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Health and Social Care Delivery Research

Synopsis

Understanding and addressing factors affecting carers' mental health during end-of-life caregiving: synopsis of meta synthesis of literature and stakeholder collaboration

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Abstract

Background: Family carers provide crucial support to patients nearing end of life. This can affect carers' own mental health negatively. It is important to understand what factors may affect carers' mental health and convey this information to stakeholders who can effect change. We conducted reviews of the qualitative, observational and intervention carer literature and worked with carer advisors and other stakeholders to make findings useful and accessible.

Aim of the synopsis: To provide a synopsis of (1) project methods, (2) findings and implications from the evidence syntheses, (3) outcomes of our carer Review Advisory Panel collaboration and (4) feedback from wider stakeholder consultation.

Method: Searches of MEDLINE, Cumulative Index to Nursing and Allied Health Literature, PsycInfo, Social Sciences Citation Index, EMBASE, Cochrane Central Register of Controlled Trials and Database of Abstracts of Reviews of Effects 1 January 2009–24 November 2019. Studies included adult family carers for adult patients at the end of life cared for at home, considering any factor related to carer mental health. Collaboration with the Review Advisory Panel over nine meetings helped map review findings into a framework, shape their presentation and create Review Advisory Panel recommendations. Four workshops, two discussion groups and a survey with stakeholders (carers/patients, practitioners and policy-makers/commissioners) informed output formats and suggested actions.

Results: Thirty-one qualitative, 60 observational, 12 intervention and 3 mixed-methods studies were identified. Factors associated with carer mental health were: (1) patient condition, mainly psychological symptoms and quality of life; (2) impact of caring responsibilities, mainly life changes, workload and carer burden; (3) relationships, particularly carer–patient; (4) finances, whether sufficient; (5) internal processes, particularly self-efficacy; (6) support, particularly adequacy and quality; and (7) contextual factors, mainly age and gender.

The Review Advisory Panel comprised five carers and a carer chair. They created recommendations for supporting carers based on syntheses findings, including: awareness raising for carers and practitioners; a road map to help carers navigate caregiving; bespoke carer support through carer assessment; assessment of patient's actual rather

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than ‘managed’ needs; co-ordinated care through a single contact point; addressing basic practical needs. Other key recommendations included holistic, co-ordinated patient care and cover of basic carer financial needs.

Thirty-six stakeholders participated in workshops and discussion groups and 43 in the survey, to review synthesis findings and Review Advisory Panel recommendations. Stakeholders generally valued the qualitative evidence and recommendations over the quantitative evidence, although all outputs resonated with them. There was little consensus regarding where responsibility for carers may lie, pointing to a need for bespoke carer support roles. Some issues may require systemic-level changes.

Limitations: Findings are from Organisation for Economic Co-operation and Development country English-language publications on adult carers and patients within home care, and carer advisors and stakeholders were based in the United Kingdom, which may limit the transferability of findings.

Conclusions: Findings provide some clear indicators of factors affecting carer mental health and recommendations. Improvements may require investment in bespoke carer support roles (e.g. carer support nurses) and systemic change (e.g. improving carer identification and assessment, and financial security). Given the enormous contribution carers make to health and social care, they deserve such investment to support them in their work.

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Introduction and project background

Global population ageing and older people living with increased numbers of complex health conditions present challenges for health and social care provision worldwide.[1] Challenges encompass supporting healthy ageing as well as meeting increased demands for palliative care. Care provided by friends, family or other unpaid people (hereafter ‘carers’) currently contributes substantial support to health and social care services. It has been estimated that this care exceeds the value of the UK NHS[2] and that its value amounts to nearly £1000 per week during end of life (EOL) care per patient.[3]

Over the coming years, there will be increased numbers of deaths,[4] and in England and Wales, it has been forecast that an additional 160,000 people will need palliative care by the year 2040.[5] Carers will likely have a substantial role in providing the support patients require, particularly given that many prefer to die at home; this preference has accelerated in the UK since COVID-19, partly due to the strain on services during that period.[6]

There are estimated to be approximately 500,000 EOL carers in the UK.[7] Estimates further suggest that carers provide around 70 hours of care per week in the patient’s last 3 months of life.[8] Carers may also require specialist medical knowledge and skills for which they often have not received adequate training,[9] a situation likely to increase as carers take on more caregiving tasks as population demands for care increase and stretch health and social care provision. Many take on the carer role willingly[10] and it often entails positive outcomes such as increased closeness with the patient, sense of meaning, personal growth and satisfaction.[11] However, many also struggle with the demands of caring at EOL and report poorer outcomes. It has been estimated that 34–72%[12–17] of carers experience anxiety and 39–69% experience depression,[18,19] with levels of clinically significant psychological symptoms occurring in 83% of carers in the final 3 months of EOL care.[20] High workload, in the form of hours spent caring, appears to exacerbate poor outcomes for psychological or general health when combined with being female, younger, and caring for a patient with a greater number of psychological and physical symptoms.[21]

Given the high prevalence of psychological morbidity among EOL caregivers, there are legitimate public health concerns related to the long-term effects this may have post bereavement, as evidence suggests poorer health during caregiving is linked to poorer outcomes post bereavement.[22,23] Equally, if carers become unable to meet the needs of the patient due to their own deteriorating health, there are implications for the standard of care-provision as well as a likely increase in inpatient admissions and costs associated with this.

It is therefore important to understand further what may predict carers’ psychological health. This is likely to be influenced by a variety of factors both observable (e.g. demographics, financial situation) and subjective to each caregiver (e.g. willingness to care, sense of control). Some of these factors may be targets for intervention, for example, people’s financial situation and sense of control may to some degree be improved. Other factors, such as age and gender, can be highlighted as a means to identify carers who may benefit from early assessment and monitoring and targeted support to maintain or improve their psychological health.

There is a considerable body of literature reporting research into these factors, but the challenge of gaining a comprehensive overview may prevent stakeholders in key positions to act on this information. Such stakeholders include health and social care professionals, carers themselves, charity and third-sector organisations, and policy-makers.

To address this, we conducted a systematic synthesis of the total body of literature on factors related to the psychological morbidity of EOL caregivers from 2009 to 2019 through two work packages. Work package 1 comprised three reviews of qualitative, observational and intervention studies, respectively. Findings were synthesised into a comprehensive, yet accessible, framework. Central to shaping this work was involvement of carer stakeholders in a carer Research Advisory Panel (RAP). Work package 2 comprised a wider stakeholder consultation to inform the translation of these empirical findings into formats useful to different stakeholder groups and to begin to understand whether and how they might be operationalised within primary care.

The purpose of this synopsis report is:

1. To summarise the methods, findings and outputs from work package 1, including
   a. Academic evidence synthesis of the qualitative, observational and intervention literature. For details, see Bayliss *et al.*,[24] Shield *et al.*[25] and Grande *et al.*,[26] respectively.
   b. Collaboration with the carer RAP, including RAP carer recommendations, and shaping of academic materials. For details, see Grande *et al.*[27]

2. To report on work package 2 stakeholder consultation on the usefulness of evidence synthesis findings and RAP recommendations, how to best disseminate outputs and how to use the project outputs in practice.
3. To consider the implications for practice and research arising from the findings of the project.
4. To provide a linked index of all related publications and outputs arising from the project.

Academic evidence synthesis of qualitative, observational and intervention literature

Methods

Full details of methods are presented in separate qualitative,[24] observational[25] and intervention and summary[26] reports for the project. The key components are presented here.

Search and selection strategy[26]

An electronic search of the literature 1 January 2009–24 November 2019 included the following databases:

- MEDLINE (Ovid Online)
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus (EBSCO)
- PsycInfo (Ovid Online)
- Social Sciences Citation Index [Institute for Scientific Information; Clarivate Analytics (Philadelphia, PA, USA) platform]
- EMBASE (Ovid)
- Cochrane Central Register of Controlled Trials
- Database of Abstracts of Reviews of Effects (University of York Centre for Reviews and Dissemination).

See *Appendix 1* for the full search strategy. *Box 1* describes the inclusion and exclusion criteria for the synthesis.

BOX 1 Evidence synthesis inclusion and exclusion criteria[26]

All studies had to report peer-reviewed, empirical research published in academic journals and consider Population, Factor, Outcome and Setting as defined below:

- *Population* – Lay adults who were supporting and caring for an adult patient who was at EOL. EOL was conceptualised as a palliative, terminal or otherwise 'advanced' or 'end stage' phase of care where the patient was likely to die within a year. Articles which did not give enough information to ascertain disease stage/palliative phase were excluded.
- *Factor* – Any factor which may have affected psychological morbidity in carers.
- *Outcome* – Psychological morbidity, defined as anxiety, depression, distress, quality of life and other outcomes that carer advisers considered to be important.
- *Setting* – Care had to be predominantly provided in a home-care setting.

Studies were excluded based on the following criteria:

- Factors or outcomes related to bereavement only.
- Papers which reported that most care occurred while the patient was in a facility (i.e. care home, hospital), given the focus on carer mental health during home care.
- Studies outside Organisation for Economic Co-operation and Development (OECD) countries, to ensure healthcare structures were comparable with the UK.
- Languages other than English or Scandinavian, which would require further translation.
- Systematic reviews.

Design-specific inclusion criteria:

- Qualitative synthesis: studies should aim to investigate psychological morbidity in informal carers from the perspectives of EOL carers themselves, using data collected through qualitative techniques such as unstructured interviews, semistructured interviews or focus groups, either as stand-alone methodology or as a discrete part of a larger mixed-method study.[24]
- Observational synthesis: studies should investigate associations between factors and carer mental health outcomes statistically, using cross-sectional, longitudinal or case-control design.[25]
- Intervention synthesis: studies should have carer mental health as an intervention outcome and show that the intervention led to a significant change in a factor associated with mental health, as identified in the qualitative or observational syntheses (*Box 2*[24,25]); using a randomised controlled trial (RCT), non-randomised trial, controlled before-after study or interrupted time series with a clear comparator in the form of usual care, enhanced usual care, 'no intervention' or waiting list controls.[26]

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Ten per cent of both titles/abstracts and full texts were screened independently for eligibility by two reviewers. Over 90% agreement was established across study designs, and subsequent studies were screened on title/abstract and full texts by one reviewer.

Data extraction

Qualitative data first-order themes were extracted for 10% of studies by two researchers and carer RAP members. The remaining data extraction was conducted by one researcher. Second-order themes were created by one researcher, reviewed by a second and sense-checked by the carer RAP. Observational study data extraction was conducted independently by two reviewers on 10% of studies. The remaining data extraction was conducted by one reviewer with a random sample of 10% checked by a second. Intervention study data extraction was conducted independently on 30% of studies by two reviewers due to the small data set. Remaining data extraction was carried out by one reviewer and reviewed by a second.

Quality appraisal

The qualitative review used the Critical Appraisal Skills Programme (CASP) Qualitative Studies checklist.[28] The observational review used an adapted version of the Newcastle–Ottawa Scale (NOS) for cohort and case-control studies,[29] modified to encompass cross-sectional studies based on an adjusted NOS.[30] The intervention review used the CASP checklist for RCTs.[31]

For qualitative and observational studies, quality appraisal (QA) was carried out independently by two reviewers on 10% of the studies. Over 90% agreement was achieved, and subsequent studies were quality-assessed by one reviewer. For all intervention studies, QA was carried out by one reviewer and checked by a second.

Analysis

The qualitative synthesis developed a thematic framework of factors related to carer mental health which was then used to integrate findings from the other syntheses. The qualitative thematic synthesis used principles of meta ethnography, creating first-, second- and third-order constructs from the data[32] in collaboration with the carer RAP. The third-order construct stage entailed development of a best-fit conceptual framework which integrated findings from the observational and intervention reviews.

Observational review factors were synthesised thematically into subthemes using box scores,[33] showing number of investigations finding a positive, negative or no relation to mental health for each factor, in collaboration with the carer RAP. Each subtheme was then mapped onto one of the thematic groupings identified in the qualitative synthesis. Finally, intervention review findings were similarly synthesised into subthemes with box scores and mapped onto the thematic framework.

Meta-analysis was only possible for a limited number of observational studies, and none of the intervention studies, due to the wide range of factors and range of mental health outcomes considered, variation in measurement of factors, and missing information.

Results

Figure 1 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for the whole project. The synthesis comprised 103 single-method and 3 mixed-method studies. The latter appear in more than one review. Thirty-three studies contributed to the qualitative review,[24] 63 to the observational[25] and 13 to the intervention review.[26] A list of included studies can be found in the respective review publications. See *Report Supplementary Material 1* for a list of excluded studies.

Summary of findings

Box 2 shows the main themes or factors guiding the evidence synthesis. The qualitative synthesis yielded the first six main themes, and other review findings were integrated into these. Additionally, contextual factors were identified by the observational synthesis. Findings are summarised below under the seven main themes. For full details, see the qualitative,[24] observational,[25] and intervention and academic summary[26] reports. The order of themes does not imply order of importance; themes have been presented in the same order across all syntheses for consistency.

BOX 2 Main themes guiding evidence synthesis

1. Patient condition
2. Impact of caring responsibilities
3. Relationships
4. Finances
5. Carer internal processes
6. Support
7. Contextual factors

Theme 1: Patient condition

Patient condition factors were investigated in 37 observational studies (31 with bivariate analyses, 6 multivariate only) and 5 intervention studies, and identified in 19 qualitative studies.

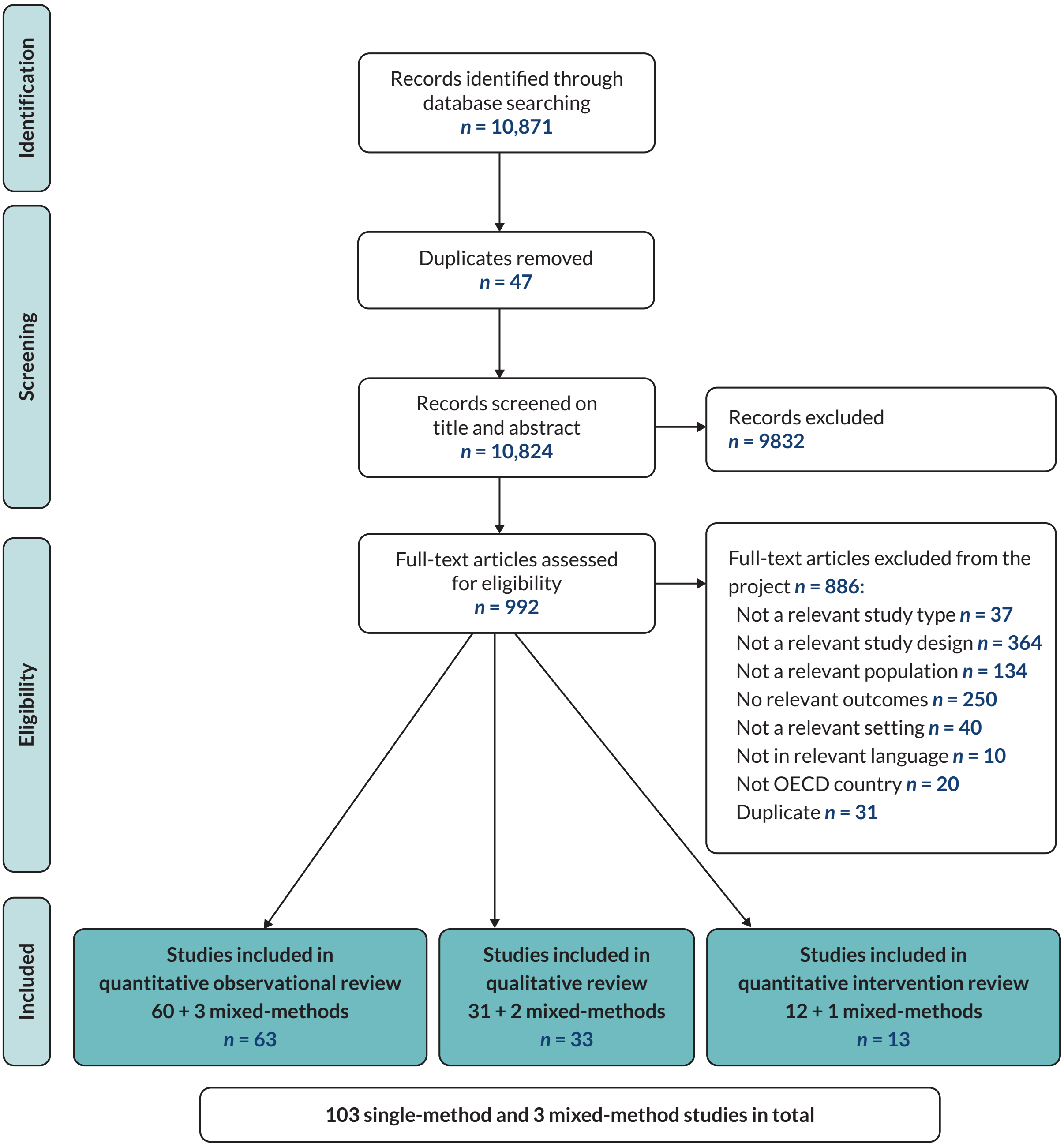

FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram of study identification and selection.[26]

Qualitative studies showed the importance of the patient's condition for carer mental health, and they highlighted the negative emotional connotations for the carer of the patient's physical and cognitive decline. Quantitative studies correspondingly found that worse patient psychological symptoms were related to worse carer health, and better patient quality of life to better carer health. Quantitative findings for physical and functional decline were more mixed.

Theme 2: Impact of caring responsibilities

Factors within this theme were investigated in 17 observational studies (14 bivariate, 3 multivariate only) and 3 interventions studies, and identified in 18 qualitative studies.

Qualitative studies highlighted how carers felt their mental health was affected by the caring workload, added responsibilities; exhaustion, physical impact and crises experienced from caregiving; the associated lack of rest, respite and opportunity for self-care; and the resulting isolation and loneliness. Quantitative observational studies showed consistent relationships between worse carer mental health and greater lifestyle adjustments, demands of caregiving and level of carer burden. Intervention study findings were few and inconclusive.

Theme 3: Relationships

Relationship factors were investigated in 10 observational studies (8 bivariate, 2 multivariate) and 1 intervention study, and identified in 13 qualitative studies.

Qualitative findings showed a potential negative impact on carers' mental health from relationship changes, strains or conflicts caused by the patient's illness or by caregiving. Quantitative evidence indicated that better carer health was related to better-quality patient–carer relationships or family relationships, but evidence was limited.

Theme 4: Finances

Finances were considered in only 6 observational studies (all bivariate investigations) and no intervention studies but identified in 14 qualitative studies.

Qualitative findings highlighted how carer mental health can be affected by the costs, concerns about finances and impact on work associated with caregiving. Quantitative evidence was limited, but it indicated a relationship between carer mental health and the sufficiency or insufficiency of financial resources, and care-related changes to employment.

Theme 5: Carer internal processes

Carer internal processes were considered by 17 observational studies (13 bivariate, 4 multivariate) and 11 intervention studies, and identified in 22 qualitative studies.

Qualitative findings showed potential negative impacts on carers' mental health from a loss of self-determination, autonomy and control, a lack of confidence in performing their caring role, and the impact of transitions and coming to terms with these. Quantitative observational findings indicated that self-efficacy and preparedness overall were associated with better mental health. Intervention studies indicated that improved self-efficacy, confidence, mastery, autonomy, control and communication had positive effects, but they found no associations with preparedness or competency. Quantitative research appeared to focus more on self-management factors such as self-efficacy, mastery and preparedness than carers themselves did in the qualitative research.

Qualitative findings highlighted the importance of coping strategies, particularly strategies to enable time for respite, but also noted strategies of positive self-talk, spirituality and sometimes ignoring own emotions and needs. Quantitative findings on coping strategies were mixed and lacking in clear results. However, observational study findings may indicate that a lack of acceptance and greater avoidance or substance abuse relate to worse carer mental health, and optimism and having time for oneself relate to better mental health. Intervention research may indicate that increased healthy behaviours and decreased avoidant coping relate to better mental health.

Theme 6: Support

Support was considered by 19 observational studies (18 bivariate and 1 multivariate) and 1 intervention study and identified in 29 qualitative studies, making it the most prominent factor for carer mental health as considered by carers themselves.

Qualitative findings found that formal support system factors that carers felt worsened their mental health included limited availability and quality of care, disjointed care, a lack of information, practitioner skill and good pain management. Detrimental aspects of interactions with practitioners included lack of empathy, poor communication, a failure to listen to the wishes of patients and carers, lack of recognition of carers' expertise and a lack of collaboration. Sometimes additional cultural barriers related to language could also be negative. Observational findings regarding formal support indicated that unmet needs in general related to worse mental health, and carer satisfaction with support to better health. However, observational findings generally showed a lack of relationship or mixed results, but studies may not have focused on formal support delivery components that mattered to carers.

Qualitative findings indicated that a lack of support from family, friends and others in the same situation was negative, while presence of such support was positive for mental health. Quantitative observational findings indicated that such support was associated with better mental health, although some studies found no relationship.

Theme 7: Contextual factors

Contextual factors were only considered in observational research, within 23 studies (16 bivariate, 7 multivariate).

Older carer age seemed generally to be associated with better carer mental health, and being female with worse mental health. Findings were otherwise predominantly non-significant and too inconsistent to draw further conclusions.

Limitations of the literature in illuminating factors

The qualitative research provided a framework for factors affecting carers' mental health grounded in carers' own perspectives but could not test for associations between factors and health. The observational research had a predominance of cross-sectional designs and may sometimes have considered factors that were easily measured, rather than those that were most important. Intervention studies did not specifically test for the impact of factors. Generally, observational and intervention research lacked conceptualisation and theory and may not have focused on factors of importance to carers.[26]

Collaboration with the carer Research Advisory Panel

The researchers worked closely with a carer RAP throughout to ensure carer perspectives fully informed the understanding and presentation of factors that can impact on carer mental health and how to preserve or improve carer mental health.

A key contribution was RAP recommendations on how to support carers to sustain or improve their mental health. The RAP also helped shape the presentation of project findings to stakeholders. Further details of the RAP collaboration, the full gains to the project and lessons learnt about patient and public involvement (PPI) are reported elsewhere.[27]

Methods

Creation of the carer Research Advisory Panel

A carer co-applicant (JF) helped develop processes and information materials for recruitment. Recruitment included social media advertising, contacting local carer support groups and approaching personal contacts. Information included a Plain English Summary, accompanied by more detailed information on project aims, RAP role and processes, eligibility criteria and payment policy. To help ensure equitable selection and maximise group diversity, a defined selection process was used, involving a brief application form and a telephone conversation with candidates. This created a panel with a balanced number of men and women, ethnic minority community representation, and carers with experience of supporting those with cancer or non-cancer conditions, long- or short-term caregiving and none or extensive PPI. Unfortunately, the carer from an ethnic minority community then had to withdraw before the first RAP meeting.

Five recruited RAP members contributed to a substantial part of the project and four to the whole project. Additional to these five members, the RAP was chaired by the carer co-applicant (JF), ensuring involvement of a minimum of five carers throughout.

Review Advisory Panel meetings

Nine meetings were held between February 2020 and July 2021. Six were planned originally, but RAP members' wish for greater involvement (see below) increased this number. Early groundwork included building relationships, clarifying expectations, agreeing how to work together and training. Three researchers attended the meetings, including the project lead, to emphasise the value of the RAP to the project. Other meeting principles included circulating materials well in advance, providing ongoing training, setting clear agendas but with flexibility to follow carers' own agendas, communication between meetings, and appropriate and prompt reimbursement. These principles continued when moving from face-to-face to online meetings during the COVID pandemic.

Review Advisory Panel contributions

The RAP reviewed the search strategy; contributed to qualitative review analysis; reviewed findings from the observational and intervention syntheses and helped shape the presentation of these findings; helped consider how all three syntheses could fit together within a comprehensive framework; advised on how the total set of findings could be presented; supported the work package 2 stakeholder consultation; and reviewed final project products.

Additionally, the project was enriched by allowing for some flexibility to accommodate carers' agendas within meetings and adapt the project accordingly. First, RAP members wanted a greater role in the qualitative synthesis as a group. They therefore helped extract and create first-order themes, and reviewed and assessed second- and third-order themes, adding insights and validity (see *Methods*, *Analysis* and reports[24,27] for details).

More importantly, the RAP wished to produce their own recommendations from the project. Originally, the project purely aimed to present synthesis findings in accessible formats for relevant stakeholders (e.g. practitioners, policy-makers), then let stakeholders decide how they could act on findings. However, the RAP felt it was important also to consider what the findings told us about the support carers needed and to produce recommendations for stakeholders from carers' own perspective. Consequently, two RAP meetings covered development of carer recommendations. RAP members reflected before and during meetings on synthesis findings and their implications for actions to improve carer mental health. Their feedback was synthesised by one of the researchers and reviewed by RAP members and researchers by e-mail to arrive at the final recommendations.[27] The RAP recommendations were presented to stakeholders in work package 2 of the project alongside the findings from the evidence synthesis itself.

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Products from Research Advisory Panel collaboration

The RAP recommendations and an overview of the shaping of evidence synthesis materials for stakeholders are presented below.

Carer Research Advisory Panel recommendations

The RAP developed recommendations on how the support and care system should ideally be set up to maintain or improve carer mental health based on evidence synthesis findings.[27] Recommendations reflected synthesis themes, including helping carers ensure that the patient's care is managed and that the patient is OK; reducing the impact of caregiving; ensuring financial security; enabling carers to stay in control and feeling empowered; maintaining a quality relationship with the patient; and providing holistic, but tailored carer support. However, many recommendations addressed several themes. Therefore, they were divided into 'Overarching principles' representing recommendations spanning several review themes, and 'Theme-specific' recommendations which aligned more closely with a single theme.

The RAP highlighted that recommendations should be seen within the following context:

- Core to recommendations was an overall aim to help carers better fulfil their role, including reducing unnecessary demands on their time in order to allow more time to look after the patient. If carers felt they were not providing 'optimum care', this could significantly affect their mental health.
- A crucial part was ensuring that carers felt empowered, were heard and had proper engagement with services as active participants within their caregiving role.
- Recommendations focused on overcoming common carer challenges to help support the mental health of the majority, but it must be recognised that experiences of individual carers will vary.
- Recommendations aimed to be pragmatic and consider the constraints on service provision, rather than provide a 'gold standard'.

TABLE 1 Carer RAP recommendations

Overarching principles	Theme-specific recommendations
1. **Awareness raising** To connect carers to existing services by: • Making carers aware of the support services for carers or the patient • Raising awareness among healthcare professionals of the need to address the impact of EOL caregiving on carers	1. **Patient condition** To maintain/improve carer mental health there should be: • Accessible, timely information about the patient's condition • Control of the patients' symptoms • Recognition of, and referral for, treatable patient conditions, for example, for opticians, dentists • Holistic approach to patients' treatment and care • Co-ordinated and continuous, rather than fragmented, patient care: ◦ Remove need for carers to tell their 'story' repeatedly, for example, consider folder that can be taken to appointments with patient information ◦ Consistent provision regardless of postcode ◦ Seeing the same general practitioner throughout EOL care
2. **Road map to support carers to navigate the EOL caregiving** • Provide carers with a comprehensive 'road map' with all the relevant information to help them navigate each stage of EOL caregiving and bereavement, including ◦ help available locally ◦ how to access specialist equipment and services for the patient at home ◦ practical advice, including legal, financial and service advice ◦ lists of useful telephone numbers, websites and e-mail addresses	2. **Impact of caring responsibilities** • Carers should be able to spend quality time with the person they are caring for and have sufficient time for caregiving, and their own concerns. Helping carers with co-ordination, administration and navigation through the stages of EOL caregiving would help free up their time and reduce the impact of caring responsibilities

TABLE 1 Carer RAP recommendations (*continued*)

Overarching principles	Theme-specific recommendations
3. **Bespoke support which recognises the carer has needs and identifies them through assessment** This should recognise that carer needs are holistic and tailor support where possible to individual carers' needs and situation, by: • recognising that carers have needs and using appropriate tools to assess them • comprehensive assessment, including medical, personal and social needs • considering carers' actual needs, rather than just what services can offer • taking into account carers' personal circumstances	3. **Finances** This was a fundamental issue, overlapping with recommendations for practical considerations • Carers should not be financially disadvantaged by caregiving, and require an absolute minimum of sufficient finances (e.g. through a decent Carers Allowance) to meet basic needs (paying rent, bills, food) • Carers should have access to practical advice, including early legal and financial advice (e.g. Power of Attorney), and will making • Carers should receive timely advice on eligibility for funding for care costs, including housing adaption grants
4. **Standardised comprehensive assessment to assess 'actual' rather than 'managed' needs of the patient** • Patients should be assessed for their 'actual' needs as opposed to their 'managed' needs, to avoid overestimating patients' capabilities, ensure that their dependency on carers' support is fully recognised, and ensure carers feel able to manage caregiving tasks • Assessment should be standardised across services and provide a comprehensive assessment of the patient's actual needs	4. **Relationships** While acknowledging that carers may differ in their feelings about being a carer and the quality of the patient–carer relationship: • Carers should be enabled to spend adequate time with the patient. Easing navigation through the caregiving journey would take pressure off carers and free up time for them to do so
5. **Co-ordinated and timely care by providing a single point of contact for the carer** Carers may need support with navigating the health and social care system and articulating their specific needs: • Provide carer access to a key worker as a single point of contact, to ensure patient care is timely, continuous and that both carer and patient care are co-ordinated. This support should extend to: ◦ Comprehensive assessment of needs ◦ Helping carers with administrative tasks, for example, forms ◦ Signposting or referral to relevant services ◦ Follow-up by relevant services, including post bereavement ◦ Advocacy support to help carers articulate need	5. **Carer internal processes** Recognising that some carers may need 'permission' to feel the way they feel: • Carers need to have an outlet for 'venting emotions'
6. **Practical considerations/essential resources:** This needs to take into account that carers have to self-declare to be recognised as a carer, which some find difficult; that they may not live in the same household as the person cared for; and that time is of the essence for EOL caregiving. As a minimum: • Carers need to feel confident that their basic physical needs will be met, both during EOL caregiving and post bereavement • Carers should not be financially disadvantaged by their caregiving role and need sufficient finances (see *Finances*) • Equipment for the patient should be easily accessible and provided when needed. Equipment should be retrieved promptly and sensitively following death. • Carers should have access to practical advice, including legal and financial advice (see *Finances*) and Do Not Resuscitate where appropriate • Carers should be given timely advice on their eligibility for funding for care costs (see *Finances*)	6. **Support** a. Recommendations about support for the patient Given that carers' mental health is likely to be better when the cared-for person receives sufficient care and support: • Support for patients should be readily available, responsive, accessible and flexible ◦ With the option of receiving support at home or close to home wherever possible ◦ With home care services flexible and responsive to the patient's needs, including timing of visits • Joint support should be available for the carer and the person cared for if that is their preference b. Recommendations about support for the carer • Service providers should recognise that carers have needs and use appropriate tools to assess them [see recommendation (3) bespoke support] • Individual formal carer support should be available ◦ Availability of general counselling if carers need a safe space to 'vent' ◦ Permission to remain in the system post bereavement for bereavement support • Individual informal carer support should be available ◦ Availability of early access to local support/peer support groups, which may help identify further sources of support
	7. **Contextual factors** All recommendations should take into account the specific context, personal circumstances and preferences of individual carers, wherever possible

Source: Adapted from Grande *et al.*[27]

Shaping of academic materials for stakeholders

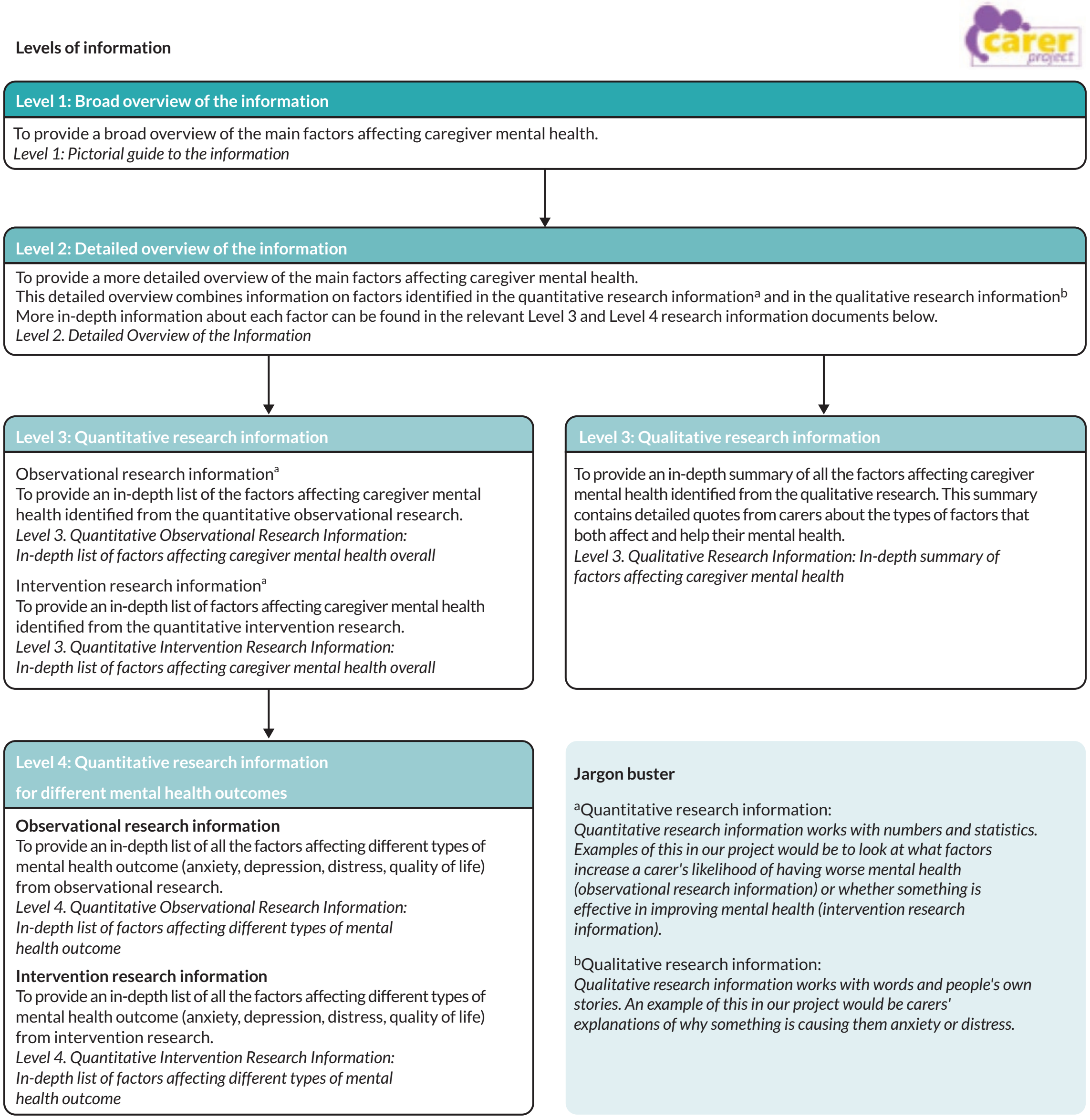
The RAP advised on how to present the total body of evidence syntheses to help stakeholders (a) gain an overview of information available, (b) navigate to the information of interest and (c) make sense of findings. A hierarchy of presentation was chosen, where Level 1 gives the simplest overview of available information, and subsequent levels present information in increasing detail. See *Figure 2* and the project website https://arc-gm.nihr.ac.uk/carer-project- for an overview of levels and materials at each level and Bayliss *et al.*[24] for qualitative, Shield *et al.*[25] for observational and Grande *et al.*[26] for intervention review and summary reports.

Level 1: One-page pictorial diagram showing information available

The diagram presents each theme as an image together with a green up arrow indicating the amount of evidence showing a relationship with improved mental health and a red down arrow indicating the amount of evidence showing a relationship with worse mental health (larger arrow, more evidence).

Level 2: Table combining syntheses findings within one conceptual framework

The table lists each theme with its subthemes and describes in simple language each factor's association with mental health within each. Text colours indicate which factors stem from qualitative research, quantitative research, or both.



Levels of information

Level 1: Broad overview of the information

To provide a broad overview of the main factors affecting caregiver mental health.
Level 1: Pictorial guide to the information

Level 2: Detailed overview of the information

To provide a more detailed overview of the main factors affecting caregiver mental health.
This detailed overview combines information on factors identified in the quantitative research information[a] and in the qualitative research information[b]
More in-depth information about each factor can be found in the relevant Level 3 and Level 4 research information documents below.
Level 2. Detailed Overview of the Information

Level 3: Quantitative research information

Observational research information[a]
To provide an in-depth list of the factors affecting caregiver mental health identified from the quantitative observational research.
Level 3. Quantitative Observational Research Information: In-depth list of factors affecting caregiver mental health overall

Intervention research information[a]
To provide an in-depth list of factors affecting caregiver mental health identified from the quantitative intervention research.
Level 3. Quantitative Intervention Research Information: In-depth list of factors affecting caregiver mental health overall

Level 3: Qualitative research information

To provide an in-depth summary of all the factors affecting caregiver mental health identified from the qualitative research. This summary contains detailed quotes from carers about the types of factors that both affect and help their mental health.
Level 3. Qualitative Research Information: In-depth summary of factors affecting caregiver mental health

Level 4: Quantitative research information for different mental health outcomes

Observational research information
To provide an in-depth list of all the factors affecting different types of mental health outcome (anxiety, depression, distress, quality of life) from observational research.
Level 4. Quantitative Observational Research Information: In-depth list of factors affecting different types of mental health outcome

Intervention research information
To provide an in-depth list of all the factors affecting different types of mental health outcome (anxiety, depression, distress, quality of life) from intervention research.
Level 4. Quantitative Intervention Research Information: In-depth list of factors affecting different types of mental health outcome

Jargon buster

[a] Quantitative research information:
Quantitative research information works with numbers and statistics. Examples of this in our project would be to look at what factors increase a carer's likelihood of having worse mental health (observational research information) or whether something is effective in improving mental health (intervention research information).

[b] Qualitative research information:
Qualitative research information works with words and people's own stories. An example of this in our project would be carers' explanations of why something is causing them anxiety or distress.

FIGURE 2 Levels of information diagram.

Level 3/4: Tables with detailed findings of each review

Level 3 has a qualitative table with a full set of quotes underpinning each subtheme within themes.

Level 3 also displays observational and intervention syntheses tables for each subtheme within themes, using colour-coded box scores for each factor:[25,26] green for number of investigations showing a factor relates to improved mental health, red for worse mental health, neutral for no relationship. Level 4 tables are identical to Level 3 quantitative tables, but with findings broken down into anxiety, depression, distress and quality of life.

Work package 2: stakeholder consultation on usefulness, dissemination and use of project outputs

Methods

The stakeholder consultation occurred over two stages:

1. Workshops and discussion groups – to identify the most useful information and priorities for each stakeholder group, and guide the development of outputs and dissemination strategies, including operationalisation into primary care settings.
2. Online survey – questionnaire with mixed-mode responses to supplement findings from workshops and discussion groups.

Both the findings from the evidence synthesis itself and the RAP recommendations were presented to stakeholders at each stage.

Stage 1: Workshops and discussion groups

Participants and recruitment

Stakeholders (carers/patients, health and social care practitioners, policy leads/commissioners and carer organisation leads) were invited to participate in online workshops and discussion groups. E-mail invitations were distributed through national and local carer organisations, carer charities, local NHS Trusts, local clinical commissioning groups, the Royal College of General Practitioners and the Queen's Nursing Institute. We also advertised via our project Twitter page; @CarerProject, and web pages; https://arc-gm.nihr.ac.uk/carer-project-. Eighty-seven people responded and were followed up for availability.

Procedure

Four 2-hour workshops (one for carers/patients, one for commissioners/policy-makers, two for practitioners) and two 2-hour joint discussion groups for carers and general practitioners (GPs) were held online via Zoom (Zoom Video Communications, San Jose, CA, USA). At least one member of the carer RAP attended each session. Carers and NHS staff were offered reimbursement for preparation time and attendance.

Content was tailored for each stakeholder group. The research team presented an overview of the project and findings from the evidence synthesis (levels of information documents: Level 1, Level 2, Level 3-qualitative and Level 3-quantitative) and the carer RAP recommendations. Copies of workshop materials were distributed to participants at least 1 week before the event.

Workshops

Participants were asked their views about the documents, including usefulness and relevance of the evidence, clarity of presentation and best methods to communicate findings. Carers/patients were additionally asked how meaningful the recommendations were to them, and about the relative importance of the individual recommendations.

Discussion groups

The discussion groups for GPs and carers considered how the findings could be used to support carers in primary care settings. Participants were asked about the extent to which the information was useful and relevant and how the findings/materials could be used in practice to improve carer support.

Synthesising the consultations

Workshops and discussion groups were recorded via Zoom. Footage was reviewed by the research team (DH, TS, CR) and structured notes were taken based upon questions posed to participants. Recordings of the groups were deleted once notes were complete. No formal analysis of content was undertaken; instead outlines of key points and consensuses of opinion are presented.

Stage 2: Online survey

Participants and recruitment

Surveys were sent to the 87 people who responded to adverts for workshop and discussion group participation, using personalised invitation e-mails with survey links accompanied by information about project findings (levels of information: Level 1, Level 2, Level 3-quantitative and Level 3-qualitative) and the carer RAP recommendations. E-mail reminders were sent out 2 weeks after the initial invite. The survey was live for 31 days.

Design

A brief survey was based on the questions posed during the workshops and discussion groups. There were two separate versions: one for those who attended a workshop/group ('attendees') and one for those who did not attend ('non-attendees'). These contained the same questions but with wording appropriate to respondents' exposure to the project. Response options to closed questions were informed by some of the responses given in the workshops/discussion groups. Surveys were designed and hosted in QualtricsXM (Version June 2021, Qualtrics, Provo, UT).[34]

Results

Participants

Thirty-six participants in total took part in the workshops and discussion groups. Participant characteristics are summarised in *Table 2*. Eight participants took part in the carer/patient workshop, 18 in the 2 practitioner workshops (7 and 11 in each) and 2 in the policy-maker/commissioner workshop. There were nine participants in the two discussion groups for carers and GPs: five in the first (four carers and one GP) and four in the second (two carers and two GPs). One GP from the practitioner workshop also took part in the carers and GP discussion group.

A total of 43 people responded to the surveys (49.4% response rate: 20 attendees, 23 non-attendees). The largest respondent group were practitioners (44.2%), although there was good representation from carers/patients (20.9% overall) (*Table 3*).

Findings

Findings from the groups are summarised according to the main themes explored via the topic guide. Survey data are also presented within these topics.

Usefulness and relevance of evidence

Participants across all stakeholder groups agreed that the synthesis and interpretations of evidence were valid,

TABLE 2 Characteristics of stakeholders taking part in workshops and discussion groups

	Total	Carers/patients	Practitioners	Policy-makers/commissioners
	N = 36	*n* = 14	*n* = 20	*n* = 2
Male	9 (25%)	5 (36%)	2 (10%)	2 (100%)
Female	27 (75%)	9 (64%)	18 (90%)	0 (0%)
Role n (%)				
Carer		13 (93%)		
Patient		1 (7%)		
GP			7 (35%)	
Nurse			4 (20%)	
Social worker			4 (20%)	
Healthcare assistant			2 (10%)	
Other: Palliative care consultant, Counsellor, Service Manager, Head of Advocacy, Policy Advisor			3 (15%)	2 (100%)

TABLE 3 Survey participant stakeholder groupings

	Total	Carers/patients	Practitioners	Policy-makers/commissioners	Other[a]	Did not respond
Attendee	20	6 (30%)	7 (35%)	2 (10%)	2 (10%)	3 (15%)
Non-attendee	23	3 (13%)	12 (52%)	0 (0%)	3 (13%)	5 (22%)
Total	43	9 (21%)	19 (44%)	2 (5%)	5 (12%)	8 (19%)

[a] Participants were invited to specify: attendees *n* = 1 practitioner and carer, *n* = 1 practitioner and policy-maker/commissioner; non-attendees *n* = 1 'hospice', *n* = 2 did not specify.

Note

Attendee = participated in a workshop or discussion group, non-attendee = did not participate in a workshop or discussion group.

meaningful and recognisable. There was a sense that the evidence was 'not new', raising questions about *why* the issues highlighted are not already being addressed.

There was validation for the RAP recommendations from all stakeholders, with several practitioners across different roles stating that these were the most useful output, being both easy to digest and useful for practice. It was felt that the points reflected issues often raised in local conversations, but it was valuable to have this articulated in a written document, informed by research and, in particular, shaped by carers themselves.

Not all survey responders completed all questions. However, of those who responded, 100% of 9 attendees and 91% of 11 non-attendees found the qualitative, rather than quantitative, evidence most helpful. A smaller majority also found the recommendations, rather than the synthesised evidence most useful (50% of 10 attendees; 90% of 10 non-attendees).

Carers and GPs at the discussion group felt that findings and RAP recommendations would be most useful for raising awareness, and carers felt they covered factors requiring awareness-raising about their situation, although anticipatory grief may need more emphasis.

Some of the recommendations were felt to be too specific or targeted (i.e. placing responsibility on specific practitioners or services), when issues may need resolving at wider organisational or systemic levels.

How findings can be applied to support carers in primary care

A considerable amount of discussion concerned carer needs assessment, as flagged in RAP recommendations, including the statutory Carer's Assessment.

Some carers reported that they had not received a statutory Carer's Assessment or, if received, that it had not felt comprehensive. The project findings and recommendations may provide a useful framework to address this. Several practitioners felt that the RAP recommendations could be used to inform monitoring and holistic consideration of needs or, conversely, as a checklist by carers themselves to say what had and had not been offered/provided. Similarly, the Level 1 pictorial diagram overview could also be used as a checklist by practitioners. Carers commented that the recommendations may provide a 'road map' to help prepare and guide them on their caregiving journey and prompt and empower carers to seek help.

There was recognition that it may not always be possible or desirable for GPs to conduct assessments of carers. For example, carers may feel uneasy in approaching their GP with concerns not directly health related. Discussions also included how the information could be used within brief consultations, to provide emotional support via a therapeutic relationship without providing formal counselling. However, this was coupled with concerns over medicalising social problems, lack of time within clinic and complications of 'coding time' for carers not registered as patients on GPs' system. One GP asked: '*How do we "unlock" GPs but not burden them or infantilise people?*' It was agreed that instead of a GP, a key or link worker, a carer support nurse, community palliative care team, health coach, social worker, or multidisciplinary team may serve as main carer contact or facilitator.

It was further suggested that organisations, including third-sector organisations, may wish to choose a smaller subset of recommendations to focus on or engage people with lived experience and other stakeholders in providing support or in prioritisation exercises.

An idea raised was that a roadmap based on carer RAP recommendations could be pre-populated with potential resources and solutions to consider (both national and local). This could be adapted to different areas and highlight gold standards and where these are falling short. It could also serve as an *aide memoir*. Linking recommendations to applicable legislation where relevant may also serve as a reminder of a responsibility to act. However, templates would need to be simple with practical and tangible outcomes, dynamic and updatable to reflect constant change, and heed the RAP caution that individual carer experiences and circumstances will vary. Such templates were recognised as being beyond this project, but as something local teams could achieve using project documents.

Additionally, given the systemic issues impacting the provision of carer assessment and support, one group noted the need to have enablers enacted into policy, to enable introduction of the anticipatory planning carers have recommended.

Other options raised included funded Primary Care Network carer co-ordinators with the knowledge for supporting carers; a designated person within integrated care boards with carer responsibility, better linkage between secondary and primary care, co-ordinating GP care for carer and patient, increasing the Carers Allowance and extending bereavement support if required.

Participants also flagged the importance of supporting the patient as a way of supporting the carer and helping carers to care well, and providing bespoke support tailored to individual carers and their immediate needs.

Importantly, some feedback also noted the role of peer support and community development to facilitate compassionate streets, neighbourhoods and supportive networks within communities, highlighting that carer support did not only reside within formal care system provision.

Organisation and presentation of evidence

The organisation of evidence into levels was well received. Participants generally liked the option to delve deeper if needed rather than being overwhelmed by all the evidence in one place. It was felt this could be helpful for training and education purposes and translating information into policy. Although some participants ideally wanted even easier navigation to specific information, for example, to address a policy point, this may be achieved through word searches within downloadable documents from each level.

Feedback on specific documents

Overview of levels – Some felt this was still rooted in academic language and could be made simpler.

Level 1 – The one-page pictorial diagram overview was felt by some to provide a useful, quick visual representation which can form the basis for thinking further about needs of carers, and *'grabs the attention with the promise that there's something further to get stuck into'*. However, others felt there were ambiguities arising from some design features which may need further work.

Level 2 – The table of combined syntheses was received well by most; however, a few felt that this document was less clear in its aims and that it could benefit from further information describing what was being presented.

Level 3 – The tables with detailed findings from the qualitative and quantitative evidence were felt to be useful. While one person noted that direction of effect in the quantitative tables was not always clear, this reflects that tables show association rather than causation. The qualitative evidence was universally well received. Evidentiary quotes were viewed as particularly powerful by practitioners, as being both emotive and important for a deeper level of understanding and prompting reflection.

Carer RAP recommendations – The length of the document and number of recommendations could be challenging. It was agreed that a short, top-line summary version would be helpful. Further, it was agreed that a brief, infographic representation would be useful as a 'quick' reference within an office or clinical setting.

Optimal communication methods

Recommendations from stakeholders (from meetings and surveys) on the best ways of disseminating findings included:

- Audio – including podcasts that can be 'listened to on the go'.
- Infographics – including short visual guides to use a reminder or teaching aid.
- Digital media – including social media, e-newsletter with links, and website.
- Hard copy summary, for example, to be distributed within GPs or via carer groups.
- Seminars and/or webinars delivered to key organisations such as primary care network direct enhanced services and leads, and GP educational networks, Alzheimer's Society, dementia or well-being teams.
- Practitioner newsletters, magazines and forums.
- Promotion during 'Carers Week' organised by Carers UK.
- Summary document/executive summary.

Products created

Project website

A project website has been created where all outputs from the project can be accessed: https://arc-gm.nihr.ac.uk/carer-project- or https://arc-gm.nihr.ac.uk/projects/Addressing-psychological-morbidity-in-informal-carers-at-the-end-of-life; accessed 11 December 2024.

Evidence synthesis: information guidance and tables

In response to stakeholder recommendations for improvements, we worked closely with an infographics specialist to implement colour coding and redesign documents at all levels with a visual perspective in mind. Further clarity was added by creating a short guide to using levels and documents, using less academic language and adding footnotes and explainers to documents in strategic places and presented in ways which would tie into the visual aesthetic but remain informative. The full set of evidence synthesis documents can be accessed under the heading 'Information guidance and tables' on the project website.

Carer recommendations

The carer RAP recommendations were produced both as a summary with bullet points and a longer, streamlined version. The recommendation documents can be found under the heading 'Carer recommendations' on the project website.

Visual one-page summaries of factors and recommendations

Research Advisory Panel recommendations (see *Table 1*) and the existing Level 1 pictorial guide on factors affecting carer mental health (see *Figure 2*) were both developed into visual diagrams in A5 and A4 poster and leaflet formats so that stakeholders can display or circulate these as would be most helpful to their context. These posters and leaflets can be found under the heading 'Think Carer – Posters and leaflets' on the project website.

Recognising the challenges of delivering presentations in real time to multiple organisations, recorded webinars are available on the project website to explain the background to the project, the findings and recommendations on the main project web page and under the heading 'Blogs and presentations'.

We have created a series of podcasts wherein each evidence synthesis theme is discussed, as well as an episode hosted by our carer RAP chair where the recommendations are discussed. These can be found on the project website under the heading 'Blogs and presentations'.

Project publications are also hosted on the website under 'Publications and Reports'.

Discussion

Summary and implications from work package 1

The evidence synthesis identified seven main themes encompassing factors associated with carers' mental health: patient condition, impact of caring responsibilities, relationships, finances, carer internal processes, support and contextual factors. Both qualitative and quantitative research identified factors within each of these themes, adding to their validity, except contextual factors which were only investigated through observational research.

The evidence synthesis in turn formed the basis for carer RAP recommendations for how the care system should support carers to mitigate the potential impact of the identified factors.

Visual one-page summaries of the seven factors and six overarching RAP recommendations are available at https://arc-gm.nihr.ac.uk/carer-project- 'Think Carer – Posters and leaflets'.

Assessments of the gaps in the literature and the strengths and weaknesses of the different research approaches were translated into a set of implications for research. Concurrently, conclusions from the evidence synthesis findings were translated into a set of implications for practice.[26] Below we summarise the implications for research, implications for practice and RAP recommendations.

Evidence synthesis: implications for research[26]

The resulting implications for research from the synthesis are:

- There is limited research into finance and relationships and more research is needed into their impact on carer mental health.
- There are gaps in our knowledge of how carer experience is affected by ethnicity, race and culture that need to be addressed.
- Observational research must focus more on factors that are important to carers (e.g. more meaningful formal support delivery variables) and variables that can truly illuminate what affects carers' mental health, rather than what can easily be measured.
- Intervention studies should also conduct more investigation into formal support delivery components that matter to carers and into 'self-management' interventions more closely aligned with carers' own concerns.
- In general, intervention research should seek to develop more effective interventions based on existing knowledge about factors likely to affect carers' mental health, and employ designs that utilise the full power of intervention research to investigate the underlying causal relationships.
- Both observational and intervention research would benefit from more use of longitudinal design with repeated measures and path analysis, and from clearer conceptualisation of key variables, for example, carer burden, coping strategies, mastery.
- There should be consideration of where dyadic interventions or carer-only interventions may be most effective.
- Many factors important to carer mental health (finance, life impact factors, context) are not feasible to study using RCTs, and quasi-experimental designs may be utilised more.

This synopsis should be referenced as follows:
Grande G, Rowland C, Shield T, Bayliss K, Flynn J, Harris D, *et al.* Understanding and addressing factors affecting carers' mental health during end-of-life caregiving: synopsis of meta synthesis of literature and stakeholder collaboration [published online ahead of print February 19 2025]. *Health Soc Care Deliv Res* 2025. https://doi.org/10.3310/RTHW8493

- This field of research would benefit from greater use conceptual frameworks and theories to guide further enquiry and ensure more coherence, and possibly, agreement on core sets of factors to be included in observational and intervention study measurement.

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Evidence synthesis: implications for practice[26]

The factors likely to affect carers' mental health during EOL caregiving cover a wide spectrum. Correspondingly, the solutions for sustaining or improving carers' mental health need to be multifaceted, where different stakeholders are likely to be able to influence different factors. Some factors are amenable to change, others can highlight where carers are at risk of worsening mental health and may require closer monitoring and support. We need to consider that many factors also are likely to be interlinked, for example, relationships, support from social network, and impact of caring responsibilities on carers' lives.

The synthesis indicates that the following are important in supporting carers:

- Maintaining patient well-being, and monitoring and responding to the impact on carers of patients' psychological symptoms and general decline.
- Providing help with negotiating transitions, support with care tasks and respite to prevent exhaustion and promote self-care.
- Bolstering the relationship between patient and carer and within the wider family and facilitating open and constructive communication.
- Ensuring carers have access to benefits and are aware of entitlements to flexible working and carer leave (which may include helping carers to recognise themselves as 'carers').
- Improving financial benefits and employment conditions for carers longer term.
- Improving carers' sense of control and self-efficacy in their carer role, enabling carers to take breaks and help maintain a positive outlook and acceptance.
- Improving formal service provision, including ensuring it is co-ordinated, responsive, listening and providing good information and communication.
- Assessing support within carers' social networks and facilitating peer support.
- Being aware of and supporting carer demographic groups at risk of worsening mental health, such as younger or female carers.

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Research Advisory Panel recommendations: implications of findings for carer support[27]

The RAP considered the implications of the findings for carer support which led to both general recommendations spanning several main themes and recommendations relating to specific themes (see Collaboration with the carer Research Advisory Panel and Grande *et al*[27]).

General recommendations – important aims:

- Awareness raising for carers about services, and for professionals about impact of caregiving on carers.
- A road map to support carers to navigate EOL caregiving.
- Bespoke support which recognises that the carer has needs and identifies them through assessment.
- A standardised, comprehensive assessment to assess 'actual' rather than 'managed' needs of the patient to take into account carer's contributions.
- Co-ordinated and timely care by providing a single point of contact for the carer.
- Cover of practical considerations and essential resources, including meeting basic physical, and financial needs and providing timely equipment; this may require helping carer to self-identify as a carer.

Theme-specific recommendations – important aims:

- Ensure holistic and co-ordinated patient care.
- Address practical impacts of caring responsibilities to allow carers proper time for the patient, caregiving and own concerns.
- Ensure sufficient finances to meet basic needs, including advice on legal, financial and funding matters.
- Enable carers to spend quality time with the patient.
- Ensure carers feel they have permission to feel the way they feel and have an outlet for 'venting' emotions.

- Ensure that support for the patient is responsive, accessible and flexible, and that support for carers involves assessment of carers' needs, individual formal support, including counselling and post bereavement support, and individual informal support, including early access to local support and peer support groups.
- The carer's specific context, personal circumstances and preferences should be considered.

Summary and implications from work package 2

Stakeholder responses attested to the validity of the evidence synthesis and recommendations. These reflected many familiar issues, raising the question why these remain unresolved. However, having issues articulated within evidence-based documentation was here seen as valuable.

Stakeholders on balance saw the qualitative evidence and RAP recommendations as more useful than the quantitative evidence. This poses a dilemma for researchers seeking to establish clear, measurable relationships between variables or interventions and health outcomes, if so-called 'softer' evidence is what speaks to stakeholders. Quantitative researchers need to grapple with how to bridge this communication gap and make their information accessible and impactful, as immensely valuable information may otherwise not resonate with those able to act on it. Stakeholders found the organisation of information into different levels a helpful way of making the evidence accessible, and simplification of quantitative information, for example, through colour coding also aided understanding. However, more investment in communicating quantitative evidence to stakeholders is needed.

Stakeholder discussions also highlighted challenges in translating evidence into specific changes, particularly in the context of carer support. The project information was seen as highly valuable for awareness raising about carers and for providing frameworks for more holistic, comprehensive assessment, checklists or roadmaps. However, no consensus was reached regarding where in the care system and with whom responsibility for carer support may lie. Although GPs may be well placed for this, participants also suggested a range of other health and social care providers. However, discussions indicated that designated, funded carer focused roles may be better, for example, carer support nurses or nurse co-ordinators or integrated care board members, as support for carers may be difficult to accommodate within existing roles.

Stakeholders also noted the need to consider systemic levels, policy enablers and mobilisation of community networks, in line with the project assumption that improvement of carer mental health would need to be tackled at several levels.

The project was unable to recruit commissioners for work package 2 despite invites, including local clinical commissioning groups. There was therefore little input from those who may influence how funds are spent. Responses were mainly from practitioners and carers, with policy input limited to two participants involved with advocacy and policy advice. Stakeholder input therefore mainly represents practitioner and carer perspectives, although they have relevance beyond these stakeholder groups.

General discussion

The strengths of the project include the synthesis and integration of findings from diverse research approaches, each bringing different yet complementing insights, to provide the most comprehensive picture to date of factors related to carers' mental health during EOL caregiving. A further strength was the efforts invested in making this information relevant and accessible to stakeholders: first, through close collaboration with the carer RAP to ensure its relevance to carers themselves and develop recommendations; second, through broader engagement with stakeholders in a position to use this information to effect change.

The range of factors related to carers' mental health indicate that solutions also need to be multifaceted and responsive and involve a range of stakeholders. Indeed, while reviews of trials generally have found limited effects of carer interventions, multicomponent interventions are most likely to show improvements in carer health compared to those with a narrower scope;[35] further, carers consistently prefer interventions that are person-centred and needs-based, rather than standardised and 'one-size-fits all'.[35] While recognising the need for a multifaceted approach, we highlight some key elements below to help guide meaningful action.

Finance emerged as the theme with the greatest difference in emphasis between sources. It received little attention in quantitative research but was a substantial theme from carers' own perspective in the qualitative literature and highlighted as a core issue by the RAP. The impact of financial challenges on carers may have been partly 'hidden' due to lack of attention, not because it is not highly significant, but because there has been a failure to investigate. Caregiving financially disadvantages many carers as they often have to reduce or quit paid work, while facing increased care costs.[36] We need greater spotlight on how caregiving affects carers financially, who is affected, and when carers are left with sufficient

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Grande G, Rowland C, Shield T, Bayliss K, Flynn J, Harris D, *et al.* Understanding and addressing factors affecting carers' mental health during end-of-life caregiving: synopsis of meta synthesis of literature and stakeholder collaboration [published online ahead of print February 19 2025]. *Health Soc Care Deliv Res* 2025. https://doi.org/10.3310/RTHW8493

or insufficient resources to manage and meet basic needs. This is particularly pertinent in the context of a cost of living crisis, and, not surprisingly, deprived groups suffer more.[37] Amelioration of any financial impacts would require greater system changes and political will, for example, through changes to the Carers Allowance, available grants, and caregiving-related employment and pension rules.[2,38]

Support, or the lack of it, was the most prominent factor related to carer mental health as identified by carers in the qualitative literature, and a strong focus in the RAP recommendations. Quantitative research also indicated that insufficient support was detrimental. However, achieving proper support for carers during EOL care probably requires, first, that carers become a defined target for support in their own right separate from the patient, whose needs are assessed separately; second, that structures and roles to support carers are embedded in the wider system.

Carers used to be a separate target for support within UK palliative care policy,[39] but policy has strongly shifted towards treating them solely as part of a patient/family unit of care within EOL care.[40] There is some sense in merging carer support with patient support and considering them jointly, given that carers' mental health is closely interlinked with patients' well-being, as highlighted by our review and RAP recommendations. However, this is likely to miss that carers also have considerable support needs that are separate from and different to patients' needs, and perhaps also how much the patient's well-being depends on efforts by carers to provide, co-ordinate and follow up care. In a joint patient/family unit of care, the patient will naturally always remain the focus, where practitioners' consideration of carers' needs will end up as an occasional add-on if time permits, and carers will be reluctant to consider or voice their own needs over those of the patient.[41]

Separate consideration and person-centred assessment of the carer is therefore essential in EOL care, and RAP recommendations highlight the need to ensure bespoke carer support recognising carers' needs using carer assessment. Although there is a statutory Carer's Assessment, Carers UK[2] report that a minority of carers receive this and many feel it does not lead to improvements, an experience echoed by project stakeholders. Further, this Carer's Assessment is aimed at longer-term social care rather than EOL care, whereas EOL carers have considerable healthcare-related support needs in addition to social care needs: first, a need for information and skills to cope with the patient's EOL care; second, a need to ensure their own healthcare needs are addressed.[42,43] Support needs assessments for EOL carers need to encompass these healthcare aspects and probably involve healthcare professionals. The RAP recommendations also highlight how patient assessments need to improve by assessing 'actual' rather than 'managed' needs to make more visible how dependent the patient's well-being is on carers' contributions and to help ensure carers feel able to manage caregiving tasks.

While reinstating a policy and practice aim to assess and address carers' support needs separately is a crucial starting point, this would need to be underpinned by structural changes to lead to consistent improvements. Consistent support for carers would require that there is consistent identification of patients' main carer(s), information on their situation, a recording system for carer information separate from patient data, and a protocol for assessing carers and responding.[41] However, GPs, for instance, can normally only record information on a patient's carer, their needs and any supportive input if that carer is also a patient of their practice. Also, consistent carer support requires practitioners with training, time and workload capacity to support carers, and who have support from senior managers and key colleagues.[41]

Implementing such change is possible, but it takes resources and time. Further, without dedicated, protected time allocated to it, carer support may still evaporate in the face of pressures to deliver patient care. Therefore, ultimately, consistent carer support may require designated carer support nurses, carer co-ordinators and/or carer leads for carer support, as proposed by stakeholders.[44] In particular, the key worker role recommended by the RAP, and also development of local 'road maps' with resources, may be difficult to deliver by workers who are also juggling other responsibilities, and may consequently require roles with a dedicated carer remit.

Preservation of carer mental health does not solely rest with finance, employment and formal care. Evidence synthesis, RAP recommendations and stakeholders also highlighted the importance of family and friends, peer support, wider social networks and caring communities.[45,46] These may be essential in mitigating some of the impacts of caregiving, for example, through prevention of isolation and loss of social life, limiting exhaustion through practical help and sitting, and support from peers 'who have been in the same boat'. As identified in our evidence synthesis, other factors will also play a part, but greater awareness of the range of potential factors and proper assessment should help ascertain what particular factors affect the individual carer and how.

Supporting carers properly during EOL care will require investment. Investment in an increased Carer Allowance and policies to support working carers to remain in employment would help towards addressing carers' financial concerns.[2,38] Further, improved formal carer support is unlikely to happen without being supported by resources, for reshaping existing care systems to register who carers are, assess their needs and record needs and actions (not unlike what happens for patients) and for dedicated roles to support carers. Even facilitating community networks and carer support groups will require some resource investment. This is contentious in times of increased economic pressures. However, our patient care is heavily dependent on carers and demographic changes mean that dependency is likely to increase over the coming decades.[4,5,47] Carers save health and social care enormous sums of money.[2] At present, the UK Carers' Allowance only amounts to 7% of the estimated value of carers' contributions to care in patients' last 3 months of life.[3] Given the savings to health and social care, in return carers deserve investment in initiatives to support them to do the best job they can without suffering financial hardship and threats to their mental health. This should also bring added economic gains through prevention of inpatient admissions, savings on mental health care, and enabling people to maintain employment or return to work.

Limitations of the project

The evidence synthesis was limited to home care, OECD countries and papers published in English/Scandinavian and to adult carers of adult patients. The RAP work and stakeholder consultation entailed a UK perspective and was dependent on a self-selected sample. The findings therefore may not have fully captured relevant information and feedback outside these contexts, nor be wholly representative of UK stakeholder views. Further, the project only considered mental health during caregiving, but further work on mental health after the patient's death is required. Finally, within the literature reviewed, there was limited research into ethnicity, race or culture However, within these limitations, the project is likely to have captured core factors associated with carer mental health that resonate with carers and other stakeholders and to have identified meaningful actions.

Equality, diversity and inclusion

Regarding the research itself, the evidence synthesis project ensured that carers' own perspectives were highlighted from the synthesis; first, by ensuring the qualitative review was solely based on research that focused on carers' own accounts of their experiences; second, by making the qualitative review the central review which then guided the synthesis of the quantitative reviews. Further, all reviews considered the ethnic composition of reviewed studies, and all review reports presented any findings on ethnicity and noted the limited representation of ethnic minorities in the literature. The evidence synthesis was limited to OECD countries to enable comparison with countries whose healthcare systems were likely to be comparable with the UK, and limited to publications in English and Scandinavian due to resource constraints, and this was noted as a limitation of the project. The work with the carer RAP and the stage 2 stakeholder consultation sought to ensure that project findings were presented in formats accessible to all carer groups and stakeholders.

Regarding the research team and other involvement, the project was shaped and guided by carers themselves: first, by having a carer co-applicant help develop the project and second, by recruiting a strong and active carer RAP who helped shape the search strategy, conduct the analysis, interpret the results, and shape the presentation of project materials and dissemination, and whose carer recommendations became a key project outcome. Further, in the project's stage 2 stakeholder consultation, carers constituted nearly a third of the meeting participants. Unfortunately, a carer from an ethnic minority community group who was due to join the carer RAP had to withdraw before the first RAP meeting. However, in stage 2 of the project a 10th of the meeting participants were from ethnic minorities.

Conclusions

This project has provided a comprehensive evidence synthesis of the range of factors associated with carer mental health during EOL caregiving (patient condition, impact of carer responsibilities, relationships, finances, carer internal processes, support and contextual factors), accompanied by carer-developed recommendations for supporting carers. A wider stakeholder consultation (with carers/patients, practitioners, policy-makers/commissioners) attested to the validity and value of findings. The project is new in its comprehensiveness, in-depth focus on factors related to carer mental health, and stakeholder involvement. However, many of the factors were recognised by stakeholders or have been identified in earlier reviews[11,48] and more recent literature,[21,49,50] which suggests that the same problems persist over time with little improvement. This project arms us with a comprehensive, evidence-based overview of issues that need to be addressed, but we now need a greater emphasis on the actions required for improvements.

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The *General discussion* covers potential actions in more detail. However, these include changes to carer finance and employment; a separate and defined focus on carers within care provision, with separate carer needs assessment encompassing health and social care needs, underpinned by designated systems and roles for carer support (e.g. consistent carer identification; carer support nurses and co-ordinators); and facilitation of supportive social networks. Research will remain important, but now needs to focus more on what is meaningful to carers and how to facilitate change.

Additional information

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Margaret Booth (RAP member): PPI input (equal), Formal analysis – qualitative review data (supporting), Writing – RAP recommendations (equal), Writing – review and editing (supporting).

David Cotterill (RAP member): PPI input (equal), Formal analysis – qualitative review data (supporting), Writing – RAP recommendations (equal), Writing – review and editing (supporting).

Lesley Goodburn (RAP member): PPI input (equal), Formal analysis – qualitative review data (supporting), Writing – RAP recommendations (equal), Writing – review and editing (supporting).

Cedric Knipe (RAP member): PPI input (equal), Formal analysis – qualitative review data (supporting), Writing – RAP recommendations (equal), Writing – review and editing (supporting).

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Data-sharing statement

All data for this report and the project as a whole are accessible via our website https://arc-gm.nihr.ac.uk/carer-project- and contained within the referenced literature, tables and appendices of our reports. For further information on the evidence synthesis and the PPI processes and materials, please contact the corresponding author.

Ethics statement

This is a report of an evidence synthesis of existing literature, and no research data were collected for the project. The collaboration with the carer RAP and participants in work package 2 constitute PPI and stakeholder consultation, respectively, rather than research. Consultation with the University of Manchester Research Practice Governance Office established that the project did not require ethics approval.

Information governance statement

There were no personal data involved in the production of this report.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/RTHW8493.

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Christine Rowland
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Danielle Harris

Funded post

- NIHR ARC NIHR200174: Research Assistant NIHR Applied Research Collaboration Greater Manchester Healthy Ageing Theme.

Morag Farquhar
Grants

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- NIHR HS&DR NIHR 16/02/18: An evidence synthesis of holistic services for refractory breathlessness in advanced malignant and non-malignant disease (CI Maddocks). £128,612, 14 months, start February 2017.

- NIHR SCPR FR11: Seedcorn funding for SNAP2 preparatory work. (CI Gardener). £9696, 3 months, start December 2016.

Maria Panagioti
Grants

- NIHR GMPSTRC-2012-1: NIHR Greater Manchester Patient Safety Translational Research Centre (CI Campbell), £7,562,320; 60 months, start 1 April 2017.

- Project 390 NIHR School for Primary Care Research: Improving the evidence base for primary care: NIHR Evidence Synthesis Working Group (CI Heneghan), £1,917,000, 36 months, start 1 April 2018.

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- PR-R20-0318-21001 NIHR Policy Research Programme: Reducing avoidable patient harm in prison health care (CI Shaw). £1,233,446; 48 months, start 1 June 2019.

Alexander Hodkinson

Fellowship

- NIHR 'Three Schools Mental Health' Senior Fellowship. £250,350, 30 months, start January 2020.

Penny Bee

Committee memberships

- Member of NIHR RfPB Northwest Funding Panel 2016–8 and renewed membership for a second term between 2018 and 2020.

- Invited member of the Scrutiny Sub-Committee for the RfPB/RfSC Mental Health Research Call in Northern England 2021.

- Holder of 4-year tenure on Subcommittee A Stage 2 Programme Grants from 2022.

Grants

- NIHR ARC NIHR200174: NIHR Applied Research Collaboration for Greater Manchester (CI Cullum) – Mental Health Theme. £8,999,722 (£2M Mental Health), 60 months, start 1 October 2019.

- NIHR i4i NIHR203827: Improving mental health literacy among children and young people aged 11–16 in the United Kingdom (CI Brooks). £150,000, 12 months, start 1 January 2021.

- NIHR RfPB PB-PG-0418-20011: Co-Adaptation of a Social Network Intervention to Support Recovery for People living with Severe Mental Illness (ConNEct) (CI Brooks), £150,000, 18 months, start 1 July 2019.

- NIHR HTA NIHR 17/80: Psychosocial intervention to address the mental health needs of parents/carers of children newly diagnosed with autism (CI Green), £1,395,164, 42 months, start 1 May 2019.

- NIHR HS&DR NIHR 17/09/08: Services to support early intervention and self-care for children and young people referred to Children and Young People's Mental Health services (CI Pryjmachuk), £643,000, 36 months, start 1 October 2018.

- NIHR PGfAR RP-PG-1016-20010: Enhancing the quality of psychological interventions delivered by telephone (CI Bee), £2,524,745, 60 months, start 4 February 2018.

- NIHR HTA 16/101/02: De-escalation techniques and the use of restrictive interventions in adult mental health units (CI Price), £520,112.84, 30 months, start 1 January 2018.

- NIHR HTA 15/38/04: A non-inferiority RCT comparing the clinical and cost-effectiveness of one session treatment with multisession CBT in children with specific phobias (CI Wright), £1,371,954.00, 48 months, start 1 January 2016.

- NIHR HTA 14/68/08: Multicentre RCT of a group psychosocial intervention for postnatal depression (CI Husain), £1,964,501, 48 months, start 1 February 2016.

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About this synopsis

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Copyright

Glossary

Carer: The term 'carer' is defined according to the broad definition adopted by the National Institute for Health and Care Excellence: [National Institute of Clinical Excellence. *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer: The Manual*. NICE Guideline; 2004. p. 159. URL: www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005 (accessed 11 August 2024)] 'Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management', which relates to unpaid carers who might be a partner, family member, friend or neighbour of the person they are caring for.

List of abbreviations

CASP	Critical Appraisal Skills Programme
CI	Chief Investigator
CINAHL	Cumulative Index to Nursing and Allied Health Literature
EOL	end of life
GP	general practitioner
NOS	Newcastle–Ottawa Scale
OECD	Organisation for Economic Co-operation and Development
PPI	patient and public involvement
QA	quality appraisal
RAP	Review Advisory Panel
RCT	randomised controlled trial

List of supplementary material

Report Supplementary Material 1
Evidence synthesis excluded studies – attached file

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/RTHW8493).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

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Appendix 1 Search strategy[26]

Search strategy

Caregiver
MeSH terms related to caregiver:
MEDLINE (Ovid Online):
- *Caregivers*

EMBASE (Ovid):
- *Caregiver*
- *Caregiver burden*
- *Caregiver burnout*
- *Caregiver Strain Index*
- *Caregiver support*

PsycInfo (Ovid Online):
- *Caregivers*
- *Caregiver burden*

CINAHL Plus (EBSCO)
- *Caregiver burden*
- *Caregiver attitudes*
- *Caregiver support*

Social Sciences Citation Index
(Institute for Scientific Information; Clarivate Analytics)
TOPIC
- *Informal caregivers*
- *Family caregivers*

Cochrane Central Register of Controlled Trials (CENTRAL)
- *Caregivers*

Database of Abstracts of Reviews of Effects (DARE) (University of York Centre for Reviews and Dissemination)
- *Caregivers*

Cochrane Qualitative Reviews
- *Caregivers*

- Use MeSH term for carer where database allows. For example, Caregiver in MEDLINE. Avoid home nursing as a MeSH term as this will incorporate healthcare workers.
- Search for additional string carer terms as both a key word and within ti,ab.
- *family care giv*; family caregiv**
- *informal caregiv*; informal care giv**
- *family care* or informal care**
- Combine: (MeSH term) OR (additional string carer terms)

Rationale:
- Incorporates use of MeSH term.
- Looks to capture additional relevant literature on carers not indexed under the database MeSH term. Using MEDLINE as the test database, a number of different terms for carer were searched to determine the most relevant terms for capturing additional literature not included within the MeSH term ‘Caregiver’. Using *‘family caregiver’* as a key word and *‘informal caregiver*’ in a title and abstract search were shown to include two additional relevant references while *‘family carer(s)’ and ‘informal carer(s)’* are terms often used in the literature to represent carers.
- By combining appropriate MeSH terms for carer along with additional string search terms, the risk of missing papers not captured by the MeSH terms is reduced.

Search strategy	

Palliative Care
MeSH terms related to palliative care:
MEDLINE (Ovid Online):
•*Palliative Care*
•*Hospice and Palliative Care Nursing*
•*Terminal Care*
•*Terminally Ill*
•*Hospice Care*
•*Hospice*
EMBASE (Ovid):
•*Cancer palliative therapy*
•*Palliative nursing*
•*Palliative therapy*
•*Terminal Care*
•*Terminally Ill Patient*
•*Terminal Disease*
•*Hospice*
•*Hospice Care*
•*Hospice Nursing*
PsycInfo (Ovid Online):
•*Palliative Care*
•*Terminally Ill Patients*
•*Hospice*
CINAHL Plus (EBSCO)
•*Palliative Care*
•*Hospice and Palliative Nursing*
•*Terminal Care*
•*Hospice Care*
Social Sciences Citation Index (Institute for Scientific Information; Clarivate Analytics)
TOPIC:
•*Palliative Care*
•*Palliative Care Nursing/Hospice and Palliative Care Nursing*
•*Terminal Care*
•*Terminally Ill*
•*Hospice Care*
•*Hospice*
Cochrane Central Register of Controlled Trials (CENTRAL)
•*Palliative Care*
•*Hospice and Palliative Care Nursing*
•*Terminally Ill*
•*Terminal Care*
•*Hospice Care*
•*Hospices*
Database of Abstracts of Reviews of Effects (DARE)
(University of York Centre for Reviews and Dissemination)
•*Palliative care*
•*Hospice and palliative care nursing*
•*Terminally Ill*
•*Terminal Care*
•*Hospice Care*
•*Hospices*
Cochrane Qualitative Reviews
•*Palliative Care*
•*Hospice and Palliative Care Nursing*
•*Hospices*
•*Hospice Care*
•*Terminal Care*
•*Terminally Ill*
AND
'*Qualitative Research*' as MeSH or '*Qualitative*' in Title, abstract or keyword search
	• Use MeSH terms where database allows for:
	  • Palliative Care
	  • Palliative Care Nursing/Hospice and Palliative Care Nursing
	  • Terminal Care
	  • Terminally Ill
	  • Hospice Care
	  • Hospice
	• Search for end of life as both key word and within ti,ab.: *end-of-life; end of life*
	• Combine: (All MeSH terms) OR (additional end of life terms)
	• Where database does not index papers under the specific MeSH terms above, use the most relevant alternative MeSH term given. If there is no relevant MeSH term given, search the term as both a key word search and as a search within title and abstract. Depending on numbers of papers, expand terms – for example, use 'palliative' instead of 'palliative care' to increase numbers.
	Rationale:
	• Incorporates search terms used by Flemming *et al.* (2019) and MEDLINE MeSH search terms used in Candy *et al.* (2011) systematic reviews*.
	• Looks to capture additional relevant literature on palliative care not indexed under palliative care as a MeSH term.
	• Each included MeSH term has been tested using MEDLINE as a test database to confirm the retrieval of additional relevant papers which would not have been captured by Palliative Care MeSH term only,
	• 'end-of-life' and 'end of life' have previously been tested using MEDLINE as a test database to confirm the retrieval of additional relevant papers which would not have been captured by ***any*** of the MeSH terms above.
	* Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database Syst Rev* 2011(6):CD007617. ISSN 1469-493X. https://doi.org/10.1002/14651858.CD007617.pub2
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Databases	MEDLINE, CINAHL Plus; PsycInfo; Social Sciences Citation Index; EMBASE; Cochrane Central Register of Controlled Trials (CENTRAL); Database of Abstracts of Reviews of Effects (DARE); Cochrane Qualitative Reviews.
Year	1999–2019