Public Health England

Protecting and improving the nation's health

Caring as a social determinant of health

Findings from a rapid review of reviews and analysis of the GP Patient Survey

Report and key findings

Contents

Executive summary

Unpaid carers provide critical support for people with health and social care needs. The majority of recipients of unpaid care are older parents or spouses and partners and changes in the make-up of our population indicate that the number of dependent older people in the UK will increase by 113% by 2051.[1] Supporting those who provide unpaid care to older people is therefore hugely important, and evidence is needed on how best to do this. The support provided by carers is often physically and emotionally demanding, with consequences for carers' own health and wellbeing.

In this work, PHE commissioned Newcastle University to a) explore the consequences of being an unpaid carer of older people, and b) identify evidence about how best to support this group of carers. To address these aims, a rapid review of existing evidence reviews (an 'umbrella review') was conducted, alongside analysis of data on carers (for any population) from the NHS England GP Patient Survey.

This work was undertaken during 2019 to 2020, prior to the COVID-19 pandemic. Therefore the work does not take into account the impact of COVID-19 on both the number of people providing unpaid care, the consequences of providing this care or mechanisms to support carers during COVID-19. This is recognised as a limitation of the work, however, many of the findings in relation to the impact of caring on the physical and mental health of carers will remain relevant in this context.

Key findings

Carers experience poor physical and mental health, but also have unmet care needs themselves

The evidence available suggests that the consequences of caring for older people are not significantly different to the consequences of caring for other populations. The rapid review evidence indicates that carers of older people experience poor mental health, including anxiety and depression, alongside 'carer burden'[*], stress and poor quality of life. This aligns with findings from previous research about the impact of providing unpaid care (for any population) on mental health.

The rapid review identified very little evidence about the physical health of carers of older people. However, the findings from the GP Patient Survey analysis of carers for any

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* The term 'carer burden' is the term used by the published studies included in this rapid review, and it is used in this report specifically in reference to those studies' findings.

population, including those caring for older people, showed that carers are at increased risk of illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep.

Evidence about the extent to which the health of carers differs from non-carers is limited. Taking into account age and other sociodemographic factors (see table 2.3), carers are 16% more likely than non-carers to live with 2 or more long-term health conditions. Among carers living with 2 or more long-term conditions, arthritis and high blood pressure are the most common conditions. Limited evidence (one review) from the rapid review of reviews indicates that mental health outcomes may be worse for carers compared to the general population. Overall, this evidence suggests that carers have their own complex health needs that are likely to be exacerbated by the demands of caring. Yet carers also report that they feel their general, mental health and long-term health care needs are not being met. This is supported by the observation that carers are less likely than non-carers to report using 5 or more medicines (polypharmacy), despite being more likely to live with multiple health conditions. This may suggest that carers struggle to access adequate services and support.

Different groups of carers may have different support needs

The rapid review of reviews suggests that younger carers, and carers with poor social and financial support, may experience higher 'carer burden' when caring for older people. Support that is specifically targeted at reducing the emotional, physical and social hardships associated with caring may be particularly beneficial for these groups. Findings from the analysis of survey data also indicate that older carers, and carers living in the most disadvantaged areas, are providing the most care (in terms of the number of hours per week). More time spent caring may place carers who are older or living in disadvantaged areas, at greater risk of poor health and delays in meeting their own needs. Support that enables access to services to meet carers' own health needs and reduces the risk of exacerbating existing poor health as a result of caring, may be helpful for these groups of carers.

There is a lack of clear and robust evidence about how best to support people caring for older populations, and gaps in evidence on key outcomes

The overall quality of the evidence about caring for older people was poor (with some exceptions), and the rapid review of reviews identifies key gaps in what is known. Clear, quantified estimates of the impact on mental health and 'burden' is needed to improve the quality of evidence. There was also a lack of evidence about the impact of caring for older people on physical health, social relationships and financial wellbeing. This points to a need for robust, high quality systematic reviews of these important, but overlooked, outcomes. Evidence is also needed to ascertain how best to support those caring for older people. Carefully designed interventions with clear pathways to impact (for example physical therapy to improve back pain) and robust evaluation are needed.

Considerations

Caring places demands on carers that affect their physical and mental health. Based on this work, 5 key considerations are offered for supporting carers:

- support for those caring for older people should aim to lessen the impact on their mental health, with targeted specialist support for depression, anxiety and stress when needed
- measures to prevent poor physical health that arise as a consequence of caring (for example injuries, back pain, high blood pressure) are an important part of supporting those caring for other people
- carers often have their own long-term conditions and disability, which should be addressed as part of any support package
- support is needed to reduce the perceived emotional, physical and social hardships associated with caring and improve quality of life for carers; contact with other carers may help to achieve this
- some groups of carers are at greater risk of poor health, and of experiencing the adverse consequences of caring – these groups may benefit from additional support

This work has also identified key gaps in evidence about the impact of caring for older people. To address these gaps, it is suggested that organisations involved in planning or commissioning research consider:

- a high quality comprehensive systematic review to identify the impact of caring for older people on physical health and social and financial wellbeing outcomes
- a high quality systematic review or primary research study to assess and identify the prevalence and severity of specific illnesses experienced by carers of older people, with comparisons to the general population
- robust evaluations of promising interventions for carers of older people, with clearly established pathways to impact on appropriate outcomes
- a national mapping of existing practice to gain a clear picture of what support and interventions are in place and develop a shareable resource of emerging and established good practice

Conclusions

This work contributes to mounting evidence that unpaid caring should be considered a social determinant of health. Carers experience poor physical and mental health, struggle to access services and are at risk of financial hardship. More robust evidence is needed to identify if there are unique consequences for those people caring for older adults and how best to support them.

Glossary

Term used in this report	Definition
Carer	Any person providing unpaid care to family members, friends or partners who have an illness, disability or frailty and require support. In this report, the term carers refers to adult carers of any age and ethnicity, and does not include those aged <18 years of age.
Caregiver/carer burden	In this report, we refer to caregiver or carer burden as an outcome reported by systematic reviews that were included in the rapid review of reviews. Typically, systematic reviews did not offer a clear definition of what constituted the outcome caregiver/carer burden, nor did they specify how the studies within the review defined it. We acknowledge that caregiver/carer burden is an ambiguous and potentially contentious, term. This criticism is also noted by others.[2] For the purposes of this report, we interpret caregiver/carer burden using the broad definition offered by Ge (2018): the perceived emotional, physical and social hardships associated with caregiving.[3] However it is important to acknowledge that the operationalisation of caregiver/carer burden may have differed between reviews and the studies included within them. We use inverted commas ('carer burden' or 'burden') throughout this report where the term is used to reflect the terminology used in the literature that we are reporting or synthesising.
Chi Square (X^2)	A statistical test of the relationship between 2 categorical variables.
Multimorbidity/multiple long-term conditions	In this report, we use these terms to refer to the presence of 2 or more long-term health conditions.[4]
Older people	There is no single definition of what constitutes an older person. In this report, we use this term to refer to those aged 60 years and over. However, for the purpose of the rapid review of reviews reported here, an age threshold was not used to define older people as many systematic reviews did not report this.

	Instead, reviews were included if they reported evidence about carers of older people, or carers of populations likely to include older people (for example people with dementia). The reader is referred to the methods section in Part 2 of this report for further detail.
Polypharmacy	In this report, we use this term to refer to the use 5 or more medicines.
Rapid synthesis/review	An approach that streamlines systematic review methods, in particular the selection and synthesis of studies, to produce a timely overview of evidence.
Review of reviews	A method of synthesising evidence from existing systematic reviews to produce an overview of what is known in response to a pre-specified question (also known as an umbrella review).
Role strain	In this report, we refer to role strain as an outcome reported by systematic reviews that were included in our rapid review of reviews. However, the systematic reviews that report role strain did not define this term. For the purposes of this report, we interpret role strain as the difficulties associated with a particular role or responsibility.[5] However, it is important to acknowledge that the operationalisation of role strain may have differed between reviews and the studies included within them. We use inverted commas ('role strain') throughout this report where the term is used to reflect the terminology used in the literature that we are reporting or synthesising.
Study weights/ weighted methods	A statistical method to adjust data so that a study sample more closely matches the population from which it is drawn.[6]
Systematic review	A method of identifying, pooling and summarising evidence on a given topic. Each stage of a systematic review is conducted in a way to minimise bias and thus achieve a robust and impartial summary of evidence.
Umbrella review	A method of synthesising evidence from existing systematic reviews to produce an overview of what is known in response to a pre-specified question (also known as a review of reviews).

Introduction and overview

There are approximately 5.8 million people in England and Wales providing unpaid care to ill and disabled family members, friends or partners. A typical carer is female, with those in their 50s and 60s most likely to be providing care.[8] Approximately 400,000 carers in the UK are aged over 85 years,[9] and the population of carers aged over 65 years is expected to increase to 1.8 million by 2030.[10] Care recipients are a diverse group, but the majority are older parents or spouses and partners.[8] Whilst the amount of care provided varies, around 14% of carers are providing 50 hours or more of unpaid care a week.[8] The economic contribution of this unpaid care is estimated to be up to £132 billion per year.[11]

Against a backdrop of increasing demand for social care, reduced state provision and an unstable private care market,[12-15] the role and contribution of carers to health and social care in England is critical.[16] Maintaining the mental and physical health and wellbeing of carers is therefore essential. Yet premature death, higher levels of disease and neglect of their own health care needs are known to be common amongst carers.[10] They are also twice as likely as non-carers to experience poor physical and mental health, with these outcomes exacerbated by social isolation, poor information and support, and financial stress.[17] Older carers are a particularly high-risk group: they are more likely to be living with long-term conditions and disability.[10]

The recent publication of National Institute for Health and Care Excellence (NICE) guidelines for supporting carers signals the high priority this issue has in health and social care policy.[18] A focus on carers of older populations is especially important. Those aged 85 years and over are in the fastest growing age group in the UK, and this population is expected to double to 3.2 million by 2041.[19] The growth in numbers of people aged over 85 will most likely translate to a growth in care needs. Indeed, estimates indicate that the number of dependent older people in the UK will increase by 113% by 2051.[20] Supporting carers of older populations should, therefore, be a priority for the UK.

The study presented here addresses 2 key questions relating to carers of older populations. First, what are the consequences of being an unpaid carer of older people? Second, how can this group of carers best be supported?

A rapid review of existing reviews (an 'umbrella review'), and analysis of data on carers (for any population) from NHS England's GP Patient Survey are the main components of this work. In addition, a set of resources is provided to support future research and practice: a profile of data sources on caring; local examples for health

and social care commissioning leads; and a set of considerations for future research and practice.

Structure of this report

This document is the main report and summarises the key messages. An annex document includes the methodology for the analysis presented in this report. The methodology is in a separate technical document to make this report more accessible, however it is recognised that many readers would welcome the scientific details. This report's key messages are structured in 4 parts. Key messages of the rapid review of reviews are reported in part 1, and the analysis of data from the GP Patient Survey in part 2. Part 3 draws together these findings and presents a set of considerations for future research and practice for supporting carers of older people. Finally, part 4 showcases local case examples.

Part 1: Rapid review of reviews

Key messages from this review about caring for older people

This rapid review of reviews aimed to summarise evidence about the consequences of caring, and the effectiveness of interventions, for those caring for older people.

The key messages are the following.

Quality and scope of the evidence

The overall quality of systematic reviews in this area was poor; only 2 high quality systematic reviews were identified, both reporting evidence about respite interventions.

Evidence mostly concerned mental health, quality of life and 'carer burden'. There were key gaps in evidence on carers of older people's physical health, and social and financial wellbeing outcomes.

Many reviews did not specify an age threshold for 'older' care recipients (for example >65 years).

Definitions of terms used as outcomes (for example 'burden', 'role strain') were frequently absent, meaning that it was difficult to identify what characteristics or aspects of carers' experiences had been measured.

Consequences of caring

Carers of older people experience poor mental health, poor quality of life and 'carer burden', but existing reviews provide little information on prevalence or severity.

Very few reviews included evidence about carers of older people's physical health, or their social and financial wellbeing.

Evidence that carers in general experience worse outcomes compared to the general population is limited in existing reviews.

Younger carers (for any population) with low levels of social and financial support may be at greater risk of 'carer burden'.

Interventions for carers

Some psychosocial interventions may have positive outcomes for carers. These were a mindfulness-based stress reduction intervention, and a combined yoga and meditation intervention. These may be considered promising interventions, but more evidence from higher quality reviews and primary studies is needed to confidently ascertain the benefits of these approaches.

The benefits of cognitive and education interventions for carers are uncertain.

There is no clear evidence that respite improves carers' mental health or 'carer burden'. However, evidence from one review indicated that carer satisfaction with respite was high, highlighting its important role in supporting them. There were also gaps in the review evidence about the impact of respite on many other types of outcomes (for example physical health), suggesting the need for additional research that aims to capture and measure other potential benefits of respite.

The potential pathways to impact for interventions targeting some outcomes were unclear. Carefully designed interventions with clear pathways to impact (for example physical therapy to improve back pain) and robust evaluation are needed.

Approach

The aim of this work was to undertake a rapid evidence synthesis to answer 2 questions which are:

- What are the consequences of caring for older people for the health, social and financial wellbeing of carers, and what do we know about how these consequences vary by age, sex, socioeconomic status and geographical location?
- Which interventions are effective (including consideration of costs) to promote health and wellbeing and access to services amongst carers of older people?

The approach to this evidence synthesis was a rapid review of published systematic reviews (from here on referred to as 'rapid review'). Preliminary scoping of the literature identified multiple systematic reviews on both the consequences of caring and associated interventions to support those caring for older people. Thus, the review of reviews ('umbrella review') approach was most appropriate as an efficient approach to assessing the evidence, without duplicating existing research. Rapid review methodology was employed, which uses a streamlined approach to study selection and synthesis in order to produce a timely overview of evidence.[21,22]

The methods of the rapid review in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines are included in the technical document

Findings

The methods for this synthesis and accompanying data summary tables are available in Appendices A and B of the technical report. Sixty-nine systematic reviews met the rapid review inclusion criteria. In addition, we found 4 reviews of reviews ('umbrella reviews') reporting evidence about the consequences of caring, and caring interventions, 3 of which were for carers of people with dementia.[23-25]

In light of 3 recently published reviews of reviews about caring for dementia specific populations, and in consultation with the project steering group, the main synthesis focused on systematic reviews about carers of older populations not specific to people with dementia. However, we have summarised these umbrella reviews of carers for dementia specific populations in Appendix C of the technical annex.

The following synthesis is, therefore, based on 12 systematic reviews that report evidence about caring for older people, not specific to those with dementia. Of these 12, 6 systematic reviews report evidence about the consequences of caring, and 6 systematic reviews report evidence about carer interventions.

A summary of the systematic reviews about dementia carers is provided in Appendix C.

Evidence about the consequences of caring

Table 1.4 (Appendix B) summarises the characteristics, outcomes and indicative risk of bias of the 6 systematic reviews reporting evidence about the consequences of caring for older people.[3,26-30]

The synthesis is reported first by the indicative risk of bias of the review (low, moderate and high), and then by the type of consequence identified in the reviews and which population sub-groups are at greatest risk of poor outcomes.

Evidence about the consequences of caring by review risk of bias

Of the 6 systematic reviews reporting evidence about the consequences of caring for older people: none were judged to have a low risk of bias; 2 a moderate risk of bias;[3,30] and 4 a high risk of bias.[26-29]

Table 1.5 (available in Appendix B of the technical document) summarises the findings of reviews by the appraised risk of bias. Consideration of the risk of bias is important as it gives an indication of how confident readers can be in the review findings. That is, the greater the risk of bias, the less confident readers can be in the review's findings and conclusions.

Evidence from reviews with a moderate risk of bias

Two reviews report that carers of older people experience 'burden', depression and anxiety, but prevalence and severity were either not quantified, or estimates varied substantially.[3,30] For example, one review reported the prevalence of 'burden' among carers ranged from 1% to greater than 35%, whilst another reported estimates ranging from 37% to 100%. One review presented limited evidence on which groups may be at greatest risk - this suggested that carers who are younger, male and with poor social and financial support may experience higher levels of 'burden'.[3]

However, this evidence was not quantified in the review and so it is not possible to describe the difference in reported 'burden' between these groups.

Evidence from reviews with a high risk of bias

Four reviews report that carers of older people experience 'burden', anxiety and stress, but prevalence and severity were either not quantified or highly variable.[26-29]

Evidence about the severity of depression among carers was variable.[26-28] For example, one review reports evidence of mild, moderate and severe depression, although it was not clear how 'mild', 'moderate' and 'severe' were defined.[26] Another review reports that the impact on depression varied, but with no further detail.[28]

One review indicated that levels of carer stress, anxiety and distress were higher than those of the general population, although by how much was not reported in the review.[28]

There was limited and mixed evidence about the consequences of caring for physical health in one review, with a positive impact on self-rated health but also evidence of increased pain and medication usage.[27]

Evidence about which groups may be at greatest risk was reported in 2 reviews.[27,28] One review reported the impact of caring on health was greater for females and married people.[27] Yet another review reported mixed evidence about whether 'burden' was greater for male or female carers.[28]

In summary

Whilst the evidence suggests that carers experience a range of poor mental health outcomes and 'carer burden', reviews do not typically quantify this, and when they do, estimates of prevalence and severity are variable. Outcome measures were

poorly defined in some reviews. What constituted low, moderate and severe depression, for example, were unclear. Only one review made comparisons with the general population, noting that stress, anxiety and distress outcomes were worse for carers. Overall, there was insufficient evidence to give confident estimates of prevalence and severity or say how these compare with the general population. There was also no review evidence about how the consequences of caring were different according to the type of care provided or how long carers had held caring responsibilities. Finally, this evidence comes from both reviews of moderate and high risk of bias, indicating a need for more robust reviews of these outcomes. Next, the synthesis of evidence is reported by the type of consequence.

Evidence about the type of carer consequences, and groups at greatest risk

In this section, evidence about the consequences of caring is summarised by the outcome reported: 'burden', depression, anxiety, distress, stress, physical health outcomes and quality of life. Evidence about which groups may be at greatest risk of these consequences is then summarised.

'Burden'
Carers experienced 'burden' (5 reviews) although there was insufficient evidence to quantify the severity of this and prevalence estimates vary.[3,26,28-30]

Depression
Carers experience depression (4 reviews), although estimates of the severity and prevalence of depression were variable (when reported).[26-28,30] Authors in one review[28] suggest the variation in this evidence may reflect heterogeneity in the measurement of this outcome.

Anxiety
Evidence indicated carers experience anxiety (2 reviews), although the severity was not quantified.[28,30] One review indicated anxiety in carers of older cancer survivors was higher than that of the general population.[28]

Distress
Evidence (one review) indicated that carers of older cancer survivors experience greater distress than that of the general population.[28]

Stress
Carers of older cancer survivors experienced higher levels of stress than that of the general population (one review).[28]

Physical health

One review reported mixed evidence about physical health outcomes for carers.[27] This may have reflected the way outcomes were measured, as there was evidence of a positive impact on self-rated health but increased pain and medication usage.

Quality of life

Carers experience lower quality of life compared to national levels or general population (2 reviews).[26,28]

Groups at greater risk

Three reviews report evidence about the risk of 'carer burden' for males and females, but evidence was conflicting between these reviews.[3,27,28] Evidence from one review indicated that a younger carer age was associated with greater 'burden', although it was not clear what constituted a 'younger' age.[3] Finally, one review indicated that those with lower social and financial support experience higher 'carer burden'.[3] The limited quantity of evidence about which groups of carers are at greater risk of poor outcomes indicates a notable research gap.

In summary, evidence from these reviews largely covered outcomes related to carer mental health, 'burden' and quality of life. There was a notable lack of evidence about physical health, social, and finance outcomes. This suggests that evidence about these outcomes may not have been subject to a systematic review. A systematic review of primary studies with targeted searches for physical health, social and finance outcomes may be warranted. Evidence about which groups were at greater risk was limited, with mixed findings regarding male and female carers. Younger carers and carers with poor social and financial support may be at high risk of 'carer burden'.

Carer consequences: summary

Six systematic reviews reported evidence about the consequences of caring for older people. Evidence largely reflected the impact on carer mental health, 'burden' and quality of life. Although no reviews were identified that were judged to have a low risk of bias, the direction of evidence across moderate and high-risk reviews was mostly consistent: carers experience poor mental health, quality of life, and 'burden'. A key limitation of these reviews is that estimates of prevalence or severity were either too variable to be informative or not quantified at all, with just one review indicating these outcomes were worse for carers compared to the general population. The lack of evidence about other ways in which caring may impact individuals, particularly physical health, social and finance outcomes, indicates a key gap in our understanding of the carer population from a research perspective. Further research may also indicate which groups are at greatest risk of poor outcomes.

Evidence about carer interventions

Table 1.6 (available in Appendix B of the technical document) summarises the characteristics, interventions, outcomes and indicative risk of bias of the 6 systematic reviews that reported evidence about carer interventions.[31-36]

The synthesis is reported first by the indicative risk of bias of the review (low, moderate and high), and then by the type of intervention identified in the reviews.

Evidence about carer interventions by review risk of bias

Of the 6 systematic reviews reporting evidence about carer interventions: 2 reviews were judged to have a low risk of bias;[34,36] one a moderate risk of bias;[35] and 3 a high risk of bias.[31-33]

Table 1.7 (available in Appendix B of the technical document) summarises the findings of reviews by the appraised risk of bias. As described earlier, considering review findings according to the risk of bias gives an indication of how confident readers can be in such findings.

Evidence from reviews with a low risk of bias

Two reviews evaluated evidence for respite interventions for carers of older people.[34,36]

There was no clear evidence in these reviews to suggest respite improved carers' mental health or 'carer burden'. However, experience in practice, and among carers, is that respite is beneficial. It is possible that discrepancies between this review evidence and real-world experiences are due to differences in the type or duration of outcome measures adopted in the studies reviewed. This is considered further below. Furthermore, respite varies greatly in type, duration and suitability; this heterogeneity may also partly account for these findings.

There were gaps in the evidence about the impact of respite on many other types of outcomes (for example physical health), suggesting the need for additional research that aims to capture and measure specific beneficial effects of respite.

One review did report that carer satisfaction with respite was high, highlighting its important role in supporting carers.

Evidence from reviews with a moderate risk of bias

There was limited evidence from one review that a mindfulness stress reduction intervention may improve carer depression and anxiety but not stress, health service use, quality of life, or self-compassion; and, a combined yoga and meditation intervention may improve carer self-compassion and quality of life.[35]

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Evidence from reviews with a high risk of bias

There was limited and mixed evidence that cognitive based interventions were beneficial to carers.[31]

Evidence about the impact of therapy interventions and psychosocial support interventions was mixed, with an improvement in some outcomes (see next section) but not others.[32,33]

In summary

There was no clear evidence that respite interventions are beneficial to carers' mental health or improve 'carer burden'. However, this likely reflects the measures adopted in individual studies and the variable nature of respite, rather than offering evidence about the overall value and impact of respite for carers. This is supported by the one review that indicated high carer satisfaction with respite care. Evidence from lower quality reviews tended to be mixed or limited in quantity based on the number of studies reporting the outcome. Next, a synthesis of evidence by the type of intervention identified across the 6 systematic reviews is reported.

Evidence about carer intervention by type

Interventions can be grouped into 5 types, according to their descriptions in the 6 systematic reviews: respite interventions, psychosocial interventions, educational interventions, cognitive interventions, and multicomponent interventions. However, there was often a lack of detail in the reviews about the nature of these types of interventions, such as their theoretical foundation, individual components or structure. Even so, the 5 types are similar to those used in other systematic reviews (for example see[31,37]). This section summarises evidence for each of these 5 types of intervention.

Respite interventions

Two reviews report evidence about respite interventions for carers.[34,36] Both reviews found no clear evidence to suggest that respite improved carers' mental health or reduced 'carer burden', although it may improve the carer-recipient relationship. Satisfaction with respite care was reported to be high in one review.[34] As noted earlier in this report, these findings do not correspond with real-world experience in practice and among carers about the value of respite. The measures adopted in individual studies likely account for some of this difference. For example, mental health outcomes may not be an appropriate measure of effectiveness of respite. That is, respite alone may not be enough to impact on mental health, with other therapeutic support potentially required alongside as an essential component of any intervention. There may also be outcomes where appropriate respite, even in the short-term, may show beneficial effects (for example stabilising physical illness or injury), but these outcomes were not measured or included in the reviews. Furthermore, the nature of respite care can vary greatly, and such heterogeneity

may offer a misleading picture of evidence. Finally, it is unclear whether the carers in the studies included in reviews had other, more pressing needs at the time that were not addressed. If respite is offered as an intervention in a study but does not meet the needs of the carer, it is unlikely to benefit them.

Psychosocial interventions

Three reviews report evidence about psychosocial interventions,[32,33,35] including: self-help and supported therapy;[32] a mindfulness stress reduction intervention and a combined meditation and yoga intervention;[35] and individual and group support interventions.[33]

There was mixed evidence about the impact of self-help and supported therapy on carer depression, anxiety and 'burden'.[32] Similarly, there was mixed evidence about the effect of individual psychosocial support interventions on 'carer burden' and depression.[33] Such individual psychosocial support interventions may improve carer stress and economic burden but this evidence was only identified in a single study in one review. There was no evidence of an effect on the outcome 'role strain'. Group psychosocial support interventions may improve carer stress, coping and knowledge but evidence was mixed for the outcomes of depression, 'carer burden' and 'role strain'.[33]

Evidence for 2 psychosocial interventions were reported in one review, but each intervention was evaluated in single studies: a combined yoga and meditation intervention, and a mindfulness stress reduction intervention.[35] There was evidence that the yoga and meditation intervention improved carer quality of life, self-compassion and mindfulness. The mindfulness stress reduction intervention also improved carer depression, anxiety, mindfulness, and self-efficacy, but not stress, health service use, quality of life, or self-compassion (defined as self-kindness, mindfulness and 'common humanity' (p.2) in the review reporting this outcome[35]).

Educational interventions

One review reported evidence about web-based educational interventions. Components of these educational interventions reported in the review included nurse and peer-led support to answer questions by email, provision of information on websites, and training in relaxation and exercise skills. There was no consistent evidence that these interventions were more beneficial than usual care.[32]

Cognitive interventions

Very limited evidence was identified for cognitive interventions (one review, identifying one study).[31] The components of this cognitive intervention reported in the review included calendar training and note taking, although the overall objective of this intervention was not clear. A small improvement in carer mood was observed in

the intervention group, whereas this outcome worsened for the control group. There was no effect of the intervention on subjective 'burden', quality of life or anxiety.

Multicomponent interventions

One review reported evidence about multicomponent interventions.[31] There was no evidence that an intervention based on support meetings with psychoeducation elements improved carer mood or 'burden'.

Key gaps in evidence about carer interventions

Table 1.8 (available in Appendix B of the technical document) maps intervention types against the outcomes reported in the reviews. Evidence for respite and psychosocial interventions was most wide ranging.[32-36] By contrast, there were notable gaps in evidence for cognitive, educational and multicomponent interventions. Outcomes reported less often were economic burden, relationships and physical health. This suggests a greater focus on these outcomes in future evaluations of carer interventions is warranted.

Carer interventions: summary

Six systematic reviews were identified that reported evidence about interventions for carers of older people. The benefits of respite were not clear in these reviews, but limitations in methodology, including a lack of clear potential pathways to impact, likely contributed to this finding. The evidence about education and cognitive interventions was limited in quantity and did not offer any convincing support for these approaches.

There were a small number of psychosocial interventions for which small quantities of evidence (single studies for each intervention in the identified reviews) suggested some positive outcomes for carers. These interventions may be considered promising, but require further evidence to clarify effectiveness and benefits for carers. These promising interventions include: a mindfulness-based stress reduction (an 8 week intervention comprised of training carers in yoga, meditation and mindfulness with in-person instruction and self-directed practice at home); and, a yoga +meditation intervention (an 8 week intervention comprised of training carers in yoga and meditation, with in-person instruction and DVD instruction for home practice).

Most evidence was focussed on respite and psychosocial interventions, with a particular emphasis on mental health, 'burden' and quality of life outcomes Less evidence was identified for other types of interventions, and physical, social and financial outcomes. Such evidence does exist in primary studies; this suggests a need for systematic reviews targeting these outcomes.

Conclusions from the rapid review of reviews

A rapid review of existing systematic reviews ('umbrella review') was undertaken to address the review questions: what are the consequences of caring for older people, and how do these vary across groups; and which interventions are cost-effective to promote health and wellbeing and access to services among carers? A large evidence base was identified. The majority of this evidence was specific to carers of people with dementia. Given that there were 3 recently published reviews of reviews on caring for this population, the project steering group and research team decided to focus the rapid review synthesis on evidence about carers for older populations not specific to those with dementia.

Drawing this evidence together, it is possible to conclude that carers of older people experience poor mental health, quality of life and 'burden'. However, estimates of prevalence and severity were either absent or too variable to be informative. Only very limited evidence gave an indication of how these outcomes compared to the general population. In terms of interventions to support carers of older people, limited evidence provided no strong support that education and cognitive interventions were beneficial. In contrast with real-world experiences, there was no clear evidence to suggest that respite care benefits carers' mental health. However, the complex, variable nature of respite, combined with the outcomes chosen to measure effectiveness, may undermine the overall value of respite care for carers. Indeed, satisfaction with respite was reported to be high. Some psychosocial interventions were identified that had positive outcomes for carers. However, evidence was very limited in quantity and further research is needed to ascertain the effectiveness of these interventions for carers of older people.

Gaps in evidence in existing reviews indicates a need for robust reviews targeted at consequences and intervention outcomes relating to physical health, social and finance outcomes. Finally, the appraisal of review risk of bias suggests a need for a more robust systematic review of both carer consequences and carer interventions for those caring for older people.

Part 2: Analysis of GP Patient Survey data

Key messages from this analysis about carers

This analysis aimed to explore data from the 2019 NHS England GP Patient Survey about carers and caring in people aged 45 years and over. It should be noted that this analysis could not identify those caring specifically for older people. The key messages are:

Care providers

Carers were more likely to be younger, female and white, compared to people who do not provide care.

Around half of carers in this survey reported providing between 1-9 hours of care per week.

Around one fifth of carers were providing more than 50 hours of care per week; of those providing more than 50 hours of care a week, the highest proportion of carers were living in the most disadvantaged areas.

After adjusting for sex, ethnicity and deprivation, older age groups were less likely than the youngest group (45 to 54 years) to be carers. However, if older people were carers, they were more likely than younger groups to be providing more than 9 hours of care per week.

After adjusting for age, ethnicity and deprivation, men were less likely than women to be carers, and less likely to be providing more than 9 hours of care per week.

After adjusting for sex, ethnicity and age, respondents living in the most deprived areas were less likely to be carers. However, if they were carers, they were more likely than those living in the least deprived areas to be providing more than 9 hours per week.

Of carers that were working full-time, more were male (56%) than female (44%); Carers in part-time work or who reported caring for the home or for family were predominantly female. Half of all female and male carers were in full or part-time work.

The health of carers

After adjusting for age, sex, ethnicity and deprivation, carers were 16% more likely than non-carers to be living with 2 or more long-term health conditions.

Arthritis and high blood pressure were the most common of all long-term conditions reported by carers.

Carers were more likely than non-carers to report feeling that their physical and mental health needs were not being met, and were dissatisfied with the availability of GP appointments.

After adjusting for age, sex, ethnicity and deprivation, carers were less likely than non-carers to report using 5 or more medicines (polypharmacy).

Approach

The aim of this component of the study was to undertake an exploratory analysis of data about carers using the GP Patient Survey dataset, guided by a predefined set of questions (Appendix D of the technical document). The methods used for the analysis of the GP Patient Survey can be found in Appendix E of the technical document.

Findings

This section reports the findings of the bivariate chi square analyses, which summarise patterns about the relationship between carers, health, access to services and employment. The findings of the logistic and ordinal regressions are then reported. These regressions model a) the factors associated with caring, b) the relationship between caring and multiple long-term conditions, and c) the relationship between caring and the use of 5 or more medicines.

Overview of carers in the survey

The 2019 annual GP Practice Survey was returned by around 760,000 respondents, a response rate of 33.1%. The majority of the sample (90%) were white, and 51% female. Of all respondents, 17% reported having some caring responsibility. The baseline characteristics of those respondents that reported providing care are described in Table 2.1 (Appendix E of the technical document). Carers, compared to non-carers, tended to be younger, female, white, and to be registered with a GP practice outside London.

Carers' health and access to services

In terms of carer health, carers were less likely than non-carers to report: being deaf or using sign language; problems with physical mobility or falls requiring medical attention in the past 12 months; taking 5 or more medicines; and to have had a recent unexpected stay in hospital.

Carers were more likely than non-carers to: have seen their GP recently; have been successful in making an NHS dental appointment; be dissatisfied with the GP appointment times offered to them; and to feel that their general, mental health and long-term health care needs were not being met.

Of carers who reported that they had not had time to visit a dentist, most (48%) cared for 1 to 9 hours per week and 26% reported caring for 50+ hours per week.

Carers were more likely than non-carers to report suffering from a long-term health condition, and to report feeling isolated. Carers were less likely to be regular smokers.

Carers and employment

More carers who reported working full or part time were in the younger age groups (45 to 54 and 55 to 64). Most older carers (aged 85+) reported being fully retired (Figure 2.1).

Figure 2.1. Employment status of carers by age group
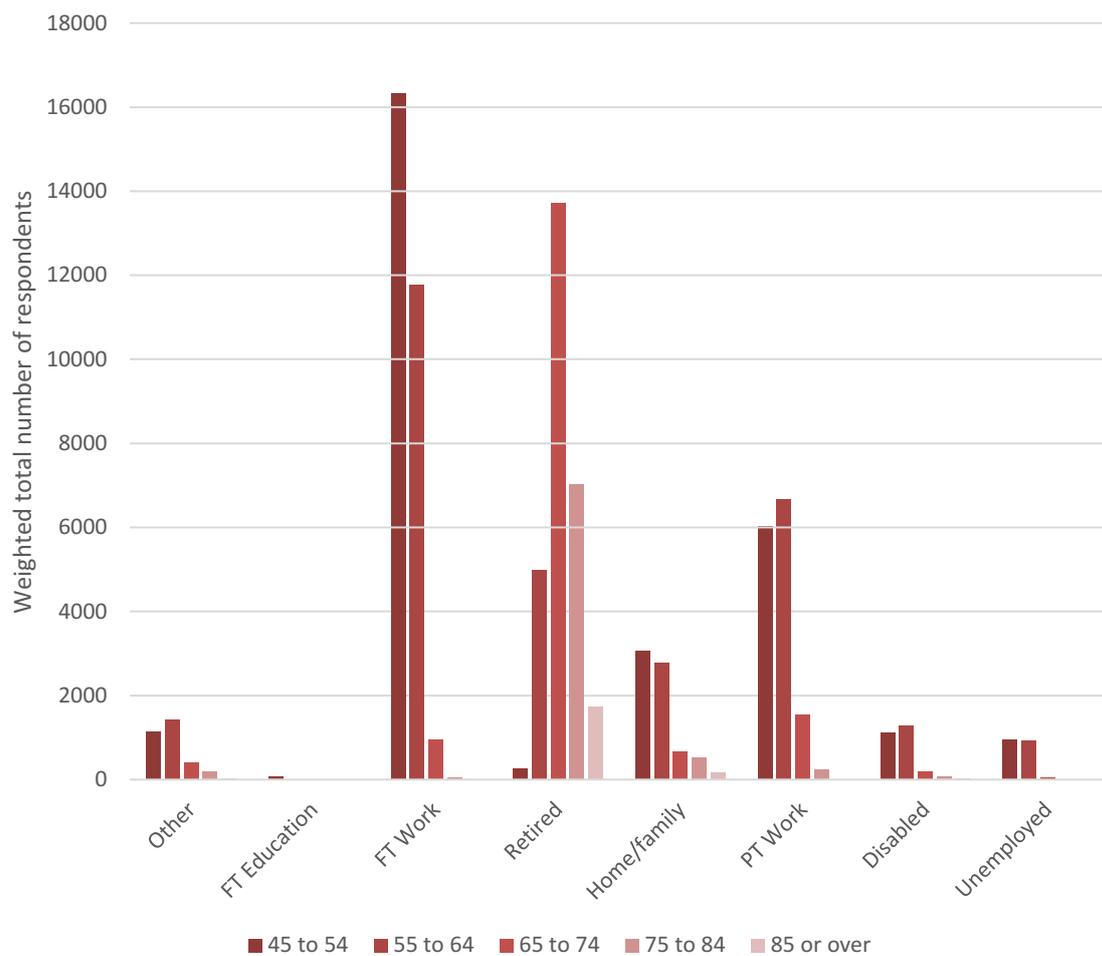
Source: Analysis of GP Patient Survey Dataset, 2019

Of those carers that reported working full-time, more were male, whereas carers in part-time work or who reported caring for the home or for family were predominantly female (Figure 2.2).

Figure 2.2. Employment status of carers by sex
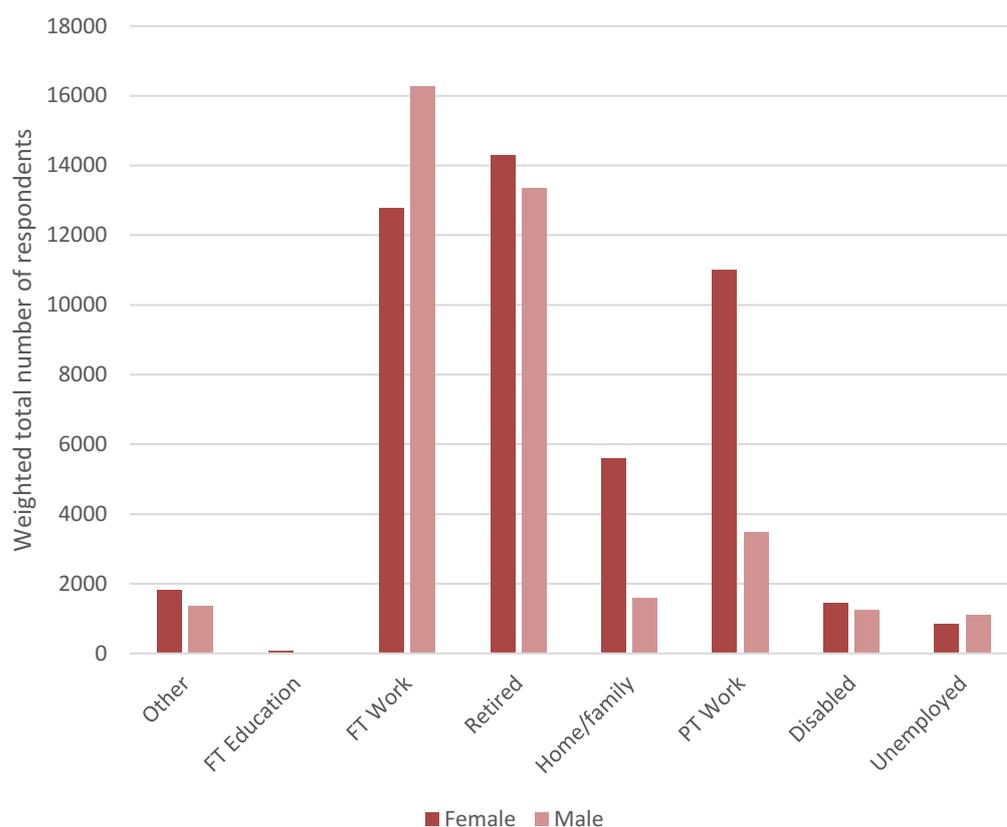
Source: Analysis of GP Patient Survey Dataset, 2019

The amount of care that carers provide

Of those respondents that reported caring, 55% reported caring for 1 to 9 hours per week, 12% reported 10 to 19 hours, 7% reported 20 to 34 hours, 6% reported 35 to 49 hours and 20% reported 50 or more hours per week. Among carers, providing 1 to 9 hours or 50+ hours of caring were the most common responses irrespective of carer age.

In older age groups, fewer respondents reported caring for 1 to 9 hours compared to 50+ hours per week, which was the most commonly reported category in the 85+ age group (Figure 2.3).

Figure 2.3. Number of weekly hours of caring by age group of carer
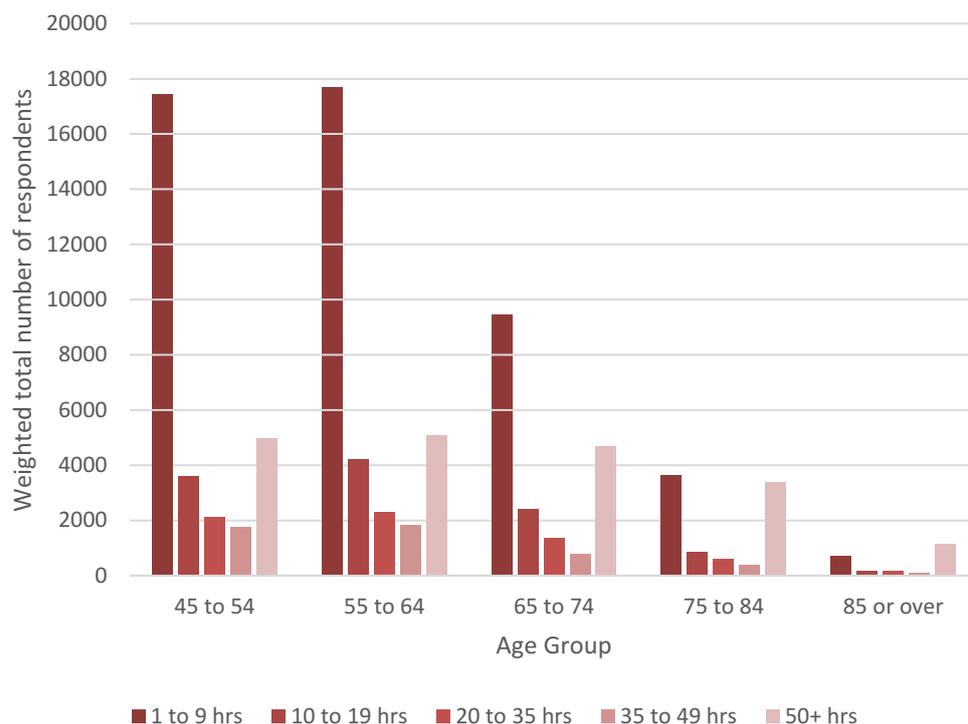
Source: Analysis of GP Patient Survey Dataset, 2019

The pattern of hours of care provided was similar between sexes, but there were more female carers providing every level of care (Figure 2.4).

Figure 2.4. Number of weekly hours of caring by sex

Source: Analysis of GP Patient Survey Dataset, 2019

26
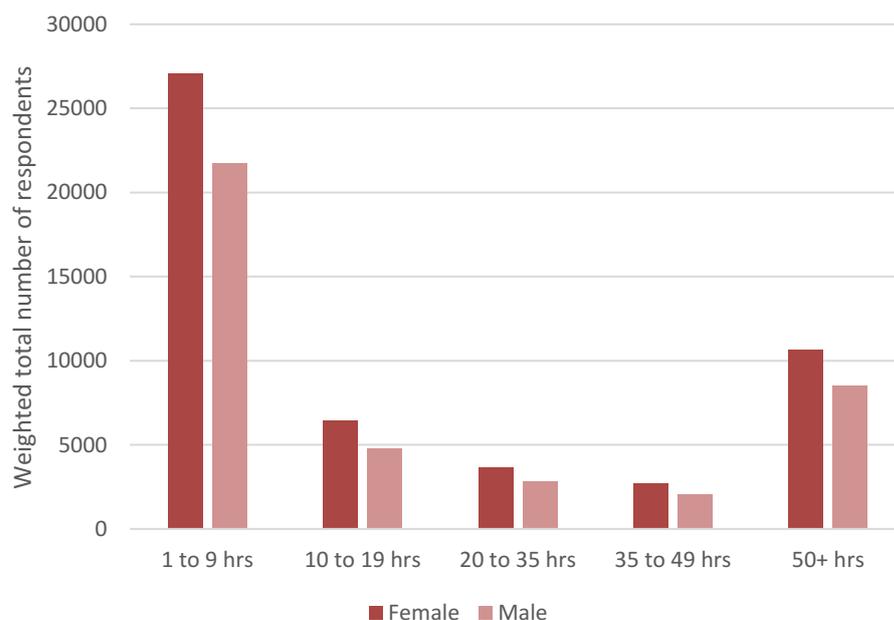
There was a trend towards greater deprivation among those carers that provided the most hours of care weekly (Figure 2.5).

Figure 2.5. Number of weekly hours of caring by tertials of socioeconomic deprivation
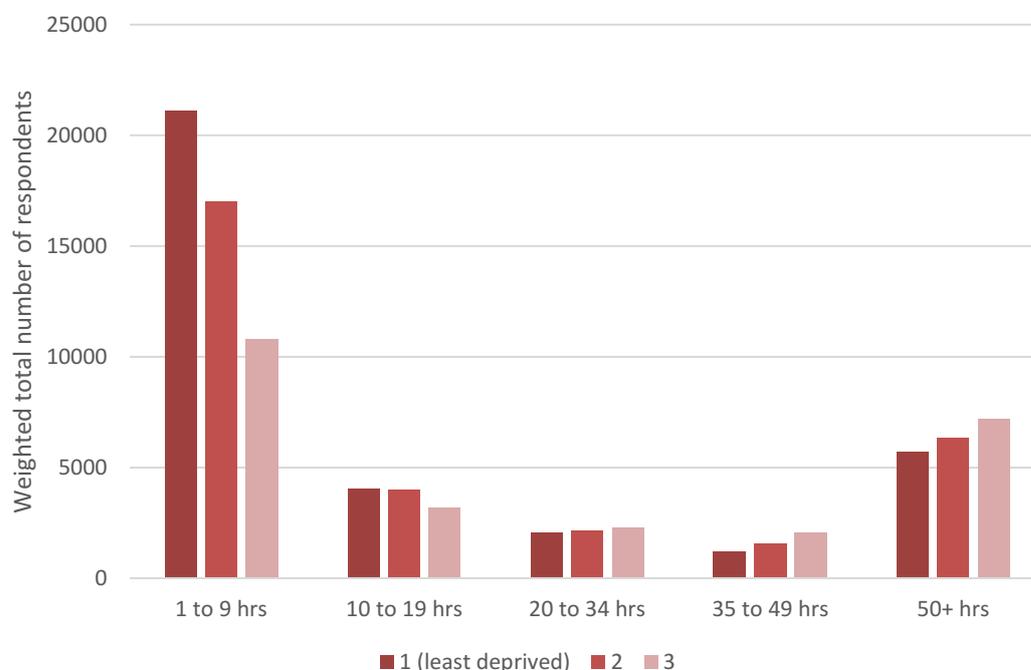
Source: Analysis of GP Patient Survey Dataset, 2019

Factors associated with being a carer

The association between age, sex, ethnicity and deprivation with caring was analysed (table 2.2, available in Appendix E of the technical document). People in older age groups were less likely to be carers, but if they were carers, then they were more likely to report caring for more than 1 to 9 hours per week. Whilst carers were less likely to be older, this may reflect the age restrictions applied to the analysis (that is those aged 45 years and over). The greater time spent caring by older carers may reflect that they are spousal carers.

Men were less likely to be carers than women and were less likely to be caring for more than 1 to 9 hours per week. Non-white respondents were less likely than white respondents to be caring at all, but if they did, Asian and 'other' ethnicities were more likely to be caring for more than 1 to 9 hours per week. Similarly, respondents in more deprived areas were less likely to be carers, but if they were carers, they were more likely to be caring for more than 1 to 9 hours per week.

The relationship between caring and multiple long-term conditions

The presence of multiple (2 or more) long-term conditions was calculated from patient responses to question 35 of the survey, excluding autism and learning disabilities (which were likely to be present since birth).

Carers reported a range of long-term health conditions. Arthritis and high blood pressure together accounted for 44% of conditions reported (Figure 2.6).

Figure 2.6. Long-term health conditions reported by carers in the 2019 GP Patient Survey
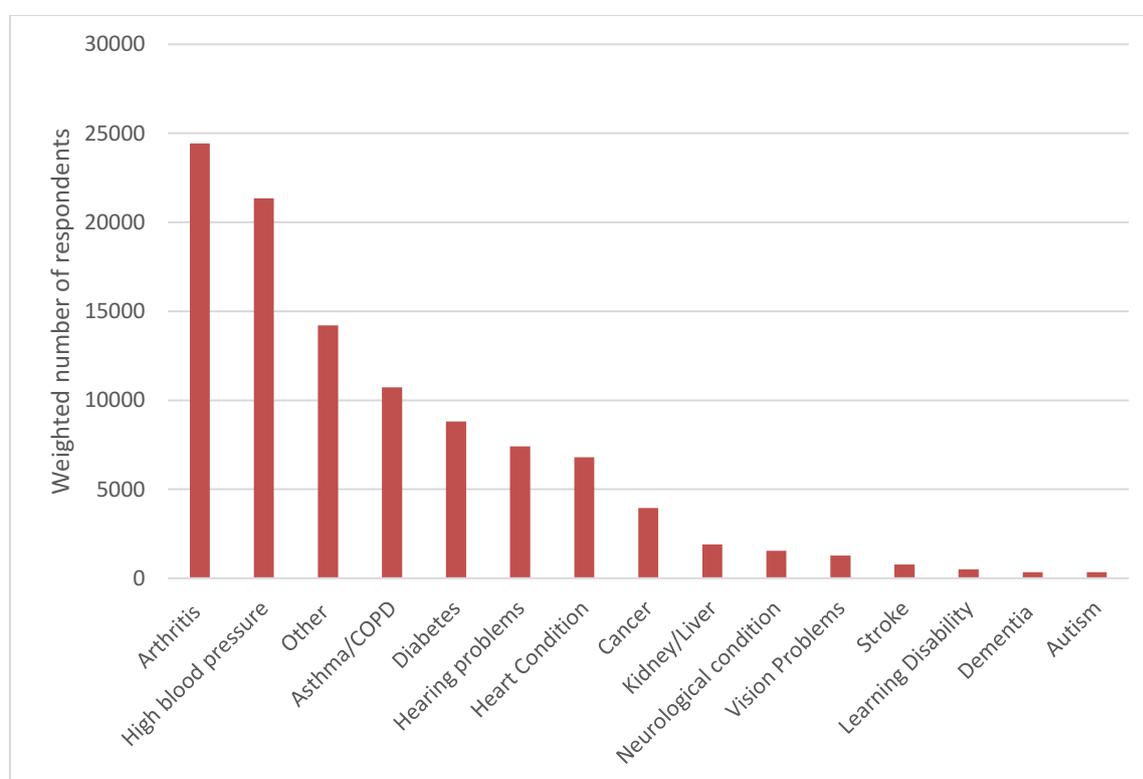
Source: Analysis of GP Patient Survey Dataset, 2019

Table 2.3 reports the results of a logistic regression model of the effects of caring (any versus none), age, sex, ethnicity and deprivation on whether a respondent reported multiple long-term conditions (available in Appendix E).The risk of multiple long-term conditions was 16% higher among carers than non-carers. Having multiple long-term conditions was strongly associated with older age, male sex, and greater deprivation status.

The relationship between caring and polypharmacy

Question 33 of the survey asked participants whether they took 5 or more medications on a regular basis (polypharmacy). This response was used in a logistic regression (reported in Table 2.4, Appendix E of the technical document). Carers were less likely to report using 5 or more medications compared to non-carers. Polypharmacy was strongly associated with increasing age, male sex, Asian and 'other' ethnicities compared to white respondents, and more deprived areas compared to the least deprived. Of those patients who responded to the questionnaire, black respondents were significantly less likely than white respondents to report using 5 or more medications.

Conclusions from the analysis of the GP Patient Survey

Data from the GP Patient Survey were analysed to explore the profile of carers. The findings suggest a nuanced picture of carers in terms of who they are and the amount of care provided. That is, carers in this survey tended be younger, women, living in the least deprived areas, and white. However, those providing the highest number of hours of care tended to be older and living in the most deprived areas. Evidence indicated that carers were living with multiple long-term conditions, yet felt that their own physical and mental health needs were not adequately addressed and reported difficulties accessing primary care. Of all long-term conditions reported by carers, arthritis and high blood pressure were most common. Finally, despite carers being more likely than non-carers to have multiple long-term health conditions, they were also less likely to report using 5 or more medications.

Part 3: Discussion and considerations

Supporting carers is a high policy priority in the UK.[18] This report focuses on the population of unpaid carers who support older people, and seeks to understand the impact of this role and how carers can best be supported. A rapid review of reviews and an analysis of data on carers (for any population) from the GP Patient Survey were conducted to explore these issues. This section of the report discusses the findings of the rapid review and data analysis, suggests considerations for those in practice and planning future research, and presents a logic model to inform future types and evaluations of carer interventions.

Summary of key findings

Table 3.1 summarises the triangulation of findings from the rapid review and the analysis of the GP Patient Survey. Four overarching findings can be drawn from this work.

Table 3.1. Triangulation of findings

	Rapid review (carers of older people)	**Analysis of survey data (carers for any population)**
What are the consequences of caring for older people?	Poor mental health including anxiety, depression, and stress 'Carer burden' Poor quality of life	Multiple long-term conditions Poor mental and physical health Arthritis High blood pressure
Which groups of carers are at greatest risk of 'carer burden' and poor health?	Younger carers ('burden') Carers with low levels of social and financial support ('burden')	The analysis could not identify which carers were at greatest risk of multiple long-term conditions and poor health. However, carers who were older and living in the most deprived areas are providing more hours of care and may be most susceptible to the consequences of caring

Caring is a social determinant of health

Carers for any population, not just of older people, experience poor physical and mental health, with those from disadvantaged areas the most severely affected. Evidence from the rapid review confirms the presence of mental health conditions alongside 'carer burden' and poor quality of life, for those caring for older people, although it was not possible to quantify prevalence and severity of these outcomes. A small quantity of evidence from the rapid review also indicated that some of these outcomes were worse for carers of older people than the general population. The analysis of the GP Patient Survey reveals the presence, and increased risk, of multiple long-term conditions among carers (for any population), with arthritis and high blood pressure accounting for 44% of this. These poor health conditions may be a direct consequence of caring, or they may pre-date the caring role. Either way, this evidence describes a population who will have a set of complex health needs that are likely to be exacerbated by the demands of caring. Despite this profile of poor health, carers were less likely than non-carers to report using 5 or more medications, with further evidence indicating unmet mental and physical health needs and difficulties accessing primary care. In the context of what is known about carers delaying their own healthcare due to caring responsibilities,[38] these findings signal a potentially vulnerable population who could benefit from preventative and targeted support.

Furthermore, evidence that carers experience worse health than non-carers would suggest that unpaid caring responsibilities should be considered a social determinant of health. Dahlgren and White's (1991) model of the social determinants of health describes the range of factors that shape health inequalities, with one group of factors relating to working and living conditions.[39] Such working and living conditions include, for example, housing conditions and workplace environment. It can be argued that an important addition to this model is the role of unpaid caring responsibilities. Such responsibilities clearly shape health outcomes and potentially contribute to health inequalities between carers and non-carers. Figure 3.1. shows an adapted version of Dahlgren & Whitehead's (1991) rainbow model of the social determinants of health, with the addition of unpaid caring responsibilities in the 'Working and Living Conditions' segment.

Figure 3.1. Caring a social determinant of health: an adaptation of Dahlgren & Whitehead's (1991) rainbow model
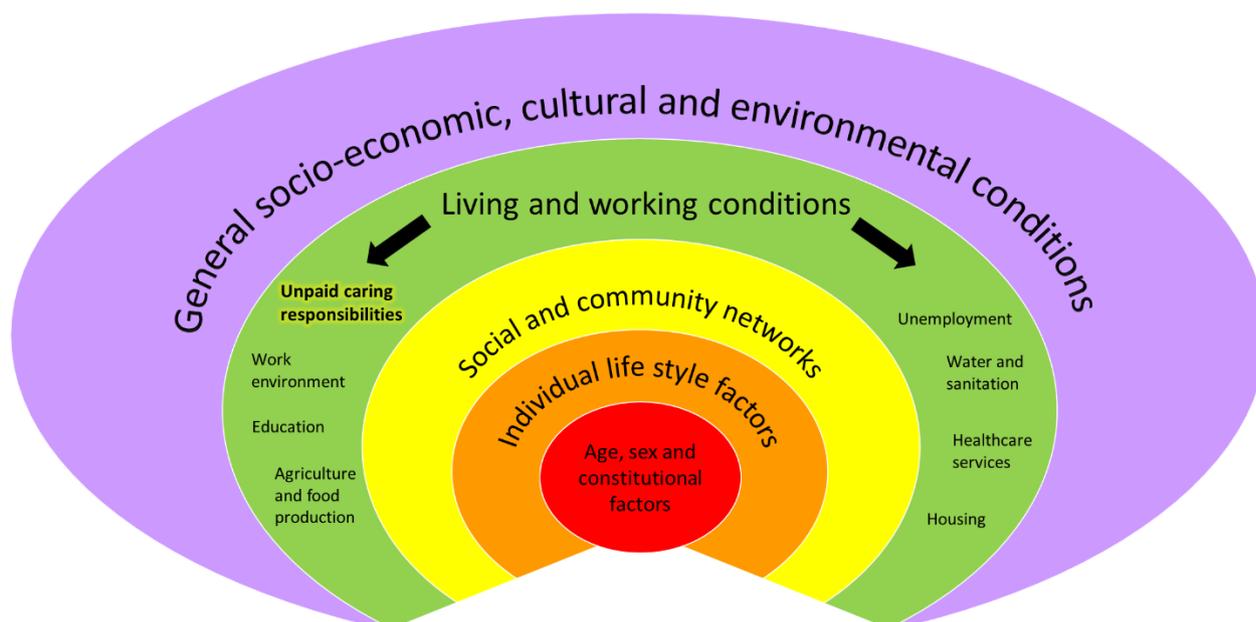
Carers at greater risk of poor health

It is unlikely that any one particular group of carers for older people may be at greatest risk of poor health, but certain groups may be more vulnerable than others to some outcomes. For example, evidence from the rapid review suggested that younger carers, and those with poor social and financial support may experience high 'carer burden' (that is are likely to experience emotional, physical and social hardships associated with caregiving). This makes sense, particularly in light of evidence from the analysis that shows younger carers are more likely to be in full time employment. Younger people may thus experience greater 'burden' if juggling caring responsibilities alongside a full time job. Similarly, greater 'burden' for those with low social and financial support is likely to reflect an absence of socioeconomic capital that buffer the demands of caring.

Findings from the survey analysis also offer a profile of caring that signals which groups may face the greatest demands and consequences of caring. In particular, older carers, and carers living in the most disadvantaged areas, were providing the most care (in terms of the number of hours). Yet older people and those living in the most disadvantaged areas (regardless of whether a carer) were also likely to be living with multiple long-term conditions, and thus may have complex health needs of their own. The demands of caring may, therefore, place these groups at particular risk of poor health.

Supporting carers

The final, overarching finding concerns how carers should be supported. There was a lack of clear, robust evidence from the rapid review about which interventions are most effective for carers of older people. Yet evidence about the consequences of care identifies the sorts of outcomes that should be targeted when supporting carers. It is possible, therefore, to outline some considerations about the types of support that may benefit those caring for older people. Furthermore, based on the gaps in evidence identified in the rapid review, considerations for those planning or commissioning further research to ascertain the effectiveness of carer interventions can also be drawn together. These considerations are set out later in this section. Next, this report summarises how these findings about caring for older populations compare with what is known about caring for other populations.

The outstanding gaps in evidence

As highlighted in part 2 of this report, the rapid review highlighted key gaps in evidence about caring for older people. This was in large part due to outcomes that were rarely reported, such as physical health, and social and financial wellbeing outcomes. Poor reporting of evidence in these reviews, notably with regards to the quantification of estimates of prevalence and severity of outcomes, also resulted in an incomplete picture about what is known. These are important omissions, and later in this section, key considerations for addressing these gaps are summarised.

How the findings about carers for older people compare with evidence about carers of other populations

The consequences of caring

Findings from the rapid review indicate that carers of older people experience mental health problems (specifically, depression and anxiety), stress, 'carer burden' and poor quality of life. This aligns with findings from previous research about the impact of providing unpaid care (for any population) on mental health.[17] Recent figures from the Office for National Statistics also show that 'sandwich carers' (that is those caring for their own children alongside a dependent family member) are more likely than the general population to experience anxiety and depression.[40] The proportion reporting these outcomes increases with the hours of unpaid care provided.

The rapid review presented in this report, identified very little evidence about physical health. However, the absence of physical health outcomes for carers of older people across reviews is not entirely surprising: others have noted that evidence about the impact of caring for older people is largely oriented towards mental and psychological, rather than physical, health outcomes.[41-43] Nevertheless, findings from the analysis of the GP Patient Survey fit with evidence about the impact of caring on physical health, with respect to those caring for other

populations. For example, 4 reviews about the impact of caring for populations not specific to older people report that carers are at increased risk of illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function and poor sleep.[41,44-46] Carers are also at increased risk of physical strain and injury, and stress-related conditions such as high blood pressure.[10,17] A similar pattern was observed in the analysis of the GP survey data reported earlier: carers were more likely than non-carers to report poor health and multiple long-term conditions, with the most common health long-term health conditions among carers being high blood pressure and arthritis.

When the impact of caring on employment is considered, previous research has shown that caring can lead to a loss of employment or a reduction in working hours[38,47,48] A Carers UK survey in 2019 found that half a million carers had ceased employment due to caring, with those aged over 54 years most likely to give up working.[49] Carers may also be juggling the demands of caring alongside employment. For example, analysis from the English Longitudinal Study of Ageing (ELSA) shows that around a quarter of carers who provide 'round the clock' care are also employed.[50] Findings from the analysis of the GP Patient Survey offer an age-break down of caring and employment. Carers in the 45 to 54 years age group are most likely to be employed full time, whilst carers in the 65-to-74 age group are most likely to be retired.

Carer interventions

In terms of evidence about carer interventions, the rapid review searches identified 4 other reviews of reviews; 3 specifically for carers of people with dementia,[23-25] and one for carers for those including, but not specific to, older populations.[51] The 3 reviews of reviews specific to dementia carers are summarised in Appendix B, alongside a summary map of evidence from dementia specific systematic reviews identified in the searches. The latter review, published in 2017, concluded that there was an absence of high quality primary research from which to draw confident conclusions about how best to support carers. The authors also noted that the most robust evidence in this review suggested that no single intervention is most effective for carers. Rather, contact with others may benefit carers, regardless of the type of intervention in which such contact is delivered. The absence of high quality research confirms what was found in the rapid review reported earlier, and signals the need for robust primary research evaluations of interventions.

Whilst there were no data in the GP Patient Survey about interventions for carers, it was possible to explore carer reports of access to care. A survey from Carers UK reported that carers often delay seeking care and treatment for their own health due to caring responsibilities.[38] To some extent, this was consistent with findings from the analysis reported in part 2 of this report. For example, carers were less likely than non-carers to report using 5 or more medications, despite being more likely to live

with multiple health conditions. This might suggest that carers may be neglecting their own health needs, but it could also indicate that they struggle to access adequate, high-quality support. Carers in this survey were also less likely than non-carers to report that their mental and physical health needs had been addressed, and were dissatisfied with the availability of GP appointments.

Considerations for practice

Whilst the rapid review could not identify a clear picture about which interventions best support carers of older people, both the rapid review and analysis of the GP Patient Survey offer some indication about where to target support. This includes which groups of carers may have the greatest need for support, and which outcomes interventions should seek to address. This section sets out 5 considerations for supporting carers, including those caring for older people.

1. Support for those caring should aim to lessen the impact on their mental health, with targeted support for depression, anxiety and stress when needed

Evidence from the rapid review indicates that carers of older people experience depression, anxiety, and stress. As carers are often likely to delay seeking help for their own health needs, a proactive joined-up approach is needed to identify those at risk of, or experiencing, these outcomes. Targeted support could include preventative measures to improve general wellbeing and reduce stress, as well as referrals to more specialist mental health services for carers experiencing depression and anxiety.

2. Measures to prevent poor physical health that arise as a consequence of caring (for example injuries, back pain, high blood pressure) are an important part of supporting those who provide unpaid care

Evidence from the survey analysis indicates that carers are more likely to experience musculoskeletal problems and high blood pressure. These may arise as a direct consequence of caring, but could be prevented with appropriate support in place. In terms of the physical demands of care, appropriate support may include health and safety training for those providing care, pain management advice and aids for the care recipient to reduce the demands placed on the carer.

3. Carers often have their own long-term conditions and disability, which should be addressed as part of any support package

Evidence from the survey analysis indicates that some carers live with multiple long-term conditions and will thus have their own health needs. Whilst these may not always be a direct consequence of care, it is possible such conditions may be exacerbated through the physical and mental demands of caring. Time pressures associated with caring mean that carers are also likely to neglect their own

healthcare and treatment. A package of support for carers should, therefore, not only target and prevent the direct health consequences of caring, but also consider how to support carers to manage their own long-term health conditions.

4. Support is needed to improve quality of life for carers; contact with other carers may be beneficial

Whilst support that is directed at specific health consequences (for example depression, anxiety, musculoskeletal conditions) is important, carers may also benefit from interventions that aim to improve overall quality of life and reduce the perceived emotional, physical and social hardships associated with caring. Evidence from the rapid review did not provide a clear picture of which interventions might achieve this. However, another review of carer interventions (where the care recipient population included, but was not specific to, older people) found that contact with other carers is an important component of any support intervention.

5. Some groups of carers are at greater risk of poor health, and of experiencing emotional, physical and social hardships associated with caring – these groups may benefit from additional, targeted support

Findings from the rapid review indicate that younger carers, and those with poor financial and social support, experience greater 'carer burden'. Support that aims to reduce the perceived emotional, physical and social hardships associated with caring may thus be particularly beneficial for these 'high-risk' groups. The analysis also demonstrates that older carers and carers living in areas of greater deprivation, were more likely to be providing a greater number of hours of care per week. These are also the groups more likely to report multiple long-term conditions. Thus, there may be greater need for day-to-day support for these groups of carers, both to enable access to care for their own health and to reduce the risk of exacerbating existing poor health as a result of caring.

Considerations for future research

This work has identified key gaps in evidence about the impact of caring for older people. In this section, 4 considerations for those planning or commissioning future research are offered, to support evidence-based implementation of carer interventions. A logic model is also presented to guide future evaluations of interventions in terms of which outcomes may be most appropriate to assess effectiveness.

1. A high quality comprehensive systematic review about the impact of caring for older people on physical health and social and financial wellbeing outcomes

The absence of evidence within systematic reviews about these outcomes highlights a clear need for a systematic review focusing on carers' physical health and social and financial wellbeing, and specifically for carers of older people. Given that such evidence may be found within non-peer reviewed sources (for example, surveys from the Office for National Statistics, Carers UK or Age UK), a new comprehensive review that seeks to identify evidence from both peer reviewed and grey literature sources would provide valuable evidence. It would also be important not to overlook relevant qualitative research literature about the impacts of caring.

2. A high quality systematic review or primary research study to quantify the prevalence and severity of mental health outcomes and other illnesses experienced by carers of older people, with comparisons to the general population

Quantification of the impact of caring on mental health and other outcomes is critical in order to gain a comprehensive understanding of these issues. Yet the prevalence and severity of most outcomes for carers could not be quantified in this rapid review due to the way these were reported in individual reviews, signalling a need for clearer evidence. This may take the form of a systematic review of primary studies that encompasses grey literature (for example, where prevalence is reported in surveys from the Office for National Statistics) and which includes only evidence where clear, quantified estimates are provided. Alternatively, a clear picture of the prevalence and severity of health outcomes for carers of older people may be obtained from a primary research study that that can provide an up to date analysis, using existing datasets (see Part 4). Comparison with the general population, and identifying carer sub-groups at greatest risk of poor health, should be a core component of this work.

3. Robust evaluations of promising interventions for carers of older people

The rapid review identified some promising interventions, where evidence was limited in quantity, and also low in quality. Robust evaluations of similar sorts of interventions, as well as any other interventions currently in practice, will provide further insight into if and how these may support carers of older people (see also consideration #4).

4. National mapping of existing practice

Services and interventions to support carers of older people are likely to be diverse and responsive to local needs. A national survey of local authorities and NHS trusts to map existing practice, and identify whether this practice is evidence-based and/or undergoing evaluation, would help to achieve a clear picture of what support and

interventions are already in place and which outcomes these are targeting. This exercise could build on existing mappings (for example NIHR-funded ESSENCE project)[52] and would provide a shareable resource of examples of emerging or established practice and which could inform the development of future evaluations. Linkage with locally aggregated data about carers may also be possible.

Evaluating the impact of carer interventions: a logic model

The rapid review identified that the overall quality of systematic reviews relating to consequences and interventions for carers of older people was poor, and there were key gaps in the evidence. Figure 3.2 maps existing intervention-outcome combinations identified in the reviews, and highlights key logical intervention-outcome pathways that are limited or absent, but have potential for impact.

As the rapid review showed, few interventions targeted carers of older people's physical health, financial burden, social relationships or quality of life. The lower section of Figure 3.2 illustrates that mental health and 'carer burden' were more often targeted. However, the interventions for these outcomes did not necessarily identify convincing potential pathways to impact. For example, reviews did not identify a substantial number of interventions that were targeting mental health (anxiety and depression) using evidence-based therapeutic support components such as talking therapies, or group therapy led by a professionally qualified therapist, counsellor or psychologist. Therapeutic support for mental health conditions such as anxiety and depression (as well as other outcomes such as anger and hostility), would also have potential to impact on carer-care recipient relationships as well as wider social relationships and capacity to engage in social activities.

Similarly, reviews did not identify physical health interventions that included physical activity or therapy, or that considered the potential to reduce injury from physical caring activities such as moving or lifting an older person. Respite was evaluated in relation to a range of different outcomes, yet the rationale for this is unclear. While regular planned respite would seem an essential ingredient underpinning other interventions, in isolation, its potential to alleviate or stabilise a diagnosed mental health condition is not supported by evidence. In addition, identifying the right quantity and type of regular respite is fundamental to meeting different individual circumstances and preferences.

The upper section of Figure 3.2 gives an indication of some key intervention-outcome combinations that have a clearer logic in their potential for impact, yet are absent or have limited presence in existing reviews. Intervention types include:

- therapeutic support
- physical skills training for example manual handling techniques
- aids and adaptations to reduce physical demands of caring
- befriending and peer support to reduce the perceived emotional, physical and social hardships associated with caring, and address isolation and loneliness
- physical therapy and activity to improve general health and address physical injuries
- financial information and advice
- pain management
- education and motivation around healthy lifestyles
- demand-responsive respite to facilitate carers attending both routine and urgent medical appointments, as well as social activities and events
- social prescribing

Appropriate and sufficient planned respite is represented by the grey box in Figure 3.2, underpinning all potential intervention types by providing the time, space and energy required for carers to absorb and follow through with the intervention components. The model also includes 'access enablers' as key in ensuring that carers are connected with relevant services and interventions on offer, to meet their individual needs. These would include people in roles such as Care Navigators or Link Workers, as well as initiatives including social prescribing. Carers' assessments provide an opportunity to identify needs and link these with appropriate interventions to address these needs.

Robust evaluation of future interventions such as those listed above would be essential to provide the clarity required about their acceptability and effectiveness in addressing some of the most common issues faced by carers of older people.

Figure 3.2. Existing and potential intervention-outcome combinations for evaluation

This logic model a) maps existing intervention-outcome combinations that were identified in the review and b) highlights key logical intervention-outcome pathways that are limited or absent in the current evidence base, but which have potential for impact.
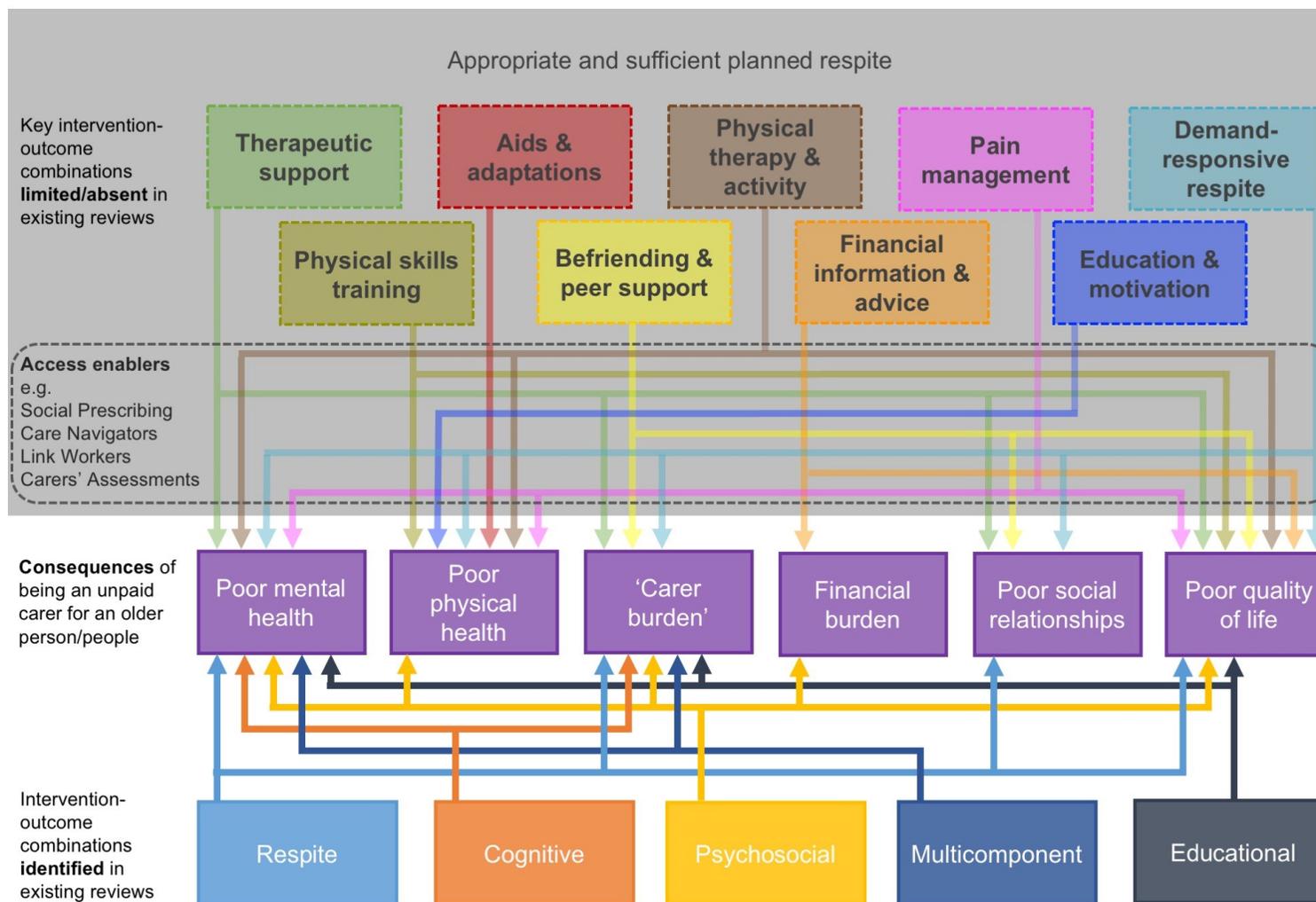
Limitations of this project

This work aimed to provide insights into the consequences of caring for older people, and the interventions that might best support this population. The methods selected to explore these topics were a rapid review of reviews and an analysis of the GP Patient Survey. These methods were most appropriate to address the brief within the timeframe available, but these approaches bear limitations that should be considered.

First, this project intended to focus on caring for older populations. Whilst this was achieved for the rapid review, the data available from the GP Patient Survey meant that it was not possible to identify those caring specifically for older people. Even so, the analysis undertaken has identified important findings about the health of carers and adds to the overall picture of what is known about the consequences of caring. A further limitation is that we were unable to explore the role of ethnicity in greater depth as the number of participants within each ethnicity grouping, pre-aggregation into white/black/Asian/mixed, were too small for robust analysis.

In terms of the rapid review of reviews, this approach was chosen to provide an overview of evidence and to avoid duplicating existing systematic reviews. This is a valuable methodological approach when summarising a broad evidence base in a short time frame. However, the focus on existing systematic reviews excludes evidence from primary studies that have not yet been subject to a systematic review. Despite this, the rapid review highlighted key gaps in evidence, from which it was possible to develop a set of considerations for those planning or commissioning future evidence syntheses. A final limitation of the rapid review is that reviews about joint carer and recipient interventions were excluded. This was necessary in order to identify evidence about outcomes relating to carers' health and wellbeing (which was the focus of the review). However, this exclusion means that some evidence about supporting carers may have been missed, where this was located in reviews about joint interventions.

Finally, this work was undertaken during 2019 to 2020, prior to the COVID-19 pandemic. Therefore the work does not take into account the impact of COVID-19 on both the number of people providing unpaid care, the consequences of providing this care or mechanisms to support carers during COVID-19. This is recognised as a limitation of the work, however, many of the findings in relation to the impact of caring on the physical and mental health of carers will remain relevant in this context.

Conclusions

A rapid review of reviews and an analysis of data from the GP Patient Survey explored evidence about the consequences of caring, and which interventions are effective at promoting the health and wellbeing of carers of older people. Carers experience poor mental and physical health, and poor quality of life, and are more likely than non-carers to be living with more than one long-term health condition. This provides support for the argument that caring is a social determinant of health. Some groups of carers may be particularly vulnerable and may benefit from targeted support. Whilst this evidence signals that those caring for older people are likely to have a varied set of support needs, evidence about how best to address these needs was limited, both in quantity and quality. Clear gaps in evidence about physical health and social and financial wellbeing outcomes signal a need for further research.

Part 4: Local examples

This section presents 4 local examples of interventions for carers.

This work sought to identify approaches which show promise in supporting and enabling carers of older people to live well. However, the rapid review revealed that the evidence base in this area is in need of development. While individual initiatives have been evaluated, the evidence is not yet strong enough to provide objective assessment of the effectiveness of particular intervention types, or key characteristics of effective approaches for carers of older people.

Instead, through liaison with the project steering group, 4 promising approaches to supporting carers have been identified. These are approaches that target the sorts of outcomes that carers experience (based on evidence from the review and analysis), and are designed to facilitate access to interventions for carers. The section below sets out how these local examples fit with current evidence from the rapid review and GP patient survey analysis, and where further evaluation is needed to measure their impact.

The 4 local examples are:

- Gateshead's Care Navigation Service
- Bristol's personalised 'breaks' from caring
- West Sussex's Carer Learning Wellbeing Programme & Carers Health Team
- Surrey's Crossroads Care home-based respite & Carers' Prescription scheme

Local example: Care Navigation Service

Gateshead's Care Navigation service aims to connect carers with help and support in the community. A website provides useful links and advice on various topics: stress and mental health issues; bereavement and loss; money worries; loneliness and isolation. In addition, trained 'Care Navigators' work with carers to help them identify their needs, and what would make a positive difference to their lives. Navigators have extensive knowledge of local support groups and services available and can signpost carers to those that are best suited to provide the required support.

Care Navigators also provide some direct support to carers, with regular contact via telephone or home visits, and by hosting 'getting to know you' events to meet with other people in similar situations.

Evidence demonstrates that carers experience poor mental health and quality of life. Linking carers of older people with appropriate interventions and services is vital in addressing their needs. Care Navigators are likely to have both direct (informal conversations and social interactions) and indirect (signposting to services that impact on health and wellbeing) impacts for carers, but research evidence about these impacts is lacking. Evaluation of navigation services would provide evidence about intervention topics where there are currently gaps, such as financial wellbeing and loneliness or isolation.

Local example: Personalised 'breaks' from caring

Breaks from caring are essential in sustaining caring relationships and ensuring that carers have time for their own lives. Bristol City Council and the local Clinical Commissioning Group offer one-off payments (non-means tested) to carers for them to use for anything they choose that gives them a 'break' from caring.

Breaks chosen by carers include: short breaks away with or without the care recipient; alternative care for the care recipient; swimming, gym and exercise classes or membership of, for example, weight loss clubs; therapy sessions, for example massage, counselling; transport; courses; craft materials; equipment for example lighter wheelchair; home cleaning; mobile phone or computer access to stay in touch with family and peers.

Evaluation of short-term effects of breaks indicates positive effects on health and wellbeing, and the ability to cope with the stress of caring. Being awarded a break is also important to carers as evidence that their caring is recognised and valued externally.

Integrated approaches that provide carers with the ability to tailor breaks to their individual needs have potential to impact on the health & wellbeing of carers for older people. This type of intervention offers carers the opportunity to prioritise issues where evidence shows there are gaps in current provision for example physical health consequences of caring; addressing social isolation & loneliness. However, the positive effects of these 'breaks' were short-term, with further evidence from robust evaluations needed to assess the longer-term impacts on specific outcomes.

Local example: Carer Learning & Wellbeing Programme

Carers Support West Sussex is a voluntary organisation that provides information and advice for carers. The organisation runs a Carer Learning and Wellbeing Programme, in the form of a series of workshops designed to improve health and wellbeing. Workshops include creativity. first aid, wills and power of attorney, end of life, coping with caring.

Other workshops are run in partnership with the NHS Carers Health Team. These workshops focus on learning relaxation and mindfulness techniques and maintaining health while in a caring role including achieving a healthy lifestyle and diet.

> Evidence shows that carers experience poor health. Arthritis and high blood pressure are the most common conditions carers are likely to live with. Recommended management of both of these conditions includes a healthy lifestyle, including exercise. However, research evidence about initiatives focusing on physical health for carers of older people is limited. Evaluation of programmes that aim to improve or maintain healthy lifestyles and diets for carers would provide much needed evidence about their benefits for physical health.

Local example: Respite service for carers

Crossroads Care Surrey provides a flexible home-based respite service for carers. Through the 'Carer's Prescription' scheme, Surrey GPs can refer carers to the Crossroads Care charity. Care plans can include outings, meal and drink preparation, light domestic duties, chatting, reading and playing games with the care recipient, personal care, and healthcare procedures including wound care and continence management.

Respite can ensure that carers get time to themselves to relax, go out with friends, enjoy hobbies or chat without having to focus on the person they care for.

> Experience in practice, and among carers, strongly indicates that respite is beneficial. However, there is not yet robust research evidence that captures these benefits. This may be due to mismatches in respite type or duration needs, and actual provision, or it may be due to other factors such as the measures adopted in research studies. Evaluation of respite services that can pinpoint and measure the long and short-term benefits of respite for carers is urgently needed.

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