or household head, young carers were less likely to have very good or good health than their peers
Lloyd (2013) ²⁴	Cross-sectional	10–11 years	Self-rated health	Young carers were less likely to report excellent health than their peers
Nagl-Cupal et al (2014) ³⁰	Cross-sectional	10–14 years	Self-reported physical health symptoms (measure not specified)	Young carers were more likely to sleep badly, be tired, have headaches, and have back pain than their peers
Robison and Egan (2017), ¹⁸ Robison et al (2020) ¹⁹	Cross-sectional	11–18 years	Illness, disability, self-rated health, physical health conditions, and hours of sleep	Young carers were more likely to have an illness or disability than their peers; young carers reported poorer health overall; young carers were more likely to report asthma, eczema, or psoriasis; stomach or digestive problems; and urinary or bladder problems; young carers reported fewer hours of sleep than their peers
Tseliou et al (2018) ²⁶	Cross-sectional	5–17 years	Long-term illness, long-term disability, and chronic mobility problems	Young carers aged 5–17 years (providing 1–19 h of care a week) were less likely to report mobility problems than non-caregiving peers; young carers providing >20 h of care a week were more likely to report mobility problems than their peers

Table 3: Studies comparing the physical health of young carers with non-caregiving peers

Self-Esteem Scale,²³ the Rosenberg Self-Esteem Scale,²⁸ or KIDSCREEN-10.²⁴ Of the three remaining studies, one only used a self-report measure of chronic mental health conditions²⁶ and two only included self-report emotions (for which the measure was not specified).^{22,30} Three studies used more than one mental health measure,^{18,19,23,28} such as the Strengths and Difficulties Questionnaire and self-report mental health conditions, or the Center for Epidemiological Studies Depression Scale and the Rosenberg Self-Esteem Scale.

Of the 12 studies examining associations between young caring and mental health, all, except one,²² found that young carers had poorer mental health than their non-caregiving peers. Young carers reported more symptoms of anxiety and depression,^{21,27–31} lower amounts of self-esteem,^{23,28} poorer health-related quality of life,²⁴ and more antisocial behaviours²¹ than their peers. Additionally, studies that examined associations with the Strengths and Difficulties Questionnaire found that young carers had higher total scores than their non-caregiving peers and higher scores on all subscales of emotional symptoms, conduct problems, and peer problems (but not prosocial behaviours).^{23,25} The Robison and colleagues studies^{18,19} only investigated differences in total Strengths and Difficulties Questionnaire score, finding that young carers had more total difficulties than their peers. Young carers were also more likely to report having a chronic mental health condition than their peers.^{18,19,26}

Some studies did subgroup analyses to assess if differences in health varied by gender, care intensity, or living arrangements. Regarding gender, Hunt and colleagues²¹ found that, for young carers aged 8–11 years, associations between caring and anxiety and depression were stronger for boys than for girls. However, gender differences were not observed for the same associations

at age 12–18 years. No other studies investigated gender differences. For care intensity, young carers who were living with the care recipient had the strongest associations with anxiety and depression.^{21,27} Furthermore, young carers providing more than 20 h a week of care²⁶ or providing daily care²⁹ had the poorest mental health, on average.

Physical health of young carers

Seven of the included studies considered physical health outcomes (table 3). Four of these studies included self-rated health^{18–20,22,24} and two included information on the presence of a limiting illness (an illness that restricts daily activities and work) or disability.^{18,26} One study asked about self-report physical health symptoms (no validated measure was specified), including sleep problems, headaches, tiredness, and back pain.³⁰ Two studies included reports of chronic mobility problems,²⁶ chronic physical health conditions,^{18,19,26} and sleep.¹⁸ Two studies included more than one physical health measure.^{18,26}

All studies that assessed physical health found that young carers reported poorer physical health, on average, than their non-caregiving peers. More specifically, young carers reported poorer self-rated health,^{18,20,24} were more likely to report a limiting illness or disability,¹⁸ physical health condition,^{18,19} or symptoms;³⁰ and reported fewer hours of sleep than their peers.¹⁸ The study by Cheesbrough and colleagues²² provided contradictory findings: young carers aged 11–17 years were less likely to report their own health as very bad compared with their peers. However, when health was rated by the parents of a young carer, they had poorer health than their non-caregiving peers. No studies reported gender differences in associations with physical health or by living arrangements.

	Study design	Sample size	Self-rated health	Mental health	Health-related quality of life	Physical health symptoms	Physical health conditions or long-term illnesses	Sleep	Study quality
Buckner et al (2010) ²⁰	Cross-sectional	Large	Negative effect on health	NA	NA	NA	NA	NA	Low risk of bias
Cheesbrough et al (2017) ²²	Cross-sectional	Large	No effects, mixed effects, or conflicting findings	No effects, mixed effects, or conflicting findings	NA	NA	NA	NA	Some risk of bias
Cohen et al (2012) ²⁷	Cross-sectional	Large	NA	Negative effect on health	NA	NA	NA	NA	Low risk of bias
Collins and Bayless (2013) ²³	Cross-sectional	Small	NA	Negative effect on health (two outcomes)	NA	NA	NA	NA	Some risk of bias
Gallagher et al (2022) ³¹	Cross-sectional	Large	NA	Negative effect on health	NA	NA	NA	NA	Low risk of bias
Hunt et al (2005) ²¹	Cross-sectional	Large	NA	Negative effect on health	NA	NA	NA	NA	Low risk of bias
King et al (2021) ²⁹	Longitudinal	Large	NA	Negative effect on health	NA	NA	NA	NA	Low risk of bias
Lakman and Chalmers (2019) ³⁸	Cross-sectional	Medium	NA	Negative effect on health (three outcomes)	NA	NA	NA	NA	Some risk of bias
Lloyd (2013) ²⁴	Cross-sectional	Large	Negative effect on health	NA	Negative effect on health	NA	NA	NA	Low risk of bias
Nagl-Cupal et al (2014) ³⁰	Cross-sectional	Large	NA	Negative effect on health (three outcomes)	NA	Negative effect on health (three outcomes)	NA	NA	Some risk of bias
Robison and Egan (2017), ³⁸ Robison et al (2020) ³⁹	Cross-sectional	Large	Negative effect on health	Negative effect on health (six outcomes)	NA	NA	Negative effect on health	Negative effect on health	Low risk of bias
Sharpe et al (2021) ²⁵	Cross-sectional	Large	NA	Negative effect on health	NA	NA	NA	NA	Low risk of bias
Tseliou et al (2018) ²⁶	Cross-sectional	Large	NA	Negative effect on health	NA	NA	No effects, mixed effects, or conflicting findings	NA	Low risk of bias

The number of outcomes in each category synthesis is one unless indicated in parentheses beside the effect direction. NA=not available.

Table 4: Effect directions for all included studies

One study explored the influence of caregiving intensity, finding that young carers aged 5–17 years who provide 1–19 h of care a week were less likely to report mobility problems than their non-caregiving peers.²⁶ However, young carers providing 20 or more h of care per week were more likely to report mobility problems than their non-caregiving peers.

Due to the variability in study design and presentation of results, a meta-analysis was not possible. A funnel plot to assess publication bias also was not possible. A summary of all study findings is shown in a table of effect directions (table 4).

Discussion

This systematic review shows that, on average, young carers have poorer mental and physical health than their non-caregiving peers. There was also some evidence to suggest that physical and mental health might be poorest for young carers providing intense care.^{21,26,27,29} Only one included study reported gender differences in associations between caregiving and

health;²¹ all other studies did not consider gender differences. All included studies, except one,²⁹ were cross-sectional in design, although most were rated as sufficiently high quality.

This systematic review has also identified research gaps. No studies were done in low-income or middle-income countries. Therefore, we do not know if the findings of this systematic review can be generalised to locations other than the high-income countries where the included studies were done (in Europe, the UK, the USA, and Australia), particularly when we know there is substantial variation in the support provided to young carers depending on location.⁴ There is therefore an urgent need to explore whether associations between being a young carer and health are similar in low-income and middle-income countries. It might be expected that in countries where there is little or no policy recognition of young carers and little support from other agencies (eg, charities) that young carers have poorer health than their peers compared with young carers in countries where there is good support.

Most included studies investigated associations between being a young carer and mental health outcomes. Those studies that considered physical health typically used self-rated health as a measure. Furthermore, the studies that considered specific physical health conditions or symptoms were poorer quality than the studies investigating mental health outcomes, most of which were cross-sectional in design. It is therefore difficult to assess if being a young carer affects physical and mental health, hence the need for more high-quality longitudinal studies that consider the physical health effects. Furthermore, few of the included studies investigated positive outcomes of being a young carer. Two studies that used the Strengths and Difficulties Questionnaire as a measure of mental health considered the prosocial scores, although both found little evidence that young carers had more prosocial behaviours than their non-caregiving peers.^{23,25} The study by Tseliou and colleagues²⁶ had mixed findings in relation to chronic mobility problems: young carers aged 5–17 years who provided 1–19 h of care a week were less likely to have mobility problems than their non-caregiving peers. However, young carers who provided 20 h or more of care a week were more likely to report chronic mobility problems than their non-caregiving peers. Future studies should focus on understanding whether there are any positive health benefits of being a young carer. However, our systematic review shows that, on average, being a young carer has a negative effect on health.

No included studies investigated the mechanisms through which young caring affected health outcomes. In adult care research, mediators of the effect of caring on health outcomes include caregiver burden,³² social support, social isolation,³³ and risky health behaviours (such as substance misuse or smoking).³⁴ The mechanisms by which being a carer leads to poor health could be different for young carers than for adult carers, but we do not yet know the extent to which this is true. Longitudinal studies are the best way to answer these research questions. Hence, there is a need for more longitudinal studies in this research area, particularly studies that have information on mediating factors over time to inform secondary prevention initiatives.

A further issue is that the causal effects of being a young carer cannot be estimated. Cross-sectional studies provide information on caring and health at one timepoint, but it could be that young carers have poor mental and physical health before becoming a carer. Longitudinal studies enable a researcher to disentangle the temporal ordering of care and health and therefore strengthen causal claims. Only seven of the included studies adjusted for important confounders when establishing associations between young caregiving and health. If confounders are not adjusted for then it is difficult to make confident conclusions. The longitudinal study by King and colleagues²⁹ applied causal inference techniques (augmented inverse probability weighting) to

estimate the causal effect of being a carer at age 14 years or 15 years on depressive symptoms at age 18 years or 19 years, reporting an average treatment effect of 1.10 (95% CI 0.37–1.80). Therefore, caring has a probable causal effect on the health of young people, but more high-quality studies that apply causal inference techniques and include comprehensive consideration of confounders are needed.

Research on the health of adult caregivers found that women are more likely to report adverse health consequences of caring than are men,⁸ as women are more likely to provide personal care. However, in this systematic review, only one study reported gender differences, finding that boys aged 8–11 years who were carers reported more anxiety and depression than girls who were carers and the same age.²¹ No other studies examined gender differences—consequently, gender differences are another knowledge gap that warrants further investigation.

There were no studies that investigated whether associations between being a carer and health differed by the reason for care (eg, the health condition of the care recipient). Again, this area should be researched in the future as findings from adult care research might not be generalisable to young carers. Research shows that adults caring for a relative with dementia is associated with particularly poor caregiver health.⁸ However, dementia typically occurs in older adults, for whom partners or adult children are most likely to provide care. If young carers are providing care to an older person (eg, a grandparent) with dementia, the role is likely to be as an auxiliary caregiver with less intense responsibilities.³⁵ Young carers (when they are primary caregivers) are most likely to be providing care for a parent and most often for a parent with mental health conditions.³⁶ Therefore, research into whether the health effects of being a young carer differ by the type of relationship between the caregiver and the care recipient is needed. Findings from adult care research show that providing care to a spouse or partner is associated with the worst caregiver health,³⁷ which will not apply to most young carers. The findings from Hunt and colleagues²¹ regarding carer living arrangements indicate that providing care for a parent is associated with poorer health than providing care for another type of relative. However, research that explicitly asks about the relationship between the carer and the care recipient, as well as the health conditions of the care recipient, is needed.

Finally, no studies assessed whether effects differed by ethnicity. Evidence from adult care research suggests that people from minority ethnic groups are more likely to be informal caregivers and to report worse psychological health than their peers.³⁸ Again, this research area warrants further investigation to establish if these differences apply to young carers.

This systematic review had some limitations.¹⁹ First, different studies used different age ranges for young

people. This lack of standardisation meant it was not possible to directly compare study findings due to differences in age of the study samples. Second, only studies published in English were included, so relevant studies published in other languages could have been missed, including a study excluded from this systematic review because it had an English abstract but Japanese full text.³⁹ The consequence of this exclusion criteria is the possibility that studies from high-income countries were more likely to be included. Importantly, there are also variations in awareness and identification of young carers between countries. Third, a formal analysis of publication bias was not possible, but most included studies did report statistically significant results (hence publication bias could be present). The meta-analysis by Pinquart and Sörensen⁸ found evidence of publication bias in adult caregiver research. Finally, it was not possible to establish much information about subgroup analyses (eg, gender differences) as the health of young carers is an under-researched area.

Implications and conclusions

This systematic review provides some evidence that young carers have poorer mental and physical health than their peers. The highest-quality studies (scoring eight stars in the quality assessment)^{25,26,29} had effect sizes suggestive of moderate clinical importance. For example, the study by King and colleagues,²⁹ which applied causal analyses, found that young carers had an average score two points higher than their non-caregiving peers on the Kessler Psychological Distress Scale (19 vs 21). This difference between total score represented a change from “No significant feelings of distress”²⁹ to “Mild depression and/or anxiety”.²⁹

Our Review also highlights that the association between young caregiving and health is a relatively new research area, at least in terms of quantitative studies (all studies identified were published since 2005). It is also an area of research with substantial knowledge gaps. There is a clear need for longitudinal studies investigating the health of young carers, ideally using causal inference methods and testing the mechanisms through which health is affected. Furthermore, all studies included in this systematic review were from a few high-income countries, in which young carers have at least some recognition in both policy and support programmes. Therefore, more research is needed to assess the health of young carers in other countries and social policy contexts, particularly in countries in which young carers receive no or little recognition or support. Furthermore, there is a need for research that explores differences by gender, health condition of the care recipient, relationship between the carer and care recipient, and ethnicity—such research could have the potential to inform policy and support programmes as to which young carers need the most support.

Contributors

REL conceptualised and designed the study, did the searches, reviewed all papers, did the quality assessment, extracted the data, and drafted the manuscript. AM designed the study, reviewed all papers, did the quality assessment, and commented on the draft manuscript. BX designed the study and commented on the draft manuscript. REL directly accessed and verified the underlying data reported in the manuscript and acts as guarantor for this study. All authors consented to submitting the manuscript for publication.

Declaration of interests

We declare no competing interests.

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