



research article

British unpaid carers' perspectives on what impacts their resilience when providing end-of-life care at home: a scoping review

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Support from family or friends is fundamental to people dying at home. Understanding what impacts unpaid carer resilience is essential if services are to support them effectively. Seven databases were searched using a scoping review methodology. Delimiters included date, geographical area and language. A total of 647 articles were identified, with 11 articles meeting the inclusion criteria. Most studies focused on coping strategies ($n = 9$), not resilience. Nearly all identified studies involved bereaved carers ($n = 9$), with no studies focusing purely on current unpaid carer experience. Further research is needed to explore what current unpaid carers identify as impacting their resilience.

Keywords: resilience • unpaid carers • end of life • palliative care

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Introduction

If asked where they would like to die, home is the preferred place of death for most people globally (Gomes et al, 2012; 2013). This is clearly demonstrated in the UK; over the last two decades, the number choosing to die at home has increased, and this trend is expected to continue (Baylis et al, 2023). Furthermore, population forecasts for England and Wales estimate that the number of deaths out of hospital may overtake the number of deaths in hospital by the 2030s and that more than three quarters of all deaths will occur out of hospital by 2040 (Bone et al, 2017). Support from family or friends

(unpaid carers) is fundamental for people choosing to die at home (Grande et al, 2018) and is relied upon heavily by UK healthcare services (Higgerson et al, 2019). Unpaid carers provide a range of support to the cared-for person, including practical, physical, psychological and emotional support (Hudson and Payne, 2009; Carers UK, 2023). While some unpaid carers find supporting someone at home who is nearing the end of life challenging, they also describe it as a fulfilling and positive experience (Henriksson et al, 2015; Henwood et al, 2019; Penny, 2019). However, for others, caring has a lasting impact on their health and well-being pre-bereavement (Aoun et al, 2018; Grande et al, 2018; Thomas et al, 2018) and their life post-caring (Penny, 2019). This negative impact on carers can be mitigated by the appropriate assessment and prioritisation of unpaid carer support needs by professionals (Ewing and Grande, 2013; Aoun et al, 2015; 2018). Despite unpaid carer support remaining a key priority in UK health and social care policy (Department of Health, 2014; NHS England, 2019; National Palliative and End of Life Care Partnership, 2021) and the arguably ethical obligation of health services to support unpaid carers (Henwood and Turnpenny, 2024), evidence suggests that supporting unpaid carers remains an issue for palliative and end-of-life care services in the UK (Payne and Morbey, 2013; Higgerson et al, 2019; Butler et al, 2022).

In the UK, palliative and end-of-life care at home is provided by a range of professionals, including general practitioners (GPs), district nurses and care staff, with specialist palliative input when there is a specialist need (Pask et al, 2022). Supporting the unpaid carers of the person nearing the end of life is an essential aspect of good palliative care (National Palliative and End of Life Care Partnership, 2021). Reasons suggested for the inconsistency in unpaid carer support include specialist palliative care referrals being made late into the disease process and the current fiscal pressures on health and social services. Both of these limit the time available to address unpaid carer support (Allsop et al, 2018) and lead to professionals adopting a patient-focused approach (Grande et al, 2018; Becqué et al, 2021). While framing carer support needs within the context of patient-focused care may still be beneficial for the unpaid carer (Higgerson et al, 2019; Zhang et al, 2022), a concern is that an assessment of carer support needs is easily omitted when services are under pressure (Higgerson et al, 2019). This unstructured approach fails to recognise that carers may have different needs to those of the cared-for person, resulting in inconsistent support for carers (Higgerson et al, 2019; Becqué et al, 2021). A further reason preventing services from adopting unpaid carer support as routine practice may be the complexity of the potential support needs that unpaid carers have (Hudson and Payne, 2009; Hardy, 2018; Penny, 2019). Unpaid carers are often providing this complex multifaceted support for prolonged periods while navigating their own complex health needs, as well as work, family and financial pressures (Carers UK, 2023). Professionals may be hesitant to discuss unpaid carer support needs due to an awareness that services lack the resources needed to address the needs of carers, or they may not have been educated to provide family-centred care (Hudson and Payne, 2009; Payne and Morbey, 2013; Penny, 2019; ADASS, 2023). Ensuring that services focus on factors that they can realistically influence and modify within the constraints of their service may help to promote a more consistent assessment of unpaid carer support needs (Penny, 2019; Ongko et al, 2023). To achieve this, exploring what unpaid carers themselves feel enables them to provide this care while navigating their own feelings of grief and loss is necessary (Hardy, 2018). This ability of carers to continue to care despite facing adversity demonstrates resilience and offers a useful lens through which to consider unpaid carer support needs. This review aims to identify and map the

current UK evidence available that explores factors that help and hinder the resilience of unpaid carers when providing end-of-life care at home. This review has chosen to focus on the current UK evidence available due to the wide variation in palliative care provision identified across countries (Jordan et al, 2020). Before exploring the literature, a clarification of key terms will be useful.

Key terms

Unpaid carers

In this review, unpaid carers were defined as any relative, friend or partner who has a significant personal relationship and provides a range of support to a person with a life-limiting illness, including but not limited to physical, social and psychological support (adapted from Hudson and Payne [2009] and National Institute for Health and Care Excellence [2021]). This definition is used by UK organisations like NHS England. This was further refined to only include unpaid carers supporting people who are nearing the end of life.

End of life

The definition of the end of life is taken from the 'One Chance to Get it Right' report (Leadership Alliance for the Care of Dying People, 2014). This is the definition adopted in the most recent 'Ambitions for Palliative and End of Life Care' framework (National Palliative and End of Life Care Partnership, 2021), and the use of this definition aligns with current UK philosophy on the definition of the end of life. The definition used is as follows:

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events. (Leadership Alliance for the Care of Dying People, 2014: 106)

Resilience

In this review, resilience is defined as 'effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and "bouncing back" in the face of adversity' (Windle, 2011: 163). This definition was developed after an extensive review of both academic and stakeholder perspectives through systematic review, content analysis and consultation workshops, demonstrating that resilience is a multi-level construct and that this definition can be applied to real-world settings. In the literature, 'resilience' and 'coping' are often conflated and used interchangeably

(Van der Hallen et al, 2020; Wu et al, 2020). Coping has been described as ‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus and Folkman, 1984: 141). Due to the linkages between these two concepts, this review also considers coping but focuses on resilience to stress the adaptive element of the latter.

Review question

The population, concept and context (PCC) mnemonic (Peters et al, 2020) was used to guide the development of the review question. This review aimed to answer the following question: what do unpaid carers find helps or hinders their resilience when providing end-of-life care at home in the UK?

Methods

A scoping review framework was chosen, as the review aim was to identify and map the current evidence available (Peters et al, 2020; Pollock et al, 2021). The Joanna Briggs Institute (JBI) framework for scoping reviews was adopted to enhance the clarity and rigour of the review (Peters et al, 2020), and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines were used while preparing this review for publication (Page et al, 2021).

Inclusion criteria

The inclusion criteria were developed in consultation with the doctoral supervisory team and informed by the PCC process (Peters et al, 2020) (see Table 1). The criteria were developed iteratively and refined as the author became more familiar with the literature (Arksey and O’Malley, 2005). Revisions following the initial searches included imposing a date and geographical delimiter on the hits generated and excluding secondary research, such as systematic reviews. Articles were included if they represented qualitative and/or quantitative primary research from the UK that explored unpaid carer views of what helps and hinders resilience and coping when providing end-of-life care. Articles using secondary data analysis of primary research were also included. Grey literature that focused on the resilience and coping of unpaid carers providing end-of-life care at home was identified through supplementary searches of the reference lists of the identified

Table 1: The PCC framework

Population	Unpaid carers above the age of 18 providing home-based end-of-life care and receiving support
Concept	Literature that describes what unpaid carers find helps or hinders resilience when providing home-based end-of-life care
Context	Unpaid home-based end-of-life care
Objective	To identify what unpaid carers find helps or hinders their resilience when providing home-based end-of-life care to those important to them

articles. Literature that considered what unpaid carers felt impacted their coping when providing care at the end of life was also included due to an awareness that 'resilience' and 'coping' are often used interchangeably within the research literature (Van der Hallen et al, 2020; Wu et al, 2020). Literature was excluded if it was not published in English or undertaken in the UK. Literature published pre-2008 was also excluded; this is in line with the date of publication of the first 'End of Life Care Strategy' (Department of Health, 2008) in the UK, a key strategy highlighting the importance of supporting unpaid carers caring for someone nearing the end of life. Literature considering the experiences of unpaid carers supporting people in inpatient settings and the experiences of unpaid carers providing support to someone whose life expectancy was expected to be greater than a year were also excluded (for the full inclusion/exclusion criteria, see Table A1 in the Online Appendix).

Search strategy

Seven databases were searched in the spring of 2023. These were chosen to provide a broad range of literature (Pollock et al, 2021). The databases were MEDLINE, CINAHL, Embase, Scopus, British Nursing Index (BNI), APA PsycArticles and APA PsycInfo. The date range searched spanned 2008–2023.

A controlled search of databases supporting this function ($n = 6$) was conducted initially using pre-identified subject or medical subject headings (MeSH). These were used to increase the precision of the searches (Baumann, 2016). Headings like 'hospice' and 'home-based services' were used to capture literature that focused on hospice-at-home services in the absence of a hospice-at-home subject heading. From these, key search terms were identified through collaboration with a research librarian and academic supervisors. The Boolean operators AND and OR were used to combine search terms, and truncation was also used to broaden the search potential (Aveyard et al, 2021). The overall search strategy used was:

(end of life care OR palliative care OR terminal care OR supportive care OR hospice care OR comfort care OR life limiting) AND (home hospice care OR home hospice service OR home hospice programme OR hospice at home OR hospice at home service OR hospice at home care programme) AND (resilience OR strength OR coping OR psychological adaptation) AND (informal carer OR informal caregiver OR informal supporter OR unpaid carer OR unpaid caregiver OR unpaid supporter OR next of kin carer OR next of kin caregiver OR next of kin supporter OR spousal carer OR spousal caregiver OR spousal supporter OR close person OR significant other OR those important to the person OR kin or friend OR neighbour OR neighbor OR loved one OR relative OR relation OR family OR kinsfolk).

The same search strategy was used for each database to ensure consistency and sensitivity (Aveyard et al, 2021); however, each search was inputted with specific reference to the requirements of the database (see Table A2 in the Online Appendix).

The results of the MeSH searches were combined with the results of the free-text searches to ensure a breadth of literature sources (Aveyard et al, 2021). Supplementary reference list searches of included articles were also conducted.

Source of evidence screening and selection

The titles and abstracts of each identified article were screened by the author and the full text examined if the article met the inclusion criteria. To ensure the accuracy of screening and reduce potential bias, an academic supervisor acted as a second reviewer in the initial review of abstracts and titles from a sample of the identified studies. Following this, an explicit definition of end-of-life care was added to the inclusion criteria.

Data extraction

Data were extracted from each study and tabulated to show the following details: authors and date of publication; population; context; concept; methodology; and methods. A final column was included for factors identified as helping or hindering resilience or coping. To chart the data, visual mapping was used alongside the traditional tabulated format (Pollock et al, 2021).

Analysis and presentation of results

To map the key findings of the articles, any factors identified were collated into three conceptual categories to aid ease of description and comparison between the studies (Peters et al, 2020). The factors were mapped by the author inductively to represent either an organisational, personal or community factor. There was no restriction on the number of factors identified per article, meaning that multiple factors could originate from one article. The use of conceptual categories provided a clear distinction between the different types of factors reported: organisational factors were identified as factors that required external agency involvement; community factors related to the community around the unpaid carer; and personal factors included factors that the unpaid carer themselves only had agency over.

Results

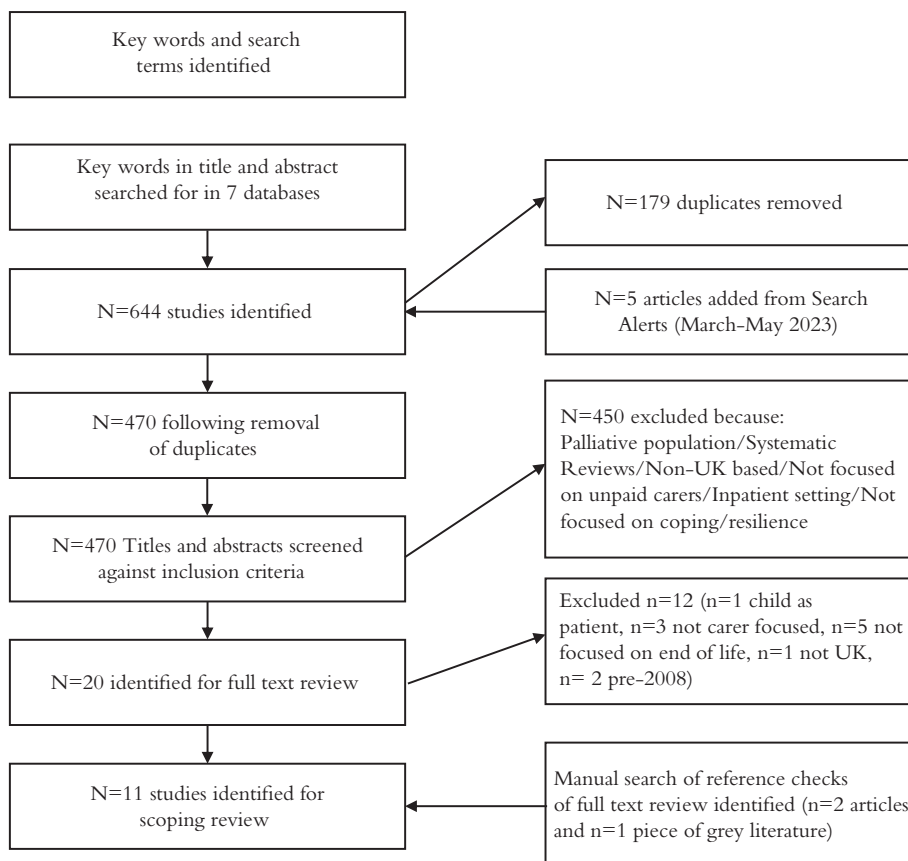
Search results

A total of 644 articles were initially identified, of which 179 were duplicates (see Figure 1). Through title and abstract screening, a further 445 articles were identified as not meeting the inclusion criteria, leaving 20 articles. The full text of each of these articles was then reviewed, and 11 articles met the inclusion criteria for the final review. Full details of the charted articles are illustrated in Table A3 in the Online Appendix.

Inclusion of sources of evidence

The articles included were published between 2013 and 2022. Data were collected between 2009 and 2014, with most of the data collection taking place between 2011 and 2014. One study did not declare the dates of data collection (Cowan, 2014). The

Figure 1: Flowchart of the study selection process



geographical locations of the studies included areas in the north and south of England, Scotland, and Wales, with both urban and rural locations and areas of affluence and deprivation being represented (Thomas et al, 2018). No studies were identified that originated from Northern Ireland.

The aim of all the studies was to explore and understand the experiences of unpaid carers providing care to someone nearing the end of life at home. Nine of the studies adopted a qualitative methodology (Cowan, 2014; Harrop et al, 2014; Seamark et al, 2014; Mason et al, 2016; Turner et al, 2016; Walshe et al, 2017; Thomas et al, 2018; Roper et al, 2019; Roper, 2022), with two using a mixed-methods approach (Morbey et al, 2013; Moore et al, 2017). Of the nine qualitative studies, three used the same data from one multicentre qualitative study (Seamark et al, 2014; Turner et al, 2016; Thomas et al, 2018) and two used data from a doctoral research project (Roper et al, 2019; Roper, 2022). The main qualitative method used was semi-structured interviews ($n = 8$), with four studies using secondary data analysis of interview transcripts (Seamark et al, 2014; Mason et al, 2016; Turner et al, 2016; Thomas et al, 2018). Other qualitative methods included focus groups ($n = 2$), observation of a pilot project location ($n = 1$) and documentary evidence, such as site reports ($n = 1$). Quantitative methods included structured interviews ($n = 1$), quantitative questionnaires and rating scales ($n = 2$). Qualitative data analysis involved thematic

analysis ($n = 7$), narrative ($n = 1$) and framework analysis ($n = 2$), with interpretive phenomenological analysis ($n = 1$) and constant comparison analysis ($n = 1$) also used. Quantitative data analysis involved descriptive statistical analysis ($n = 2$) and frequency counts of stimulus material over focus groups ($n = 1$).

Only two articles focused on the resilience of unpaid carers caring for those nearing the end of life (Roper et al, 2019; Roper, 2022), with the rest focusing on coping. Both articles that focused on resilience analysed the interview responses of the carers against the ecological framework of resilience and determined whether carers were resilient based on this (Roper et al, 2019; Roper, 2022). They then presented their findings as helping or hindering resilience based on whether the carers were identified as resilient or not.

Six of the studies reviewed considered the experiences of unpaid carers only (Cowan, 2014; Seamark et al, 2014; Turner et al, 2016; Moore et al, 2017; Thomas et al, 2018; Roper et al, 2019), with three studies including the cared-for person and the unpaid carer (Mason et al, 2016; Walshe et al, 2017; Roper, 2022) and two studies also seeking the views of professionals or volunteers (Morbey et al, 2013; Harrop et al, 2014). Bereaved carers were the most often recruited group ($n = 9$), with only five studies including current carers (Morbey et al, 2013; Harrop et al, 2014; Mason et al, 2016; Moore et al, 2017; Walshe et al, 2017). These studies considered the experiences of current carers and the person being cared for and/or professionals, with no studies being identified that focused solely on the experiences of current unpaid carers in the UK.

Participants were mainly recruited via their GP practice (Seamark et al, 2014; Turner et al, 2016; Thomas et al, 2018; Roper et al, 2019; Roper, 2022). There was a lack of consensus on when to interview carers post-bereavement: a range of between two and 24 months was adopted across the studies.

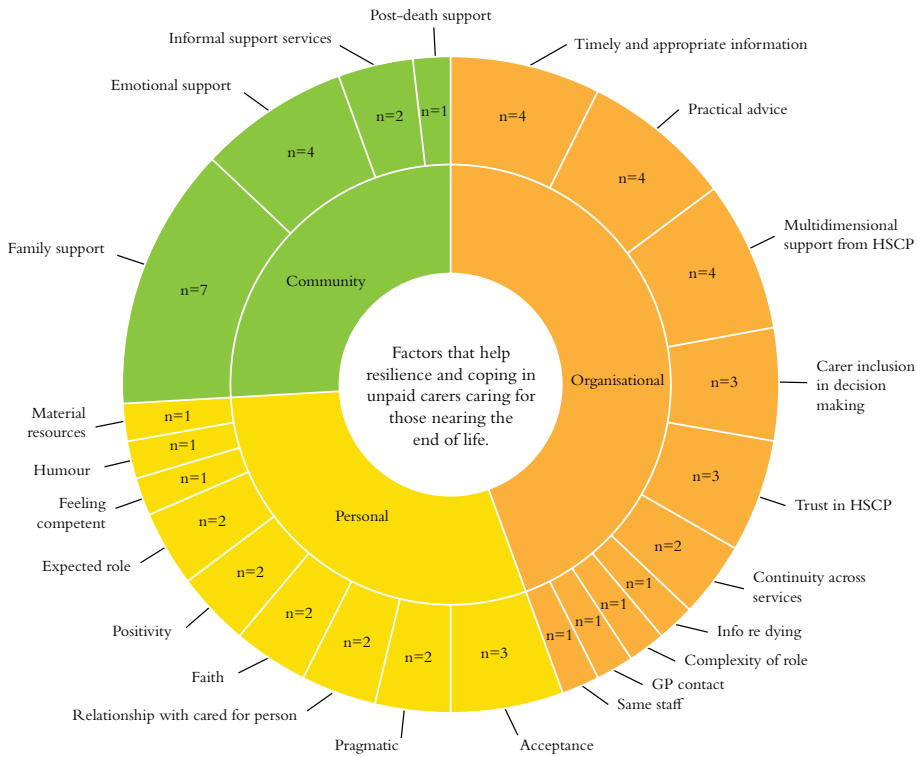
Review findings

A total of 37 different factors were identified as impacting the resilience and coping of unpaid carers in the UK. The frequency that each factor was identified in the included articles is represented visually in Figures 2 and 3.

Organisational factors

Organisational factors were the most frequently identified factors across the studies. Ten different factors were identified that were helpful to resilience and coping: multidimensional support; practical advice; timely information from professionals; trust in health and social care professionals; carer inclusion in decision making; the continuity of staff; continuity across services; GP contact; an appreciation of the complexity of the carer's role; and information about the dying process. As shown in Figure 2, multidimensional support, practical advice, timely information from professionals, trust in health and social care professionals, and inclusion in decision making were identified as the most important organisational aspects for promoting resilience or coping in this population of unpaid carers (Morbey et al, 2013; Cowan, 2014; Harrop et al, 2014; Turner et al, 2016; Moore et al, 2017; Walshe et al, 2017; Roper et al, 2019; Roper, 2022).

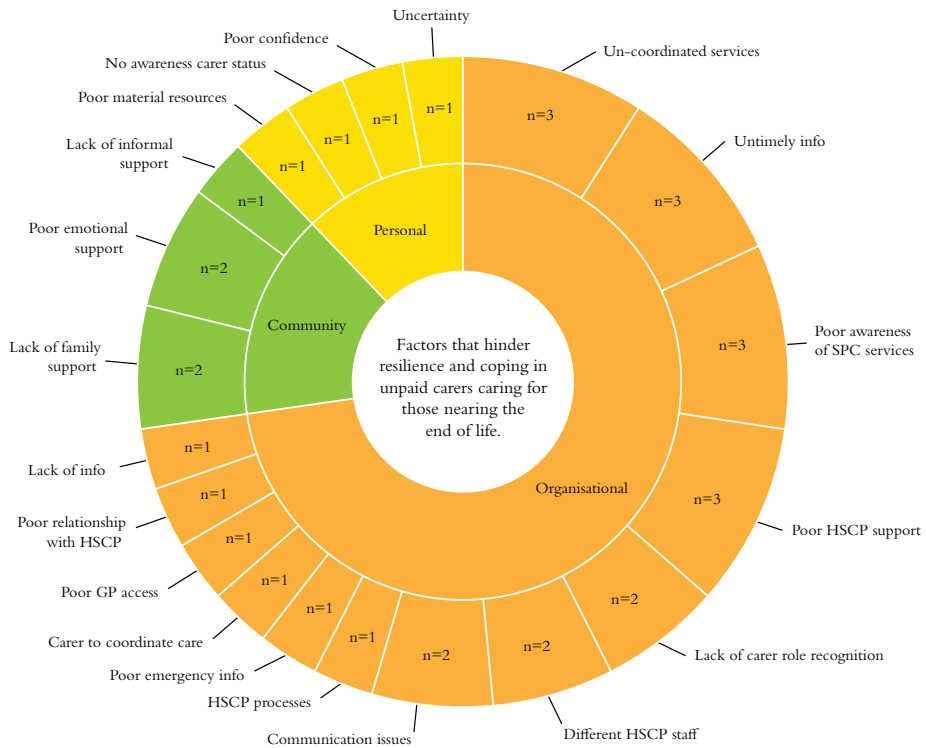
Figure 2: A sunburst chart to show the factors identified as helpful to coping and resilience



As illustrated in Figure 3, 13 organisational factors were identified as hindering resilience or coping: poor support from health and social care professionals; poor awareness of specialist palliative care services; communication issues; the untimely provision of information; the lack of information in general; uncoordinated services; the lack of continuity of staff; the lack of recognition of the impact of the carer's role; poor relationships with health and social care professionals; poor access to GP services; the lack of clarity over emergency processes; care focused on the needs of health and social care processes rather than carers' needs; and reliance on carers to coordinate contacts and care provision. The most identified factors were poor and uncoordinated health and social care support, poor awareness of specialist palliative care services, and the untimely provision of information (Cowan, 2014; Harrop et al, 2014; Seamark et al, 2014; Mason et al, 2016; Turner et al, 2016; Roper et al, 2019; Roper, 2022).

Personal factors

Nine personal factors were identified as affecting resilience and coping: material resources; positivity; faith; a prior relationship with the cared-for person; an acceptance of the situation; a pragmatic day-by-day approach; humour; feeling competent in providing care; and considering caring to be part of the expected role. Acceptance, positivity, a day-by-day pragmatic approach, faith, seeing caring as an extension of their normal role and the relationship between the carer and

Figure 3: A sunburst chart to show the factors identified that hinder coping and resilience

the cared-for person were the most frequently identified helpful factors (Cowan, 2014; Mason et al, 2016; Turner et al, 2016; Moore et al, 2017; Walshe et al, 2017; Thomas et al, 2018; Roper et al, 2019; Roper, 2022). Four personal factors were identified as hindering the resilience or coping of unpaid carers, with each being given equal weighting: a lack of confidence; uncertainty in abilities; poor material resources; and the lack of awareness of the carer's status (Harrop et al, 2014; Roper, 2022).

Community factors

Four community factors were identified as supporting unpaid carers' coping and resilience: family support; emotional support; informal support services; and bereavement support. Family support had the most positive impact ($n = 8$) (Morbey et al, 2013; Cowan, 2014; Mason et al, 2016; Turner et al, 2016; Moore et al, 2017; Walshe et al, 2017; Roper et al, 2019; Roper, 2022).

Three community factors were identified as negatively impacting unpaid carers' resilience: lack of family support; poor emotional support; and lack of informal support. The lack of family support was identified the most often (Roper et al, 2019; Roper, 2022).

Discussion

Through a systematic process, this scoping review has identified a paucity of current UK evidence available exploring the factors that help or hinder resilience in unpaid carers caring for someone near the end of life at home. The key findings of this review will now be discussed, with consideration of both the UK and international literature.

Of the 11 studies identified through this review, only two of the studies focused on resilience (Roper et al, 2019; Roper, 2022), with the remaining studies considering carer coping instead. While 'resilience' and 'coping' are similar concepts that are often used interchangeably, they are distinct psychological constructs (Van Der Hallen et al, 2020; Wu et al, 2020). As the definition used in this review illustrates, resilience is a process of 'effectively negotiating, adapting to, or managing significant sources of stress or trauma' (Windle, 2011: 163). Coping, however, relates to the cognitive and behavioural strategies an individual uses to manage or reduce a negative situation (Van Der Hallen et al, 2020), or, in this case, the thoughts and acts carers use to manage the stress of caring (Henwood et al, 2019). While coping strategies may contribute to an individual's response to challenges, they represent a distinct act or strategy used by an individual. This is different to resilience, which describes an ongoing trajectory impacted by an individual's lived experience and environmental, cultural and sociological factors (Thompson and Cox, 2020). The evidence suggests that, globally, there is recognition that research into resilience, in particular, resilience-promoting interventions, is important, especially when considering the support needs of unpaid carers providing care at the end of life (Benson et al, 2019; Roper et al, 2019; Opsomer et al, 2020; 2022; Too et al, 2023). The most recent 'State of Caring' report in the UK (Carers UK, 2023) highlights that 82 per cent of carers are concerned about the impact of caring on their physical and mental health over the coming year and 78 per cent of carers state that they are worried about being able to provide care in the future. Therefore, understanding what impacts unpaid carers' resilience is becoming increasingly important in light of the positive impact it may have on unpaid carers' well-being. This is highlighted across both the international and UK literature (Benson et al, 2019; van Roij et al, 2021; Opsomer et al, 2022; Shimizu et al, 2022).

This review has identified a lack of research focusing on the resilience of current carers that explores resilience from the perspectives of the carers themselves. Researchers chose to mostly engage with bereaved carers, with no studies identified that interviewed only current carers of the dying. This may be due to issues around accessing this population of carers (Hudson et al, 2023). In most of the studies reviewed, participants were recruited via their GP. A concern with recruiting participants in this way is that healthcare professionals may act as 'gatekeepers' (Hudson et al, 2023) and limit access to people who they perceive as being too vulnerable to take part in research (Kars et al, 2016). This may be due to an underlying assumption that it is too overwhelming for current unpaid carers to take part in research (Bentley and O'Connor, 2015; Aoun et al, 2017; Hudson et al, 2023). While there is evidence that current carers find being interviewed distressing, the evidence is that they want to be included in research despite the distress it may cause (Dyregrov, 2004; McCallum et al, 2019; Chatland et al, 2023). By focusing solely on the experiences of bereaved carers, current carers are denied a voice and an opportunity to shape and develop services. Furthermore, researchers are assuming that the narrative that a bereaved carer

shares in an interview is the same narrative that they would have shared when they were actively caring. In the studies reviewed, the earliest date at which bereaved carers were interviewed post-bereavement was two months (Moore et al, 2017), with some studies interviewing carers up to two years after the death of the cared-for person (Seamark et al, 2014; Thomas et al, 2018). The assumption is that carers can recall with accuracy which factors they found helpful a minimum of two months ago. This fails to acknowledge that memory and remembering are not objective processes. It is generally accepted that memory is instead 'an active process of creation of meanings' (Portelli, cited in Thomson, 2010: 82), meaning that recalling memories is more like storytelling than listening to a recording (Neisser, 2009). Individuals reshape their memories to make sense of their experiences, both past and present (Bryson and McConville, 2014). Consequently, even though the memory contains elements of the initial event, each time the memory is shared, it is recalled slightly differently (Bryson and McConville, 2014). While engaging bereaved carers in research may be deemed more appropriate and may offer easier access to a population with lived experience, this reshaping of memories could lead to instances of recall bias, which may impact the reliability of the research findings (Lincoln and Guba, 2013) and in turn the effectiveness of the support offered to carers.

Furthermore, in the two articles exploring resilience, unpaid carers were classed as resilient by the researchers based on how their interview answers aligned with an operationalised method of classifying resilience (Bennett, 2010) rather than the carers' own thoughts or feelings. This means that these studies considered unpaid carers' resilience from the etic (external, scientific) perspective rather than from the emic (insider) viewpoint (Fetterman, 2020). The importance of exploring what carers themselves feel is important from their emic (lived reality) perspective is evident across policy and academic literature. This is illustrated clearly by Donnellan, Bennett and Soulsbury (2015), who noted a difference between the factors that they, as researchers, had expected to impact the resilience of unpaid carers and the factors identified by their study participants. The Care Act 2014 (Department of Health, 2014) and the National Institute for Health and Care Excellence (2020) guidelines on 'Supporting adult carers' also highlight the need to engage with unpaid carers as individuals with their own lived experiences when planning or delivering support.

Another key finding of this review is that organisational factors are identified as the most influential on unpaid carers' resilience. The most frequently identified helpful organisational factors were timely and appropriate information, practical advice, and multi-professional support from health and social care professionals. Given this, perhaps unsurprisingly, such factors as poor support from health and social care professionals, poor awareness of specialist palliative care services, untimely information provision and uncoordinated health and social care services were identified as negatively impacting the resilience of unpaid carers. This demonstrates how the very services reliant on the care provided by unpaid carers impact how unpaid carers experience caring and their ability to care. It is widely acknowledged that organisational factors impact the health and well-being of unpaid carers (Healthwatch Oxfordshire, 2021; Mogan et al, 2022; Carers UK, 2023), both within the UK and internationally (Ongko et al, 2023; Tieman et al, 2023). In recent reports by both Carers UK (2022; 2023) and Healthwatch Oxfordshire (2021), carers identified the poor quality of support and continuity from National Health Service (NHS) services as negatively impacting their health and well-being, as well as their ability to provide safe, quality care. While these

reports include the experiences of a range of unpaid carers, not only those providing care at the end of life, they illustrate a clear need for research and service providers to focus on what unpaid carers need from health and social care services to enable them to continue to care, irrespective of when in the lifespan they are caring. From an international perspective, these findings are supported by the work of [Ongko et al \(2023\)](#) and [Tiemann et al \(2023\)](#), with both studies reporting the negative impact of fragmented services and poor and untimely information on the experiences of carers providing care at the end of life.

A final observation of this review is that all the studies were based on data collected between 2009 and 2014. It is realistic to suggest that due to the COVID-19 pandemic and the current pressures on health and social care services, organisational factors continue to impact the resilience of unpaid carers. With NHS waiting lists at an all-time high and pressure on primary care services making it increasingly difficult to access GP services, many carers are reporting ignoring their own health needs to prioritise those of the cared-for person ([Carers UK, 2023](#)). The impact of these pressures on organisations means that these services remain reliant on unpaid carers to support people ([Carers UK, 2023](#)). Services, policymakers and researchers therefore need to prioritise how to support unpaid carers and embed this in routine practice.

Limitations

While the use of a systematic framework is a strength of this review ([Peters et al, 2020](#)), there are some limitations. This review only focused on research conducted within the UK; including the international literature in the review may have resulted in different findings. By only including articles that focused on the experiences of unpaid carers providing care at the end of life, potential useful insights from studies focusing on resilience earlier in the disease trajectory may have been missed. The decision to include literature that considered coping rather than resilience could also be considered a limitation. By including these studies and accepting that resilience and coping are conceptually close and often used interchangeably, the author is assuming that they are impacted by the same factors, which may not be the case. This again identifies the need for further research focusing on resilience as a distinct construct. Finally, as scoping reviews do not include an assessment of the quality of the studies, the review findings may not be suitable for guiding changes to clinical practice ([Davies et al, 2018](#)).

Conclusion

The resilience and coping of unpaid carers providing end-of-life care at home in the UK is affected by organisational, personal and community factors, with organisational factors being identified the most frequently. This is reflected across the unpaid carer literature. Services need to recognise the impact that organisational factors have on the resilience of unpaid carers and ensure that services provide support that helps and enables unpaid carers' resilience. Due to the reliance of services on unpaid carers to provide a wide range of support to friends and family, especially those nearing the end of life, it could be argued that health and social care providers have an obligation to ensure that unpaid carers' support needs are addressed.

Future research needs to focus on the resilience of current unpaid carers caring for those nearing the end of life. The voices of unpaid carers need to be included in research and service development. Consideration of these findings alongside the global evidence indicates that further international research into unpaid carers' resilience would also be beneficial (Opsomer et al, 2020; van Roij et al, 2021; Shimizu et al, 2022).

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Conflict of interest

The authors declare that there is no conflict of interest.

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