London School of Economics and Political Science

Unpaid carers and unmet need for social care services in England

Nicola Brimblecombe

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Declaration

I certify that the thesis I have presented for examination for the PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

I declare that my thesis consists of 52,087 words.

Statement of co-authored work

I confirm that Chapter 3 (Paper 1) was co-authored with Dr Javiera Cartagena Farias. I am lead author and contributed the majority of the work. I designed the analysis plan and carried out the regression modelling, with help on syntax and statistical techniques from Dr Cartagena Farias, who also prepared the dataset. I carried out the literature review for the paper, did the majority of the interpretation of the findings and writing of the paper. This does however remain a collaborative effort.

Statement of use of third party for editorial help

I can confirm that my thesis was copy edited for conventions of language, spelling and grammar by Tania Wickham and by Lisa Findley.

Abstract

My study investigated inequalities in outcomes of providing care and unmet need for social care services in England from the perspective of unpaid carers. There are an estimated 5 million carers in England and Wales, many millions more worldwide. There are inequalities in who provides care by gender, ethnicity, and socio-economic status. Unmet need for social care services affects a substantial proportion of people in England and can constrain the lives of disabled and older people and the people providing care for them. However, carers are often missing from theory research on unmet need for care.

Across four papers, my thesis addresses the following research questions:

(i) How do the effects of higher intensity care provision vary among unpaid carers?
(ii) What is the extent and nature of unmet need for social care services for disabled adults or older people and their co-resident unpaid carers?
(iii) What are the consequences of unmet need for social care services for unpaid carers?
(iv) What factors additionally contribute to unpaid carers having better or worse outcomes?

My study takes an individual-structural and dyadic conceptual approach to studying unmet need for services. As such it recognises both the context of care provision and receipt, and the dyadic and inter-related nature of the caring relationship. The study design is mixed methods, although some analyses used one method only. Methods comprised secondary analysis of data from several waves of the United Kingdom Household Longitudinal Study and semi-structured in-depth interviews with unpaid carers.

My research found that female carers caring for 10 or more hours a week or within the household have worse mental and physical health and lower earnings than male carers. Asian carers have lower earnings from paid employment than White carers. Carers with lower educational qualifications (a measure of social class) have worse mental and physical health than carers with higher qualifications, are less likely to be in paid employment, and have lower earnings when they are in paid employment (Paper 1).

Male care recipients are less likely to receive services than female care recipients. Ethnic minority care recipients are less likely to receive any services or to receive services they perceive to be fully appropriate to their care needs. Care recipient-carer pairs living in lower income households or in more deprived areas are more likely to experience unmet need for services than higher income households or people living in less deprived areas respectively.

Reasons for unmet need for services include perceived or actual ineligibility; lack of availability either overall or of appropriate services; low financial resources and unaffordability; and constrained and unconstrained choice (Paper 2).

Unmet need for care services – services not being received at all or not adequately meeting care needs – is associated with negative outcomes for carers in a number of life domains: paid and voluntary employment, health, relationships, social and community participation, and leisure activities. These findings are reported in Paper 3. Lack of choice over whether or not services are received is associated with carers having poorer mental health, more difficult relationships with the people they care for, and less social connectedness.

Other factors also impact carers. Lack of material resources and concerns about current and future financial situation are associated with poorer mental health and wellbeing for carers. Living conditions – high neighbourhood deprivation, low neighbourhood cohesion and living in rented accommodation – are also associated with poorer mental health and wellbeing for carers (Paper 4).

In sum, my research shows that there are inequalities in the effects of providing care, inequalities in who receives support in the form of social care services, and variations in the effects of unmet need for services on carers. My research also shows that the nature of unmet need for care is nuanced and that this nuance matters; that the individual and structural context in which someone provides or receives care is important; and that including the presence, perspectives, and experiences of carers in conceptualisations and research on unmet need is crucial to fully understanding and addressing it. My research also shows that considering inequalities is fundamental to the study of social care and considering social care is fundamental to the study of inequalities.

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Chapter 1

Introduction

Social care and unpaid care are fundamental to societies globally. Almost all of us will be directly affected by social care either as the third of the population who will develop care needs at some point in our lives and/or as the two in three of us who will be carers (Zhang and Bennett, 2019; Department of Health & Social Care, 2021a). As many as three quarters of people with care needs in England do not get their care needs met, resulting in severe limits to their lives (Ipsos Mori, 2017). There are ethnic, gender, and socio-economic differences in whether and how care needs are met (Brown and Sondaal, 2016; Brimblecombe and Burchardt, 2021), and hence whose lives are limited, a deep inequality that is often overlooked in broader discussions of inequalities and social justice. Unpaid carers also experience constraints to their lives (Bauer and Sousa-Poza, 2015; Brandt et al., 2021) and care provision is distributed by gender, ethnicity, and socio-economic circumstances (Brimblecombe and Burchardt, 2021; Quashie et al., 2022). In general, research to date on unpaid care has not focused on inequalities in effects of caring, nor on context. Research on unmet need for care has tended to overlook unpaid carers as well as the reasons for, and consequences of, unmet need for care in the form of care services. This evidence is required if we are to fully understand the unpaid care and unmet need landscape in England and address any inequalities. My thesis seeks to answer some of these questions. The terminology around unpaid care and social care is complex and varies by country. A brief explanation of terms is in Box 1.

Box 1. Terminology

Terminology

'Unpaid carer' is defined by the NHS, and this thesis, as someone who 'looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support' (NHS, no date). A similar definition is used in national surveys. This definition excludes help that is done as part of paid work. In the United Kingdom (UK), unpaid care is the preferred term of carers themselves, and is the term most often used in UK policy. In this thesis, the term 'carer' is sometimes used as shorthand for unpaid carer. In the international literature, unpaid care is sometimes called family care, family caregiving, or informal care.

Support for mental and/or physical ill health or disability, learning disability, and wider needs such as self-neglect is usually referred to as social care in the English context and need for this support as social care need. In the international context, support for care needs is usually referred to as long-term care. The terms reflect similar types of support although social care includes long- and short-term care and tends to provide help with a broader set of needs. Both terms are used in this thesis. Long-term care is used mainly in the papers as all are for an international readership, whereas social care is used mainly in the body of the thesis.

‘Formal care’ or ‘care services’ is used in the literature and in this thesis to refer to care provided by paid professional careworkers. This can be provided by state, voluntary sector and/or private providers and may be paid for privately and/or by the state.

1.1 Motivation for the thesis

A large proportion of the population has, or will develop, care needs at some point in their lives (Department of Health & Social Care, 2021a), with people from ethnic minorities, with low income, or living in deprived neighbourhoods having disproportionately higher chances of having care needs (Brimblecombe and Burchardt, 2021). Currently, the majority of those with care needs who are receiving care – many are not – have that care provided by an unpaid carer (Verbeek-Oudijk et al., 2014a; Office for National Statistics, 2023). As a consequence, two in three of the population will also be unpaid carers at some point in their lives, and often at multiple points (Zhang and Bennett, 2019). There are inequalities in who provides unpaid care by gender, ethnicity, and socio-economic circumstances (Brimblecombe and Burchardt, 2021; Quashie et al., 2022), and numerous well-documented negative effects of providing longer hours of care or personal care on carers’ employment, including higher risk of leaving employment and of working reduced hours (e.g. King and Pickard, 2013; Nguyen and Connelly, 2014; Bauer and Sousa-Poza, 2015). Carers also experience income penalties and an increased risk of being in poverty (Keating et al., 2014; Aldridge and Hughes, 2016). There may also be impacts on long-term finances such as pensions, although information on this is now two decades old (Evandrou and Glaser, 2002). People who provide care at higher hours and/or within the household have worse mental and physical health than non-carers (Bauer and Sousa-Poza, 2015; Brimblecombe, Fernandez, et al., 2018a; Brandt et al., 2021). My thesis focuses on co-resident unpaid carers. Co-resident carers make up approximately half of all unpaid carers in the UK (Petrie and Kirkup, 2018), provide the most intense care, and experience the greatest negative impacts of care provision on their employment and physical and mental health (Brimblecombe, Fernandez, et al., 2018a). Services for one member of the dyad, or lack of them, can therefore potentially be more impactful on the other than in extra-resident caring situations.

Care needs in England, and worldwide, have been increasing (Office for National Statistics, 2014, 2018), although the most recent population census in England and Wales showed a decrease in ill health and disability (Office for National Statistics, 2023). Without action, care needs are projected to increase further over the next few decades (Wittenberg et al., 2018). Provision of social care to meet those needs has become an increasingly important societal issue and policy concern in England as well as internationally (Colombo et al., 2011; Burchardt et al., 2016). Whilst prevention or delay of care need, where possible, is also on the policy agenda, this thesis addresses provision of care services only, whilst recognising that both are important. How care is provided is core to how we structure society and enable full and independent lives for disabled and older people with care needs. Whose responsibility it is for providing care – the individual, the family, the state – and the subsequent balance between formal and unpaid care, is also part of wider debates in social policy, politics, and society about individual and family responsibility.

Two parallel trends are relevant here. One is the debate, which varies by country, time period and ideology, about the extent to which social policy should support ‘familisation’ or ‘defamilisation’ principles or both. Familisation or defamilisation principles are the extent to which welfare states ‘address the issues of financial and care dependencies between family members’ (Lohmann and Zagel, 2015). ‘Defamilising’ policies and provisions aim to reduce care and financial responsibilities and dependencies between family members, for example by having the state provide social care (Lohmann and Zagel, 2015; Bouget et al., 2016). This concept has been widely used, including to categorise support schemes for carers and the people they care for. The second trend is a concept named as ‘responsibilisation’ by some authors (Juhila et al., 2017), strongly associated with, and coming into greater prominence alongside the rise of, neo-liberal discourses of individualisation of risk and responsibility. Responsibilisation is defined as a way of governing that conceives of responsibility for causes and solutions as lying with individuals, families, and communities. It is intimately tied to concepts of autonomy and choice, a trend that can be seen in a number of social policy arenas as well as social care, including health, criminal justice, and welfare. Whether and to what extent the family or the state should provide care has varied across the history of social care policy in England and is reflected in the degree to which determining eligibility for social care for disabled or older people takes a ‘carer-blind’ approach (Twigg and Atkin, 1994; Pickard, 2001). In a carer-blind policy, services will be offered on the basis of need regardless of the existence of a carer or potential carer (Pickard, 2001).

How and whether care needs are met is also considered by many to be an important social justice issue. Access to social care services, alongside access to other services, is seen as an important social right (Armstrong, 2010; Schulmann et al., 2019), and under-access a key social injustice, both in itself and in its implications for other social injustices, such as poorer health or limited independence and opportunities (WHO, 2002). Article 19 (Living independently and being included in the community) of the United Nations Convention of the Rights of Persons with Disabilities (UN CRPD), which the UK is signed up to, states a right to ‘access to a range of in-home, residential and other community support services…to support living and inclusion in the community, and to prevent isolation or segregation from the community’ (United Nations, 2006). ‘Inclusion of people with disabilities’ and ‘long-term care’ are key components of other action plans for improving social rights such as the European Pillar of Social Rights (European Commission, 2017).

Relatedly, and a further part of the motivation for my thesis, is that unmet need for care services and the effect on unpaid carers is an important equity issue. As outlined above, there are social inequalities in who needs care and who provides it. The substantial unmet need for care for people with care and support needs is also not experienced equally (Rodrigues et al., 2014; García-Gómez et al., 2015; Vlachantoni et al., 2015; Albertini and Pavolini, 2017; Ilinca et al., 2017; Burchardt et al., 2018; Floridi et al., 2021). Unmet need for care and inequalities in unmet need is a growing research field. However, most research to date has tended to conceptualise care needs as ‘met’ regardless of how those needs are being met or by who. This has meant that unpaid carers have been very much missing from conceptualisations of, and research on, unmet need, a critical omission because of the known impacts on carers of providing care, as described above, and the equality issues. This thesis aims to address this omission.

This thesis takes as its case study, England, and for Paper 1 the whole of the UK. The analysis for Paper 1 was commissioned by the Department of Health and Social Care in response to a policy question about whether and how the effects of caring varied among sub-groups of carers in order to inform an upcoming Spending Review. The UK sample was suitable for this purpose. However, as subsequent papers looked at the effect of care services or lack of them on carers, the different social care funding and service provision context across the four nations of the UK (Needham and Hall, 2022) meant that it was more appropriate to confine the analysis sample for Papers 2, 3 and 4 to England. The choice of England as a case study is for two main reasons. As described above, social care policy and practice in England takes an explicitly dyadic approach to care provision, including care services, very much in line with my view that carers should be part of any consideration of how care needs are, or are not, met. Support for unpaid carers is well-established in the policy and political landscape in England and England is considered reasonably advanced in terms of carers' rights (Yeandle, 2016). Thus, England as a case study represents an opportunity to investigate variation in unmet need among unpaid carers and the consequences in a system with a reasonably well-developed carer support policy context. In other words, in a context where support for carers should be happening, and where any variation in that support should be related to eligibility, rather than wider determinants. The second reason for the selection of England as a case study is pragmatic. The UK has rich longitudinal large-scale, nationally-representative sources of household data on social care and on unpaid carers, and on socio-demographic characteristics, area characteristics, employment, health and wellbeing, and social participation. The data are publicly available for secondary analysis under certain conditions.

1.2 Social care and carers policy and practice context in England

Supporting carers is a key tenet of social care policy and practice in England, with a focus on supporting carers' employment, health, and wellbeing, broadly defined (Her Majesty's Government, 2014a). The 2014 Care Act, the main policy document for provision of adult social care in England, brought in a number of new rights for carers (Manthorpe et al., 2019), which in many cases exceeded those in other countries (Yeandle, 2016) in principle, if not always in practice (Fernandez et al., 2020; House of Lords Adult Social Care Committee, 2022). Key among these was the right for carers to have an assessment of their needs, regardless of the eligibility of the person they support, and the option of those needs being met by providing services to the person they care for, so-called 'replacement' care (House of Commons, 2014 paragraph 152). Since 2014, unpaid carers continue to be a key part of adult and children's social care policy. For example, there have been various Carers Action Plans, the most recent being 2018-2020 (Department of Health, 2018); the 2019 NHS Long Term Plan (NHS, 2019); and the 2022 Health and Care Act (Her Majesty's Government, 2022).

Changes in carer policy over the last few decades have been accompanied by an increase in voluntary and community sector carers' organisations at the national and local level, possibly reflecting an increase in need as well as gaps in statutory support.

Whilst there has been an ongoing focus on social care and on carers in England, this has not been the case for inequalities in care, with some exceptions. A recent government policy document on social care in England (People at the Heart of Care; Department of Health & Social Care, 2021b) does not mention inequalities as such but has as one of its three main objectives that 'people [carers and care recipients] find adult social care fair and accessible'. Improving fairness and accessibility has the potential to reduce inequalities in access. However, fairness for care recipients in this policy document is limited to fairness of care home fees between private funders and those who have their care funded by the state. Access refers to access to care that meets needs without delay, an important part of prevention across the board and that may benefit some sub-groups more than others, but that does not mention inequalities in access or other barriers to access. For carers, 'fairness and accessibility' refers only to access to clear information and 'tailored information and advice…to support and meet the needs of the person [they] care for' (Department of Health & Social Care, 2021, p. 7). This reiterates a right brought in by the 2014 Care Act, with a resultant substantial increase seen in 'information and advice' as the only source of support offered to carers (Fernandez et al., 2020). The body responsible for assessing the quality of care services in England, the Care Quality Commission (CQC), has a number of foci on inequality in its 2021 strategy and its equality objectives 2021-2025. CQC aims to use their assessment framework to make sure that health and social care are taking steps to tackle inequalities in health and care, with particular focus on ethnicity, age, gender, sexuality, and certain specified care needs (Care Quality Commission, 2022a, 2022b).

Increasing need for care, and increasing policy interest in care provision, has taken place within a context of historical underfunding of social care in England. Overall, spending on social care has increased since 2016/7. However, the years up to 2019/20 saw decreases in the number of people receiving publicly-funded social care services and an increasing gap between care need and care service provision (Bottery and Babalola, 2020). The most recent data show increases in number of people receiving publicly-funded social care services, although this may have been skewed by the COVID-19 pandemic. It remains to be seen how workforce challenges and inflationary pressures on local government have affected the picture since then (Bottery and Jefferies, 2022). In addition, over the last few years there has been a tightening of eligibility criteria resulting in proportionately fewer people in need being eligible to receive state-funded services (Humphries, 2022). Social care workforce shortages and provider failure are other concerns (National Audit Office, 2018; ADASS, 2022): limited availability of care services affects both local authority and self-funded provision. As well as eligibility criteria, there is a means test based on an individual's financial assets. Savings of less than £14,250 means that a person is eligible for full financial support if they have qualifying care needs; savings between £14,250 and £23,250 makes them eligible for some financial support; and savings of £23,250 or above ineligible for any financial support. People with eligible needs and savings above the means test level of assets have to pay for some or all of their social care services if they wish to receive them, as do people with ineligible care needs regardless of their assets. The means test upper limit has not been uprated for inflation for at least a decade, resulting in a decrease by over £5,000 in real terms (Bottery and Jefferies, 2022); as a result, financial eligibility criteria are in effect stricter.

Although responsibility for social care in England for people with eligible needs, including carers with needs, lies with local authorities, provision of care services is a complex mix of private and public funding and provision by a number of state, voluntary sector, and private sector providers, with the private sector predominating (Bayliss and Gideon, 2020; Burchardt et al., 2020). The system is highly fragmented with over 10,000 providers of home care services and high provider turnover (Bayliss and Gideon, 2020; Burchardt et al., 2020). Outside of services, and often in addition to services, unpaid care comprises the majority of care received by people with care needs (Office for National Statistics, 2023).

Social care policy in England takes a dyadic approach to the provision of care services whereby services for the person with care needs are also seen as a service for the unpaid carer (Her Majesty's Government, 2014a). Under this policy, services for the care recipient can be provided explicitly to meet the needs of the carer and/or prevent negative impacts, regardless of the eligibility of the care recipient. Possible impacts and/or carers' needs under the Act include mental and physical health, wellbeing, paid and voluntary employment, social participation, and social activities.

1.3 Overview and structure of the thesis

The research for this thesis investigates the extent and nature of inequalities in unmet need for unpaid carers, the consequences, and what other factors contribute to these consequences.

Specific research questions are as follows:

(i) How do the effects of care provision vary among unpaid carers?
(ii) What is the extent and nature of unmet need for social care services for disabled adults or older people and their co-resident unpaid carers?
(iii) What are the consequences of unmet need for social care services for unpaid carers?
(iv) What factors additionally contribute to unpaid carers having better or worse outcomes?

The thesis is structured around four empirical papers, each addressing a different research question (see Table 1) and each making distinct contributions individually and, in synthesis, to the thesis as a whole. The four papers are all either published or in submission to peer-reviewed academic journals and are therefore stand-alone papers. Although each has a distinct focus, there is inevitably some repetition in terms of policy context, previous literature presented, and descriptions of the data and research design.

The four papers are as follows. Paper 1, entitled 'Inequalities in unpaid carers' health, employment status, and social isolation', has been published in *Health & Social Care in the Community* (Brimblecombe and Cartagena Farias, 2022). This paper used quantitative analysis of secondary data to answer research question 1 (How do the effects of care provision vary among unpaid carers?) and makes empirical, conceptual, and policy contributions. The empirical contribution is to address a key evidence gap. Although a great deal is known about how caring for longer hours and/or providing certain types has negative consequences, very little is known about how these consequences vary by factors such as the carer's ethnicity, socio-economic status, or age. The conceptual contribution was to bring a social determinants perspective to the study of carers' outcomes. The paper also makes a policy and practice contribution by indicating which carers are at higher risk of poorer outcomes and therefore most in need of support. This was in response to a research and policy need highlighted by the UK government and findings from this paper thus directly informed long-term care policy.

The three remaining papers are sole authored. Paper 2, entitled 'Inequalities in receipt of care services by disabled or older people and co-resident carer dyads in England', has been published in *Journal of Poverty and Social Justice* (Brimblecombe, 2022a). Paper 2 addresses research question 2 (What is the extent and nature of unmet need for social care services for disabled adults or older people and their co-resident unpaid carers?) using a mixed-methods research design. Paper 2's empirical contributions are to provide evidence on unmet need for social care services and variations in receipt of services in the English context, where there was previously a research gap. By investigating whether care need, as set out in current legislation, is met by services, and if certain groups are better served than others, this paper also aimed to contribute empirically to an understanding of how social care policy in England operates in practice. The conceptual contribution is to bring carers back into the ‘unmet need for care’ picture where they have been missing since early formulations of the concept (Isaacs and Neville, 1976). In terms of the policy and practice contributions, understanding factors associated with unmet need for services in carer-care recipient dyads, and exploring some of the reasons for unmet need, will enable better targeting of ‘at-risk’ groups in social care policy and practice to potentially reduce barriers to, and improve uptake of, support for carers and care recipients.

Paper 3, entitled ‘The consequences for unpaid carers of unmet need for long-term care services in England’, is a qualitative paper which addresses research question 3, What are the consequences of unmet need for social care services for unpaid carers and how do these vary? Paper 3 is published in the *International Journal of Care and Caring* (Brimblecombe, 2022b). Paper 3 makes distinct empirical, conceptual, and policy contributions. A first empirical contribution is to address gaps in the evidence on the consequences of unmet need for services for unpaid carers and some of the mechanisms by which this occurs. A second empirical contribution is to look at a range of possible consequences of unmet need for services: paid and voluntary employment; health; social and family relationships; social and community participation; and leisure activities. A third empirical contribution is to add to the evidence base on the role of choice in differential effects on carers. Furthermore, by showing how unmet need for care services can affect carers, the paper aims to further make the empirical, conceptual, and policy case for including carers in considerations of unmet need for care. Lastly, this paper makes important contributions to the wider issue of how we should measure unmet, or met, need for care and, in particular, for care services. This is an issue for research and for policy.

Paper 4, entitled ‘What are the individual and structural determinants of unpaid carers’ mental health and wellbeing?’, has been submitted to *Social Policy & Administration*. The paper takes a mixed-methods approach to answering research question 4, What factors additionally contribute to unpaid carers having better or worse outcomes? Paper 4 makes the following contributions. First, it aims to contribute to the understanding of what best supports unpaid carers by investigating a wider range of possible associates of positive outcomes for carers than previous research. This is a potential contribution empirically and to social care policy and practice. Second, similar to Paper 1, it aims to bring a social determinants perspective to the study of carers' outcomes, this time supplemented by understandings from Pearlin's stress process model (Pearlin et al., 1990), a conceptual contribution. Third, it returns to the issue of measurement of met need for care services, building on learning and insights from Paper 3, an empirical, conceptual, methodological and policy contribution.

Table 1. Research question and corresponding paper

RESEARCH QUESTION	**PAPER**
1. How do the effects of care provision vary among unpaid carers?	1. Inequalities in unpaid carers' health, employment status, and social isolation Brimblecombe, N., & Cartagena Farias, J. (2022). Inequalities in unpaid carers' health, employment status and social isolation, *Health & Social Care in the Community*, 00, 1-13. https://doi.org/10.1111/hsc.14104
2. What is the extent and nature of unmet need for social care services for disabled adults or older people and their co-resident unpaid carers?	2. Inequalities in receipt of care services by disabled or older people and co-resident carer dyads in England Brimblecombe, N. (2022). Inequalities in receipt of long-term care services by disabled or older people and co-resident carer dyads in England, *Journal of Poverty and Social Justice*. https://doi.org/10.1332/175982721X16605972092524
3. What are the consequences of unmet need for social care services for unpaid carers?	3. The consequences for unpaid carers of unmet need for long-term care services in England Brimblecombe (2022). The consequences for unpaid carers of unmet need for long-term care services in England. *International Journal of Care and Caring.* doi.org/10.1332/239788222X16546112844546
4. What factors additionally contribute to unpaid carers having better or worse outcomes?	4. What are the individual and structural determinants of unpaid carers' mental health and wellbeing? Submitted to *Social Policy & Administration*.

Chapter 2

Background

2.1 Conceptual framework

As other authors have also argued, an understanding of unmet need and inequalities in care requires an understanding of structural as well as individual factors, and thus conceptual frameworks that incorporate both. I mention two authors in particular here. Vlachantoni et al. emphasise the role of structural factors – care policy – in their 2011 study of unmet need for social care amongst older people thusly: ‘the extent to which the needs of people are met by the delivery of benefits and services is a key indicator of the effectiveness of a welfare state’ (Vlachantoni et al., 2011, p5). Kröger et al. (2019) argue that the concept of ‘unmet care need’ should more fully incorporate societal or structural factors, an approach they term ‘care poverty’. Structural factors – policy on unpaid care and on social care services included – also shape and determine choices for provision and receipt of unpaid care (Twigg and Atkin, 1994; Moullin, 2007).

My thesis is also taking an individual-structural approach. Specifically, I use four main theoretical frameworks that have in common that they incorporate, to varying degrees, individual and structural elements and the interplay between them.

These frameworks are:

(i) **Social determinants of health** (Dahlgren and Whitehead, 1991; Solar and Irwin, 2010)**.**

In 1991 Dahlgren and Whitehead developed the now highly influential model of the social determinants of health. Their model includes individual determinants such as sex, age, ethnic group, hereditary factors and lifestyle; social and community networks; living and working conditions; and socio-economic, cultural and environmental conditions. The World Health Organization Commission on the Social Determinants of Health (CSDH) framework built on and further developed Dahlgren and Whitehead’s model to incorporate a wider understanding of the individual, intermediate and structural determinants of health outcomes (Solar and Irwin, 2010). Determinants in the CSDH include individual determinants (such as gender, ethnicity, social class, education); material circumstances; living and working conditions; psychosocial factors; and health and care systems. Overarching all these factors is the socio-economic and political context in which they operate: social and public policies, governance, and societal values. The inclusion of health and care systems makes the CSDH model particularly useful to my thesis, as does the inclusion of a broader range of determinants than Dahlgren and Whitehead's earlier model. I therefore use this newer framework.

(ii) **Stress process model** (Pearlin et al., 1990)**.**

The stress process model postulates that impacts of care provision depend on elements of the care itself (e.g. care hours, care type) and on the context in which caring takes place. This includes socio-economic position (gender, ethnicity, age, educational attainment, and resources) and support received.

(iii) Andersen's Behavioral Model of Health Service Use (Andersen and Newman, 2005)**.**

The Behavioral Model of Health Service Use (BMHSU) was originally developed to assess and understand inequalities in health care use, including both contextual and individual 'inhibiting'/'impeding' factors (constraints) on service access and use (Andersen and Newman, 2005; Andersen et al., 2013). The model has since been expanded to look at long-term care service access and to incorporate a wider range of factors, including psychosocial factors (Travers et al., 2020; Lederle et al., 2021). Contextual factors in the expanded models include demographics, social norms and beliefs, policy, financing, affordability, and care services organisation. Individual factors include financial resources and preferences.

(iv) Constrained choices

'Constrained choices' is a key concept in definitions of social exclusion that look to its structural causes (e.g. Levitas, 1998; Armstrong, 2010). Choice and agency are also core components of capability theories (Sen, 1992), as is a recognition that there are structural constraints to the choices people have (Robeyns, 2016). Of particular relevance to this thesis, Al-Janabi et al. (2018), and Smyth et al. (2011) have applied the concept of 'agency within constraints' to unpaid carers. These constraints are both individual (e.g. familial obligations or duty) and structural (e.g. financial resources and policy and service constraints). It is important to recognise and account for the role of choice and agency in how care needs are met and in people's outcomes; to do otherwise could be conceived to be disempowering and paternalistic. However, nor should we overestimate the role choice and agency play by neglecting the role of structural constraints on choice. As, for example, Keating et al. (2020) point out, overestimating the agency that people experiencing profound inequalities may have in reality risks deepening those inequalities by putting the onus too much on individuals and not enough on governments. Keating et al. propose the following assumption in their development of Critical Human Ecology Theory in the context of global ageing: ‘People have varying capacities to make choices and to act upon or adapt their environments. There must be shared responsibility for supporting those with limited agency.’ (Keating et al., 2020, p. 3).

Each framework has a number of strengths and limitations for this thesis and for each research question. The strengths of the CSDH are that it is multi-level and wide-ranging, incorporating aspects such as social and public policies, socio-economic position, material circumstances, living and working conditions, (health) care systems and psychosocial factors. Pearlin’s stress process model adds to this by directly considering unpaid care – care need, care provided and direct and indirect support for carers – as well as the caring context, making it particularly valuable to help answer research questions 1 and 4, although is more limited in scope and range than the CSDH, so both are used together. The BMHSU applies an individual-structural perspective to long-term care access and use rather than outcomes, making it particularly relevant to research question 2. The CSDH and its predecessors were developed to both understand and help policy makers and practitioners take action to address the determinants of health. This practical component of the concept is also well suited to my thesis aims. ‘Constrained choices’ is a helpful additional concept in considering the consequences of unmet need for services (research question 3).

2.2 Literature review

2.2.1 Unpaid carers

Unpaid carers are core to current care provision worldwide (Verbeek-Oudijk et al., 2014a). In the 2021 England and Wales population census, 5 million people aged 5 and older were identified as unpaid carers; 9% of the population (Office for National Statistics, 2023). An extensive body of literature shows that providing unpaid care at higher care hours (for example more than 10, or more than 20, hours a week) and/or within the household has significant negative impacts on carers (Brimblecombe, Fernandez, et al., 2018a). At higher care hours, unpaid carers are less likely to be in paid employment (e.g. King and Pickard, 2013; Nguyen and Connelly, 2014; Bauer and Sousa-Poza, 2015) or have reduced employment hours (e.g. Carmichael and Ercolani, 2016; Gomez-Leon et al., 2019). They also have lower income than non-carers (Van Houtven et al., 2013; Keating et al., 2014) and increased risk of being in poverty (Aldridge and Hughes, 2016). There are negative effects on carers’ mental health, wellbeing and stress levels (Kaschowitz and Brandt, 2017; Bom et al., 2019; Ervin et al., 2022). Caring for higher hours and/or providing co-resident care is associated with carers having poorer physical health (e.g. Bauer and Sousa-Poza, 2015), although findings are mixed (Bom et al., 2019) and there is much less longitudinal evidence available. There is evidence that individuals caring for 20 or more hours a week have a lower mortality risk than non-carers, but a higher mortality risk than people caring for less than 20 hours a week (Ramsay et al., 2013).

Whilst the associations between providing within-household care or higher hours of care and negative impacts on carers are very well-researched, and in some outcome domains, now well-established, there is much less information on the interaction between higher levels of care provision and socio-demographic factors such as gender, ethnicity or socio-economic position (Spiers, Liddle, Stow, et al., 2021). Perhaps most established to date is the literature on gender and higher hours of care. This shows women to be at higher risk of leaving employment than men if they are both providing higher hours of care (King and Pickard, 2013). At higher care hours, women also have worse mental health than men (Doebler et al., 2017; Verbakel et al., 2017). However, to my knowledge, the evidence on whether outcomes of caring for higher hours or within the household differ by ethnicity or socio-economic position is non-existent.

2.2.2 Unmet need for care and inequalities in unmet need

In the context of rising care need and shortages in both the paid and unpaid workforce available to meet need (Pickard, 2013; Brimblecombe, Fernandez, et al., 2018b; OECD, 2020; ADASS, 2022; Office for National Statistics, 2023), there has been growing research interest on the gap between care need and care provision. This body of research is, however, still small in comparison to equivalent research on health care. Research on unmet need for care has tended to conceptualise unmet need as lack of help with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) difficulties. ADLs include tasks such as dressing and bathing; IADLs are activities such as managing finances, housework, and laundry. Need for help with certain ADLs and IADLs underlie the national eligibility threshold in England, as set out by the 2014 Care Act (Her Majesty's Government, 2014a). As such, this definition of care need – 'normative' need in Bradshaw's typography of social needs (Bradshaw, 1972) – determines eligibility for and allocation of adult social care services.

Research on unmet need for help with ADLs and IADLs in England has shown that a substantial proportion of disabled and older people are not having their care needs met (Brown and Sondaal, 2016; Institute of Fiscal Studies, 2017; Ipsos Mori, 2017; Age UK, 2019; Vlachantoni, 2019; Burchardt et al., 2020). This too is the case internationally (Lima and Allen, 2001; García-Gómez et al., 2015; Scheil-Adlung, 2015; Hlebec et al., 2016; Hu and Wang, 2019; Kröger et al., 2019). Some researchers have tried to also incorporate measures of inadequacy into unmet need for care. For example, LaPlante et al. extended this approach to estimate the shortfall in hours associated with unmet need for help with two or more out of five 'basic' ADLs (LaPlante et al., 2004). In separate studies, Age UK (Age UK, 2019), Burchardt et al. (Burchardt et al., 2020) and DePalma (DePalma et al., 2013) used measures which combine no help and insufficient help with ADLs and/or IADLs. An alternative or additional approach, although less used, has been to also look at subjective views on unmet care needs (e.g. Reynolds et al., 2000; García-Gómez et al., 2015; Stein et al., 2016). This approach recognises individual preferences and perceptions and thus may give rise to different conclusions about unmet need (see, for example, García-Gómez et al., 2015).

Inequalities in unmet need for care (with care need defined as ADL/IADL need) have also been studied. In England, unmet need for care is higher for women in some studies (Brown and Sondaal, 2016; Burchardt et al., 2020), men in others (Vlachantoni, 2019) or found no difference (Dunatchik et al., 2016) in others. Unmet need is higher among those living in more deprived areas (Brown and Sondaal, 2016; Burchardt et al., 2020), with lower income (Burchardt et al., 2018), in lower social class groups (Vlachantoni, 2019) or in rented as compared to owner-occupied housing (Vlachantoni, 2019). Other research has found a relationship between 'social exclusion' (which they defined as material and social deprivation) and unmet need for care (Srakar et al., 2015). On the other hand, Dunatchik et al.'s (2016) study of unmet need for care among older people in England found relatively little variation in unmet need by wealth or socio-economic status. As a result, they concluded that 'the research confirms the problems with the social care system as a whole' (Dunatchik et al., 2016, p14). One reason for this difference in findings may be that, unlike other research, Dunatchik et al. explored wealth or socio-economic status as potential risk factors ten years before the onset of unmet need.

A major gap both conceptually and empirically in studies of unmet need or inequalities in care has been unpaid carers. Whilst at least one example of earlier work on unmet need for care tended to conceptualise unmet need as including care needs not being met at all or care being provided 'only at the cost of undue strain of relatives' (Isaacs and Neville, 1976), since then unpaid carers have, in the main, been missing from conceptualisations and studies of unmet need. More recent studies and frameworks have tended to take an approach to unmet need that considers care need to be met regardless of how it is being met. This is an issue for assessing and understanding unmet need and inequalities in care, and for policy and practice.

2.2.3 Unmet need for care services

Other research on social care services has taken an approach to unmet need that is more akin to the concept of ‘unmet health care needs’. Research on unmet health care needs looks at the gap between services needed and services received and is widely used in evaluations of national health care systems and studies of inequalities in access to health care (e.g. European Commission, 2013). Applying this approach to research on social care services, studies have been carried out on unmet need for services in England (Vlachantoni et al., 2015; Brimblecombe et al., 2016; Burchardt et al., 2018) and in Europe (e.g. Jiménez-Martín, 2015; Albertini and Pavolini, 2017; Floridi et al., 2021). Studies using this approach have also looked at inequality in access to or use of those services (Rodrigues et al., 2014, 2018; Ilinca et al., 2017, in Europe; García-Gómez et al., 2015, in Spain; Vlachantoni et al., 2015 in England; Wang et al., 2020, in China). Similarly to studies on unmet need for care, most approaches to unmet need for services have looked at normative need (ADLs and IADLs), although some researchers have also (e.g. García-Gómez et al., 2015) or instead (e.g. Brimblecombe et al., 2016) looked at perceived, or subjective, unmet need for services. Conceptually, inequality in social care services has synergies with other frameworks that have a strong emphasis on the importance of better understanding and addressing the ways in which public policy, in this case social care and other welfare policy, demarcates access to services and ways in which care needs are met (Vlachantoni et al., 2015; Kröger et al., 2019; Kröger, 2022).

Investigations of distributional fairness in use of social care services have found variations in utilisation by income or wealth (Sarasa and Billingsley, 2008; García-Gómez et al., 2015; Vlachantoni et al., 2015; Ilinca et al., 2017; Burchardt et al., 2018; Rodrigues et al., 2018), although other studies have not found this relationship (e.g. Broese van Groenou et al., 2006; Hlebec et al., 2016). Having higher educational qualifications has also been found to be associated with greater use of social care services (García-Gómez et al., 2015). Of particular relevance to this thesis, the studies by García-Gómez et al. (2015) and Ilinca et al. (2017) show how different conclusions will be drawn depending on the way unpaid care is considered in studies of inequalities in receipt of care, and highlight the importance of distinguishing how care need is met. Both papers found that social care services were concentrated among those with higher income and/or wealth, whereas unpaid care was concentrated among those with lower income and/or wealth. Not distinguishing the ways in which care need is met may mask associations between wealth/income and unmet need giving an incomplete picture of the risk factors.

The evidence on receipt of care services adds nuance to the literature on unmet need for care and inequalities in care and, by looking at source of support for care needs, enables a more structural consideration of unmet need and one that can take into account policy aspects. The gaps here are that there is much less research in the English context; the reasons for these gaps in service provision are little understood; and that, again, unpaid carers are largely missing from the picture.

2.2.4 Consequences for carers of unmet need for services

Research on unmet need for care has tended to focus on extent of and variations in unmet need and considerably less often on the consequences, how these vary, and why. There is some research on consequences for care recipients (Zhen et al., 2013; Allen et al., 2014; He et al., 2015; Stein et al., 2016; Hu and Wang, 2019), although still a considerable gap in the evidence. An even more substantial gap is on consequences for carers of unmet need for services. One study by Robison and colleagues using 2007 US data found that caring alone was not associated with depressive symptoms, missed work, or social isolation. However, unmet need for services for the care recipient was associated with all three. Robison et al.'s (2009) findings also suggest the presence of mediating/exacerbating factors. Depressive symptoms as an outcome were also associated with inadequate income; missed work with carer gender and age; and social isolation with co-residence with the care recipient. A small-scale study in Switzerland on carers of people with spinal cord injury showed associations of unmet need for services with carers' health, social participation, and social relationships (Tough et al., 2019). Tough et al. also found the combination of lower socio-economic position and unmet need to be associated with greater perceived carer strain, suggesting there may be inequalities in how unmet need for services affects carers (Tough et al., 2019). Whilst these studies provide valuable information on potential consequences, both have the potential limitation that they are cross-sectional. In addition, Tough et al.'s study only focused on carers of people with spinal cord injury, so may not be more widely generalisable. A study by Pickard et al. found that non-receipt of services such as home care personal assistance by the person with care needs was subsequently associated with higher odds of leaving employment (Pickard et al., 2015).

Other studies – cross-sectional, longitudinal and cross-country comparisons – have found that provision of social care support for the person with care needs is generally associated with better outcomes for carers. For example, a modelling of German data suggested that service receipt is associated with higher labour force participation (Geyer and Korfhage, 2015). A study using panel data from thirteen European countries showed that providing care 'severely and significantly' reduces carers' probability of being in paid employment, but only in countries with few formal care alternatives (Heger, 2014). This body of research on service receipt and carers' employment has made a valuable contribution to our understanding of the association between social care services and employment and the context of different welfare policies and country-level differences.

In general, there is very little research on the effect of services in supporting carers' health and wellbeing (Brimblecombe, Fernandez, et al., 2018a). However, some studies show that social care support directed at the adult they care for positively affects carers' quality of life (Rand and Malley, 2014; Rand et al., 2020b) and a cross-country comparison found positive effects of country-level service provision on carers' wellbeing (van den Broek and Grundy, 2018). Other studies have found no effect on some aspects of carer wellbeing (Tough et al., 2019; Rand et al., 2020b), or even negative effects (Rand et al., 2020b). Numerous studies on a very specific type of care service, short breaks or respite, find either no evidence for the impact of respite care on carers' physical or mental health, or in some cases evidence of negative impact (Maayan et al., 2014; Thomas et al., 2017; Spiers, Liddle, Kunonga, et al., 2021). Short breaks represent a very specific type of care service, and one that is outside of the scope of this thesis.

2.2.5 Summary of literature and research gaps

In summary, there are three main evidence gaps that this research seeks to address. First, whilst we know a great deal about impacts of providing unpaid care, especially at higher hours and/or within the household, we know very little about how different sub-populations of carers may be differentially affected. Second, research to date has shown extensive and unequal unmet need for social care services. However, there is a gap in both an understanding and conceptualisation of unmet need for care with regards to unpaid carers. Specifically, little is known about the extent of, variation in, and reasons for unmet need for services in carer-care recipient dyads in England (or indeed elsewhere). Relatedly, there is also a gap in the understanding of how social care policy operates with regards to care service provision and carers in England. Third, very little is known about the consequences for carers of unmet need for services and how and why these may vary. Overarching this, and with some exceptions, research to date on carers, unmet need and often social care overall, lacks an inequalities perspective or one that takes into consideration the individual and structural context of caring. My study sought to address these research and theoretical gaps.

Research design and overview of methods

Although the specific methods used vary by research question, with some papers using single methodological approaches, the overall methodological approach is a mixed-methods design influenced by a critical realist approach. A critical realist approach to research design is based on the premise that: ‘research is not an objective fact-finding process, but nor is a focus on subjective experience alone sufficient to capture social processes, structures or relationships of power’ (Becker et al., 2012, p. 112). This approach is particularly well suited to the individual-structural conceptual frameworks used. The mixed-methods research design for the thesis is influenced by this critical realist ontological and epistemological position; the conceptual frameworks with its emphasis on individual and structural factors and interactions between them; and the research questions, which are interested in both patterns and experiences.

The aimed-for functions of the ‘complementarity’ and ‘expansion’ mixed-methods research design (Greene et al., 1989) in this study align most closely with ‘offset’ and ‘enhancement’ functions in Bryman’s (2006) typology. ‘Offset’ recognises that each method has different strengths and weaknesses; combining them allows weaknesses to be offset and the strengths of each maximised. ‘Enhancement’ is a process whereby the findings from each method augments the other, contributing in different ways to result in a better overall picture. An additional function was to help explain any unexpected results from the other method (Bryman, 2006). The two methods used were secondary analysis of large-scale quantitative longitudinal data (the UK Household Longitudinal Study (UKHLS); also known as Understanding Society); and primary qualitative interviews with carers. Synthesis and integration of quantitative and qualitative results took place during the interpretation phase of each mixed-methods paper (Creswell and Clark, 2017).

2.3.1 Quantitative data

My research used data from Waves 9 (2017/19) and 10 (2018/20) of the UK Household Longitudinal Study (University of Essex, 2021), a large-scale, UK-representative dataset. There are two large-scale longitudinal household surveys that collect data on unpaid care and on social care use in England: UKHLS and the English Longitudinal Study of Ageing

(ELSA). There are advantages and disadvantages of both. The advantages of UKHLS over ELSA for this study are, first, that UKHLS includes carers, although not recipients of care, aged 16 and older; the ELSA is a sample of people aged 50 and older only. Using a sample with all-aged carers 16 and older meant that a wider range of caring experiences could be explored and any differences in outcomes by age could be investigated. Second, UKHLS collects data on a larger number of ADL and IADL needs than ELSA, giving a fuller picture of care needs. A third advantage of UKHLS for my study is the timing of data collection. UKHLS collects data every year, ELSA every two years. Whilst information on social care receipt is only collected every two years in UKHLS as well, data on 'outcomes' are collected every year, meaning it is possible to look at the effects on carers of formal and other support for care recipients one year later. A limitation of UKHLS is that unmet need could have changed between its measurement at baseline and the outcomes studied one year later; this would be magnified if the gap between measurement of unmet need and outcomes was two years.

The UKHLS started in 2009 and collects data annually from a sample of household members aged 10 or older living in the UK. It built on and incorporated study members from the British Household Panel Survey (BHPS). Sampling is based on a proportionately stratified, clustered sample of addresses selected by postcode, supplemented by specific additional samples added at subsequent waves (Knies, 2017). Wave 9 is the most recent year in which data are available on social care use and needs; Wave 10 enables exploration of outcomes longitudinally. The overall sample at these waves comprises members of the BHPS and Northern Ireland Household Panel Survey, the 'general population sample', the 'ethnic minority boost sample', and the 'immigrant and ethnic minority boost sample'.

The overall sample for my study is paired care recipient-carer panel members both aged 16 and older and living in England, 'paired' at Wave 9. Because this is a household panel survey and data are not collected on people outside of the household, carers in the pair will be co-resident carers only. The sample size is 1,141 dyads for whom there is information on care need, social care service receipt (or non-receipt), and unpaid caring at Wave 9. For Paper 1, the sample comprised all panel members who took part in the study in both Wave 9 and Wave 10, living in the UK, who were aged 16 or older in Wave 9, and for whom data about caring responsibilities, hours and type were available. The resultant sample for carers caring for 10 or more hours a week was 25,935: 23,586 non-carers and 2,349 carers; and for co-resident carers the sample size was 25,354: 23,586 non-carers and 1,768 carers. Ethical approval for the UKHLS was obtained by the University of Essex Ethics Committee, which has approved all data collection on the Understanding Society main study and innovation panel waves. Descriptive and regression analysis was carried out using Stata 14.2 (StataCorp, 2015).

Limitations of the quantitative data

The UKHLS has many advantages for this study. It is a large-scale nationally-representative longitudinal dataset that contains rich detail on care need, receipt of social care services, carers' outcomes in a number of domains, and a range of socio-demographic information about carer and care recipient. As it is a household survey, carers and care recipients can be paired. Using secondary data has the advantages that fieldwork has already been carried out, making it cost-effective and enabling me to analyse data that it would not have been possible to collect myself for this study. Previously validated measures have been used in the survey, adding to the robustness of the data. However, a disadvantage of using secondary data is that it is, by nature, only possible to use information that has already been collected. Although UKHLS has a very broad range of data relevant to the research questions, there are limitations to what can be studied. The questions on social care services do not cover all services. For example, meal delivery services or group activities such as day centres, memory groups or lunch clubs are omitted in data collection. A further limitation is that the service receipt question response is binary (received or not received), lacking nuance. An additional potential limitation is that questions about social care receipt are only asked to people aged 65 and older, and it is only possible to link those respondents with within-household carers. This means it is not possible to look at the research questions for working-aged disabled people, their carers, nor extra-resident carers of any age group. Using interview data helped offset many of these limitations by enabling an inclusion of a wider group of co-resident carers, more service types, more nuance about service receipt, and additional outcomes. For some research questions, qualitative data alone is used.

Non-response of the eligible population at Wave 1 was 43.3% for the UKHLS general population sample and 48% for the ethnic minority boost sample (Lynn et al., 2012). Whilst UKHLS has very little direct information about non-responders, a comparison of the small area characteristics of the postcodes of responding and non-responding households showed little or no association between these characteristics and likelihood of responding. Non-response was higher for households in areas that had higher proportions of single-person occupancy and areas with higher full-time employment and higher social class. The response rate varied between regions, with 36.8% non-response in North East England and 54.7% non-response in Inner London for the general population sample. Within participating households, individual adult level response was 81.8% in the general population sample and 71.9% in the ethnic minority booster sample. As with household response rates, individuals in households with lower income or wealth were more likely to respond than those in higher income/wealth households (Lynn et al., 2012).

Attrition is an issue for any longitudinal data collection and, whilst UKHLS takes a number of measures to minimise this, by Wave 11, 60.1% of the sample that had taken part in Wave 1 were no longer participating and in the ethnic minority boost sample this was 67.3% (Cabrera-Alvarez et al., 2022). It is difficult for the data collection team to know if this is genuine non-response or people becoming ineligible because, for example, they moved out of the UK, entered an institution (UKHLS is a community sample only) or died. This ineligibility will increase over waves as people age and are therefore more likely to die or to move to a care home (Cabrera-Alvarez et al., 2022). Attrition was greatest amongst the youngest age groups, ethnic minorities, people on lower incomes, students, people who were unemployed, renting, with poorer health or with no qualifications (Cabrera-Alvarez et al., 2022). At Wave 11 there was under-representation compared to the UK population as a whole for people from younger age groups, rented housing, and lower educational attainment (Cabrera-Alvarez et al., 2022). My study uses data up until Wave 10 only, so attrition will be slightly lower than the Cabrera-Alvarez figure of 60% (at Wave 7, attrition was 48% (Lynn and Borkowska, 2018); there has been no analysis in between). In addition, most dropouts occurred in the first four waves, with the attrition rate significantly decreasing after that (Cabrera-Alvarez et al., 2022). In addition, I use at most three waves and attrition between three waves is much lower than between eleven waves.

For comparison, by Wave 9, attrition in ELSA was 68% (Pacchiotti et al., 2021). If looking at comparable timespans (ELSA data are collected every other year, UKHLS annually), attrition was 50.2%. In order to endeavour to maintain representativeness, ELSA added on booster samples at several timepoints. UKHLS added on the ethnic minority and immigrant booster samples, which reflect the changing demographics of the UK over the time period, but do not necessarily address other unrepresentativeness due to attrition.

Initial and subsequent non-response or attrition has a number of potential problems for my study. One is that the sample I used may not be representative of the UK or English population. However, first, there seems to be a slight balancing out of the characteristics of initial non-responders (e.g. higher income) and those dropping out (e.g. lower income). This may partially be why the sample in Wave 7 was seen to be ‘reassuringly similar’ to the England and Wales population census estimates (Lynn and Borkowska, 2018), although there was still modest under-representation among certain groups: the youngest age groups, men and ethnic minority individuals. The range of characteristics still included, even with modest under-representation in some aspects, is a strength for my study and the under-representation less of an issue because I investigated comparisons between sub-groups rather than estimating overall prevalence of, say, unmet need in the English population as a whole.

A further potential issue for my study of initial non-response and attrition is that it can mean that the resultant sample is too small to enable enough statistical power for the analysis required. However, this was not the case in my study. The sample of carers at Waves 9 and 10 (Paper 1) was 2,349 carers for people caring for 10 or more hours a week in the UK and 1,768 for co-resident carers. The sample for Paper 2, which used Wave 9 data only, was 1,141 dyads and the sample for Paper 4 was 1,120 dyads (Waves 9 and 10 data). These samples were large enough for the analyses, with the exception of some population sub-groups meaning some comparisons were not possible – a limitation.

2.3.2 Interviews

One-to-one in-depth qualitative telephone interviews were carried out between February and May 2020 with 26 adult co-resident carers caring for adults (aged 16 or older) living in England. Sampling was purposive maximum variant (Patton, 2014) aiming to cover a range of carer experiences and circumstances. Recruitment took place through carer organisations and networks and from among the general public. This was in order to recruit people with caring responsibilities who identified as carers, and those who did not, and to recruit a diverse interview sample. Participants were sent information sheets beforehand explaining the purpose and nature of the research; what taking part involved; the potential benefits, risks, and burdens; confidentiality and limits to confidentiality; anonymisation of data; and the voluntary nature of participation. Consent was discussed with participants before the interview began, taken verbally and recorded on a paper version of the consent form. Ethical approval for the interviews was granted by the Social Care Research Ethics Committee in October 2019 (Ref: 19/IEC08/0046). Interviews were semi-structured and followed a topic guide, structured around the research questions. Interviews were audio-recorded with the interviewee’s permission and transcribed in full. Analysis took place in NVivo. The overall approach to the qualitative analysis was primarily deductive or ‘theoretical’ thematic analysis (Braun and Clarke, 2019), structured around the particular research questions and conceptual frameworks and with deductive and inductive analysis subsequently used to identify sub-themes within the main domains, consider meanings of initial themes, and to identify new themes.

Limitations of the qualitative data

There are a number of potential limitations to the qualitative data. Many unpaid carers do not identify as such (Hughes et al., 2013; Carduff et al., 2014; Urwin et al., 2021). To mitigate this, recruitment took place from among the general public through a specialist research recruitment agency, as well as carer organisations, and recruitment materials were carefully designed to avoid just using the term ‘carer’. Questions such as ‘Do you help support an adult with long-term physical or mental ill health, disability, or other difficulties?’ were used instead. This phrasing, and similar, is widely used in surveys aiming to capture prevalence of carers. However, some people who are carers will still not recognise themselves in this question.

There are a number of other reasons why some carers may not have taken part. Barriers to participation may include competing priorities such as caring responsibilities, paid employment or childcare. I aimed to mitigate this by being flexible about timing of interviews, but the time needed itself will be a barrier for some people. COVID-19 measures at the time meant that some people were more available, for example were not working or were working from home, but this was very job-dependent: others may have still been at the workplace. There may have been nervousness about taking part, disclosing private information, or data security. Although both the information sheet and discussions at the beginning of each interview aimed to address these issues, concerns may still have persisted. Language may be a barrier to participation. Information sheets were available in languages other than English and interpreters were offered for interviews. Information sheets were also available in easy read.

Some of the interviews took place during the COVID-19 lockdown measures in England, which resulted in cessation of or reduction in usual care service provision for many people (Carers UK, 2020; Giebel et al., 2020). The extent of unmet need for services in the interviews may thus have been higher than unmet need pre-COVID-19, although evidence from pre-COVID-19 shows generally high levels of service under-provision (Yeandle et al., 2007; Brimblecombe et al., 2016). This is a strength, in that I was able to explore newly unmet need during the pandemic, but a possible limitation, as the interviews do not necessarily reflect ‘usual’ levels of unmet need for services.

The power imbalance between myself and the interviewee may also have affected the process and potentially the findings. As a researcher from a ‘high-status’ university, and with the offer of a monetary incentive to take part, interviewees may have felt obliged to answer the questions. I aimed to minimise this by emphasising the voluntary nature of participation; that interviewees can decline to answer any question they did not wish to answer and can also end the interview at any point; and that receiving the voucher was not dependent on any answer given or not given, nor affected by them ending the interview early. There was a great deal of social isolation felt during COVID-19, especially for carers who were living with someone who was clinically vulnerable, and participants may have welcomed the opportunity to talk to someone – myself as researcher – more than in other circumstances, a further potential power imbalance or coercion, but also a possible unforeseen benefit of the research for participants. Many said they welcomed the opportunity to share their experiences and talk to someone unrelated to their situation, although I had also experienced this pre-COVID-19.

The interview questions and data analysis will also have been affected by my position as researcher bringing my own personal life experiences, social position, and ontological, philosophical and political views. Whilst not a limitation as such, it is important to be aware of and reflect on these potential biases and assumptions. To maintain the integrity of the research process and to keep aware of potential researcher bias, during analysis I aimed to be driven by the evidence, checking carefully for findings and themes that contradicted my world view, and being guided by what participants said in the interviews. Research integrity with regards to analysis and interpretation is also protected through a critical appraisal of the available supporting literature. Findings have been ‘sense-checked’ with carer advisors to the project and discussed in depth with both of my supervisors. Both advisors and supervisors provided valuable countermeasures and challenges to my assumptions.

Chapter 3

Paper 1. Inequalities in unpaid carers' health, employment status, and social isolation

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Abstract

Providing higher intensity unpaid care (higher care hours or care within the household) is associated with negative impacts on people's paid employment, mental health, and wellbeing. The evidence of effects on physical health is mixed and carers' social and financial outcomes have been under-researched. The biggest evidence gap, however, is on how outcomes vary by factors other than type or level of care provision, in particular socio-demographic factors. Our study used two waves of data (2017/19 and 2018/2020) from the United Kingdom Household Longitudinal Study for people aged 16 and older. We investigated the effects of providing care for 10 or more hours a week or within the household in interaction with people's socio-demographic characteristics. Outcomes included mental and physical health, social isolation, employment status, and earnings. We found that caring responsibilities interacted with gender, ethnicity, socio-economic status (as measured by highest educational qualification), or age to affect carers differentially in a number of areas of their lives, leading to and exacerbating key disadvantages and inequalities.

Introduction

How care needs are met, and disabled and older people enabled to live independent lives, is an important societal and social justice issue. It has had varied traction in the political and policy sphere, although has been higher on the agenda and public consciousness in recent years in many countries, the UK included (Her Majesty's Government, 2014a; Scottish Government, 2014; Welsh Government, 2014). Currently, unpaid care comprises the majority of care provided and received (Verbeek-Oudijk et al., 2014). Discussions, and policy, about the optimal balance between formal and informal care varies across country, time, and ideology. However, a consistent part of the equation is the impacts on unpaid carers. There is now a substantial body of evidence showing that at higher care hours and/or for co-resident carers, providing care has significant negative impacts on carers' paid employment, mental health, and wellbeing (Kaschowitz and Brandt, 2017; Brimblecombe, Fernandez, et al., 2018a). There are also impacts on carers' physical health when caring for higher hours and/or providing co-resident care (e.g. Bauer and Sousa-Poza, 2015), although findings are mixed (Bom et al., 2019) and there is much less longitudinal evidence available. Social and financial outcomes have been much less researched (Spiers, Liddle, Stow, et al., 2021). The biggest evidence gap, however, is on how the experiences of carers vary by factors other than type or level of care provision, in particular socio-demographic factors (Young et al., 2020). The exception is gender, where a number of studies have shown that female carers experience greater negative impacts then male carers on their employment (Carmichael and Charles, 2003; Heitmueller and Inglis, 2007; King and Pickard, 2013; Van Houtven et al., 2013), mental health (Bauer and Sousa-Poza, 2015; Bom et al., 2019), and on their physical health (Bom et al., 2019).

Few of these studies consider care hours but those that do suggest that gender differences in impacts on employment are not solely due to female carers providing higher hours of care than men (King and Pickard, 2013). Mental health was shown to be worse among women providing higher hours of care in a recent longitudinal study in Northern Ireland (Doebler et al., 2017). Cross-sectional studies show similar patterns (e.g. Verbakel et al., 2017; Office for National Statistics, 2013). Research on locus of care and gender suggests some interaction effect with regards to carers' employment (Arber and Ginn, 1995). In terms of other socio-demographic characteristics, evidence from a cross-sectional Swiss study in a very specific context (carers of partners with spinal cord injury) suggested that socio-economic position was associated with greater perceived strain. This was not moderated by care hours (Tough et al., 2019). A European study using longitudinal data found that carers with higher wealth experienced greater life satisfaction (Brandt et al., 2021), although in contrast a cross-sectional study in Japan found no interaction effect of care provision and income on depressive symptoms (Saito et al., 2018). However, in general and in the UK context, the evidence on factors other than gender – for example, age, ethnicity, and socio-economic status (SES) – is scant (Spiers, Liddle, Stow, et al., 2021).

Carers are not a homogenous group and the gap in evidence on variations in outcomes matters because of the body of work showing that factors such as age, SES, gender and ethnicity are key determinants of outcomes in many domains (Dahlgren and Whitehead, 1991; Solar and Irwin, 2010; Marmot et al., 2020) In addition, in order to best support the most vulnerable carers, we need to first identify them. Our study investigated the interaction between provision of care and key socio-demographic factors. In doing so, we utilise a social determinants conceptual framework (Solar and Irwin, 2010). In this framework, socio-economic position, which comprises social class and social stratifiers (e.g. age, gender, ethnicity, education), is a key structural determinant of outcomes. We also draw on Pearlin and colleagues' stress process model (Pearlin et al., 1990). This model postulates that impacts of care provision depend on both elements of the care itself (e.g. care hours, care type) but also on the context, including socio-economic position (gender, ethnicity, age, educational attainment, and resources). We know that providing care has impacts on people's lives in several domains and that gender, SES, ethnicity, and age also impact people's outcomes. Our study aimed to add to the evidence base by exploring the effects of care provision and socio-demographic factors in combination to better understand who is most disadvantaged and how experiences differ. We focused on carers providing the most intense care (higher care hours or co-resident carers) because of evidence showing greater, or sometimes only any, impacts at these levels and types of care provision (Brimblecombe, Fernandez, et al., 2018a).

Methods

Our methods strategy was as follows. Using data from the UK Household Longitudinal Study (UKHLS), we identified people aged 16 and older providing unpaid care at time 1 (Wave 9; 2017/19) (a) of 10 or more hours a week; (b) within the household. We then looked at how interaction of care provision and socio-demographic factors at time 1 was associated with a number of outcomes at time 2 (Wave 10; 2018/20).

Data and sample

We used data from Waves 9 (2017/19) and 10 (2018/20) of the UKHLS (University of Essex Institute for Social and Economic Research, 2021). The UKHLS started in 2009 and collects data annually from a sample of household members aged 10 or older living in the UK. Sampling is based on a proportionately stratified, clustered sample of addresses selected by postcode, supplemented by specific additional samples added at subsequent waves (Knies, 2017). Our sample comprised all panel members who took part in the study in both Wave 9 and Wave 10, who were aged 16 or older in Wave 9, and for whom data about caring responsibilities, hours, and type were available. The resultant sample for carers caring for 10 or more hours a week was 25,935: 23,586 non-carers and 2,349 carers; and for co-resident carers N=25,354: 23,586 non-carers and 1,768 carers. Attrition is an issue for any longitudinal data collection and whilst UKHLS takes a number of measures to minimise this, there is a degree of attrition between waves. However, whilst here is modest under-representation among the youngest age groups, men, ethnic minority respondents, and those on the lowest incomes, the sample is still considered representative of the UK population (Lynn and Borkowska, 2018).

Measures

Caring responsibilities

The variables for caring responsibilities were derived from three questions asked of respondents at time 1:

(i) ‘Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example, a sick, disabled or elderly relative/husband/wife/friend etc.)?’

(ii) ‘Do you provide some regular service or help for any sick, disabled or elderly person not living with you?’

And the follow-up question:

(iii) ‘Thinking about everyone who you look after or provide help for, both those living with you and not living with you – in total, how many hours do you spend each week looking after or helping them?’

Non-carers were defined as people who answered no to both the first two questions. Higher care hour carers were defined as people who answered yes to either or both questions (i) and (ii), and indicated that they were providing care for 10 or more hours a week in question (iii).

Co-resident carers were defined as people who answered yes to question (i) (either on its own or together with question (ii)).

Caring for 10 or more hours a week was selected because previous research shows that this is the threshold at which impacts on carers are greatest; few or no impacts are observed at lower hours (King and Pickard, 2013; Brimblecombe, Fernandez, et al., 2018a). In addition, preliminary analysis on the sample showed that providing care at 10 or more hours was the threshold at which negative outcomes in all domains were seen in our data. This effect was seen at the lower range (10-19 hours). Within the 10 or more hours category, some higher care hour bands were associated with worse outcomes but this was not linear and no clear pattern emerged. Co-resident caring was selected because co-resident care provision is associated with greater impacts on carers than extra-resident caring (e.g. Michaud et al., 2010; Nguyen and Connelly, 2014; Bauer and Sousa-Poza, 2015; Kaschowitz and Brandt, 2017).

Carer characteristics

The carer characteristics used as predictors in the models were gender (male=0; female=1); ethnicity (White=0; Asian=1; Black=2); highest educational qualification (degree or higher degree=0; primary, secondary, or no formal qualifications=1) as a measure of socio-economic status; and age group (16-24; 25-44; 45-65; 66-74; 75+). Highest educational qualification is a well-used measure of socio-economic status and was used in our study because it has a good response rate, is easy to measure, and includes people who are unemployed. The social class variables available in UKHLS use information from respondents' current job. As a result, over 40% of responses are 'inapplicable'.

Outcomes

We considered five outcomes separately at time 2: employment status; annual earnings from paid employment; physical health; mental health; and social participation (loneliness or isolation). Employment status was recoded into two categories: 0=in paid- or self-employment; 1=not in paid employment. The continuous variable for earnings was based on a question about monthly earnings from paid employment and thus excluded earnings from self-employment. We multiplied the monthly figure by 12 to give annual earnings. For employment and earnings, we excluded sample members who were in full- or part-time education or training at the same time as paid employment and sample members who were over the UK state pension age at the time (66 and older). For health outcomes, the variables used were the Physical and Mental Components of the Short-Form 12 Health Survey (SF12, PCS and MCS) which measure physical and mental health respectively; they have been validated for use in the general population (Ware et al., 1996). Lower scores indicate poorer physical/mental health. Social participation was derived from two questions asked at Wave 10 about how often the person felt lonely or felt isolated from others, recoded into 0 for hardly ever or never and 1 for some of the time or often.

Analysis

First, we used descriptive statistics to report the characteristics of the sample. We then investigated (a) the effect of care provision; (b) the effect of people's socio-demographic characteristics; and (c) the combined, interactive effect. We used two step multivariate regression models which used the factors on their own and with interaction terms. We looked at care provision and carer characteristics at time 1 (Wave 9) and outcomes at time 2 (Wave 10). Multivariate logistic regression was used for categorical outcome variables: employment status and social participation. Multivariate linear regression was used for continuous outcome variables: physical health score (PCS) and mental health score (MCS). For analysis of earnings, as this variable has a skewed distribution with a substantial number of zeros, we used two-part Generalised Linear Models (Mullahy, 1998). We used a modified Park test (Manning and Mullahy, 2001) to select the appropriate distribution and link function. The marginal effect of providing care at time 1 on each cost measure at time 2 could then be estimated from each regression model: this represents the mean cost at time 2 associated with a person providing care (of 10 or more hours a week/within the household) at time 1 compared to someone not providing care at time 1.

Models controlled for covariates potentially associated with each outcome, based on previous research where available (e.g. Marmot and Bell, 2012; Pickard et al., 2018) and/or initial bivariate analysis. Covariates varied by outcome but included the carer characteristics listed above excluding the one used in the interaction term as the predictor in each model. In addition, for employment outcomes (employment status, earnings), we included carers' partnership status (single or in a partnership) and health (presence or absence of a 'limiting long-term illness' (LLTI)). In analyses of health outcomes, additional covariates were partnership status and housing tenure (coded as owner-occupied, social-rented or privately rented). Social-rented housing (or 'public housing') in the UK is provided at more affordable rents, usually by local government or non-profit sector housing associations. We used the unweighted sample for the regression analysis. Where sampling weights are solely related to the independent variables, as they are in our models, unweighted estimates are preferred (Winship and Radbill, 1994).

All tests of statistical significance used robust standard errors. A significance level of 0.05 was used as the criterion to determine statistical significance and 0.10 to determine marginal significance. We conducted analyses using Stata 14.2 (StataCorp, 2015).

Results

Table 2 shows that 66% of carers caring for 10 or more hours a week were female and 34% were male. Women also made up a higher proportion of co-resident carers then men. The majority of higher care hour carers and co-resident carers identified as White. This was 85% for higher care hours, similar to the proportion in the sample overall (84%) and slightly lower (81%) for co-resident caring. Asian carers comprised 11% of higher care hour carers and 15% of co-resident carers. Two thirds of carers had primary, secondary, or no qualifications, higher than their proportion in the sample overall (57%). Proportions of both higher care hours carers and co-resident carers were highest in mid-life (45-64).

Table 2. Sample descriptives

	Non-carer and 10+ hours carer sample N=25,935 Non-carer N=23,586 (90.9%) Carers for 10+ hours a week N=2,349 (9.1%)		**Non-carer and co-res carer sample** N=26,227 Non-carer N=23,586 (89.9%) Co-resident carers N=2,641 (10.1%)	
	N	**%**	**N**	**%**
Carer characteristics time 1				
Female	1,540	65.6	1,511	57.2
Male	809	34.4	1,130	42.8
White	1,946	85.0	2,059	80.9
Asian	260	11.4	391	15.4
Black	84	3.7	95	3.7
< Degree	1325	65.8	1,496	65.7
Degree +	688	34.2	780	34.3
Aged 16-24	86	3.7	229	8.7
Aged 25-44	519	22.1	649	24.6
45-65	1,099	46.8	979	37.1
66-74	390	16.6	432	16.4
75+	255	10.9	352	13.3

Table 3 shows the association between providing care for 10 or more hours a week and each outcome; the association between outcomes and people's socio-demographic characteristics; and the combined effect of care provision and each characteristic. As expected, compared to non-carers, caring for 10 or more hours a week was associated with lower odds of being in paid employment; lower earnings; poorer mental and physical health; and higher odds of loneliness and social isolation. However, as the interaction findings show, this effect was amplified in combination with gender, ethnicity, SES, or age. The combination of being a carer and being female was, in the main, associated with worse outcomes: poorer mental health; higher odds of feeling lonely or isolated; and lower earnings. Both gender and care provision appeared to contribute to these outcomes. For example, women had lower earnings than men, and carers had lower earnings than non-carers. The combined effect of being a carer and being female was over £10,000 a year reduced earnings. Similarly, there was a combined carer and ethnicity effect on health and earnings for Asian carers. For Black carers, the picture was more complex. Being Black and providing care was associated with the highest odds of not being in paid employment. However, in our study people from Black ethnic backgrounds had significantly better mental health scores than people from White ethnic backgrounds and the interaction effect of care provision and Black ethnicity on mental health was not statistically significant.

Lower qualified carers were a particularly disadvantaged group (Table 3). The combination of lower qualifications and being a carer for 10 or more hours a week resulted in being six times less likely to be in paid employment, an earnings penalty of £12,000 a year, and having significantly lower mental and physical health scores, indicating worse health. The intersection of age and care provision had differential effects on health. The combination of being younger (aged 16-24 or 25-44) and being a carer was associated with significantly worse mental health, whereas being older and a carer was associated with significantly worse physical health. Being younger and a carer in combination was also associated with higher odds of being lonely or isolated. The interaction of being a co-resident carer and the carer's gender, ethnicity, qualification, and age showed similar results to the interaction of providing higher care hours and those characteristics (Table 4).

Table 3. Carers' outcomes at higher care hours: regression models

TIME 2 OUTCOMES	Not in paid employment[1]	Mental health score	Physical health score	Lonely or isolated	Annual net earnings from employment[1]
	Odds ratio (95% CI)	**Coefficient (95% CI)**	**Coefficient (95% CI)**	**Odds ratio (95% CI)**	**Mean cost difference (£) (95% CI)**
Care responsibilities					
Providing care for 10 or more hours a week	**1.45***	**-1.37***	**-0.96***	**1.15***	**-4635.04***
compared to non-carer	1.30, 1.61	-1.66, -1.09	-1.26, -0.66	(1.09, 1.21)	-5373.71, -3896.38
Socio-demographic characteristics					
Male (ref)	-	-	-	-	-
Female	1.0 ns	**-2.08***	**-0.73***	**1.35***	**-6977.32***
	0.87, 1.15	-2.37, -1.79	-1.00, -0.66	(1.28, 1.43)	-7408.30, -6546.34
White (ref)	-	-	-		-
Asian	**2.64***	0.43 ns	**-2.74***		**-4682.89***
	2.19, 31.8	-0.11, 0.96	-3.19, -2.30		-5288.65, -4077.13
Black	1.23 ns	**2.72***	0.22 ns		327.22 ns
	0.88, 1.71	1.82, 3.61	-0.54, 0.98		-841.45, 1495.89
Degree or higher educational qualification (ref)	-	-	-		-
Primary, secondary, or no formal qualifications	**3.34***	-0.21 ns	**-2.32***		**-7782.90***
	2.88, 3.87	-0.51, 0.08	-2.59, -2.04		-8206.87, -7358.94
Aged 16-24		**-5.29***	**14.13***	**2.65***	
		-6.14, -4.44	13.28, 14.98	(2.25, 3.11)	
Aged 25-44		**-5.40***	**10.74***	**3.00***	
		-6.02, -4.79	10.00, 11.47	(2.61,3.45)	
Aged 45-65		**-2.94***	**6.91***	**1.94***	
		-3.53, -2.35	6.18, 7.64	(1.70,2.23)	
Aged 66-74		0.15 ns	**3.20***	**1.04 ns**	
		-0.48, 0.78	2.39, 4.02	(0.89, 1.21)	
Aged 75+ (ref)	-	-	-	-	
Interaction of care provision and socio-demographic characteristics					
Male#non-carer (ref)	-	-	-	-	-
Male#carer	**2.46***	**-2.02***	**-1.71***	**1.18***	**-6812.39***
	1.73, 3.51	-2.93, -1.11	-2.68, -0.75	1.01, 1.39	-7850.68, -5774.11
Female#carer	**1.98***	**-5.13***	**-2.74***	**1.87***	**-10938.84***
	1.50, 2.60	-5.13, -4.42	-3.48, -2.00	1.65, 2.11	-11261.61, -10616.12

White#non-carer (ref)	-	-	-		-
White#carer	**2.08***	**-2.72***	**-2.08***		**-4988.23***
	1.64, 2.63	-3.32, -2.12	-2.73, -1.43		-5508.89, -4467.58
Asian#carer	**3.71***	**-2.68***	**-3.13***		**-7518.6***
	2.04, 6.73	-4.60, -0.75	-4.81, -1.45		-9165.08, -5872.06
Black#carer	**5.07***	0.51 ns	-0.34 ns		-1931.4 ns
	1.90, 13.55	-2.86, 3.88	-3.23, 2.54		-7551.52, 3688.62
Degree or higher#non-carer (ref)	-	-	-	-	-
Degree#carer	**2.46***	**-3.19***	**-1.79***		**-5506.15***
	1.67, 3.61	-4.10, -2.27	-2.73, -0.84		-6459.77, -4552.53
Lower qualifications#carer	**6.44***	**-2.79***	**-4.86***		**-12021***
	4.90, 8.46	-3.51, -2.07	-5.11, -3.61		-12382.2, -11659.61
Aged 75+#non-carer (ref)		-	-	-	
Aged 16-24#carer		**-8.61***	**10.22***	**3.22***	
		-12.52, -4.71	**7.09, 13.35**	1.99, 5.20	
Aged 25-44#carer		**-8.52***	**8.20***	**5.06***	
		-9.88, -7.16	6.84, 9.57	3.99, 6.42	
Aged 45-65#carer		**-5.11***	**4.48***	**2.62***	
		-6.08, -4.14	3.37, 5.59	2.16, 3.18	
Aged 66-74#carer		**-1.92***	**2.60***	**1.67***	
		-3.19, -0.65	1.04, 4.16	1.26, 2.19	
Aged 75+#carer		**1.44~**	-0.29 ns	**1.60***	
		-3.05, 0.17	-2.26, 1.67	1.15, 2.23	

*p <.05; ~ p=0.10; ns = non-significant. Controlling for carers’ sex, ethnicity, health (LLTI), marital status, highest qualification, age at time 1 in analysis of employment status, and analysis of earnings from paid employment; controlling for carers’ sex, ethnicity, marital status, highest qualification, housing tenure at time 1 in analysis of physical health score and mental health score; controlling for sex, health (LLTI), marital status, highest qualification in analysis of social isolation. Physical health score is Physical Component of the Short-Form 12 Health Survey (SF12 PCS; range 4.62-75.48); lower score = worse physical health. Mental health score is Mental Component of the Short-Form 12 Health Survey (SF12 MCS; range 0-75.38); lower score = worse mental health. (1) Under State Pension Age only.

Table 4. Co-resident carers' outcomes: regression models

TIME 2 OUTCOMES	**Not in paid employment[1]**	**Mental health score**	**Physical health score**	**Lonely or isolated**	**Annual net earnings from employment[1]**
	Odds ratio (95% CI)	**Coefficient (95% CI)**	**Coefficient (95% CI)**	**Odds ratio (95% CI)**	**Mean cost difference (£) (95% CI)**
Care responsibilities					
Providing co-resident care compared to non-carer	**1.35***	**-1.41***	**-1.19***	**1.20***	**-3844.92***
	1.21, 1.49	-1.69, -1.14	-1.48, -0.91	1.14, 1.26	-4582.2 -3107.64
Socio-demographic characteristics					
Male (ref)	-	-	-	-	-
Female	1.03 ns	**-2.09***	**-0.81***	**1.35***	**-7303.23***
	0.90, 1.18	-2.38, -1.80	-1.08, -0.54	1.28, 1.43	-7735.00, -6871.22
White (ref)	-	-	-		-
Asian	**2.48***	0.40 ns	**-2.66***		**-4410.12***
	2.06, 2.98	-0.12, 0.92	-3.10, -2.23		-5018.98, -3801.27
Black	1.08 ns	**2.69***	0.12 ns		401.79 ns
	0.77, 1.53	1.80, 3.58	-0.64, 0.88		-768.66, 1572.24
Degree or higher educational qualification (ref)	-	-	-		-
Primary, secondary, or no formal qualifications	**3.30***	**-0.26~**	**-2.34***		**-7910.16***
	2.89, 3.76	-0.56, 0.03	-2.62, -2.06		-8336.75, -7383.61
Aged 16-24		**-5.30***	**14.26***	**2.69***	
		-6.14, -4.47	14.42, 15.10	2.29, 3.16	
Aged 25-44		**-5.30***	**10.80***	**3.03***	
		-5.91, -4.69	10.08, 11.53	2.64, 3.48	
Aged 45-65		**-2.90***	**6.95***	**2.01***	
		-3.48, -2.73	6.23, 7.67	1.76, 2.30	
Aged 66-74		0.10 ns	**3.22***	1.06 ns	
		-0.52, 0.72	2.41, 4.02	0.91, 1.24	
Aged 75+ (ref)		-	-	-	
Interaction of care provision and socio-demographic characteristics					
Male#non-carer (ref)	-	-	-	-	-
Male#carer	**1.85***	**-2.27***	**-1.78***	**1.32***	**-3224.32***
	1.34, 2.54	-3.06, -1.47	-2.59, -0.97	1.15, 1.53	-4125.03, -2323.61
Female#carer	**1.84***	**-5.26***	**-3.56***	**2.04***	**-11125.1***
	1.39, 2.44	-5.99, -4.53	-4.34, -2.78	1.79, 2.31	-11495.78, -10754.39

White#non-carer (ref)	-	-	-		-
White#carer	**2.08***	**-2.80***	**-2.69***		**-4687.49***
	1.65, 2.63	-3.39, -2.21	-3.33, -2.05		-5218.19, -4156.79
Asian#carer	**2.40***	**-2.65***	**-3.20***		**-5050.22***
	1.44, 4.01	-4.17, -1.12	-4.50, -1.90		-6424.6, -3675.82
Black#carer	1.62 ns	0.97 ns	-1.64 ns		-1211.48 ns
	0.45, 5.87	-2.25, 4.19	-4.46, 1.18		-6560.77, 4137.82
Degree or higher#non-carer (ref)	-	-	-	-	-
Degree#carer	**1.64***	**-3.06***	**-2.23***		**-4006.08***
	1.22, 2.19	-3.74, -2.32	-3.11, -1.36		-4990.02, -3022.14
Lower qualifications#carer	**6.57***	**-3.03***	**-4.90***		**-11661.91***
	4.86, 8.87	-3.74, -2.32	-5.64, -4.16		-12007.48, -11316.33
Aged 75+#non-carer (ref)		-	-	-	
Aged 16-24#carer		**-8.31***	**12.64***	**3.26***	
		-10.72, -5.89	10.81, 14.47	2.32, 4.56	
Aged 25-44#carer		**-7.70***	**8.13***	**4.70***	
		-8.94, -6.46	6.88, 9.39	3.77, 5.87	
Aged 45-65#carer		**-5.40***	**3.87***	**3.15***	
		-6.40, -4.40	2.69, 5.05	2.58, 3.85	
Aged 66-74#carer		**-3.07***	**1.86***	**1.76***	
		-4.35, -1.79	0.28, 3.44	1.35, 2.30	
Aged 75+#carer		**-2.29***	-1.40 ns	**1.49***	
		-3.66, -0.92	-3.17, 0.38	1.11, 2.00	

*p <.05; ~ p=0.10; ns = non-significant. Controlling for carers' sex, ethnicity, health (LLTI), marital status, highest qualification, age at time 1 in analysis of employment status, and analysis of earnings from paid employment; controlling for carers' sex, ethnicity, marital status, highest qualification, housing tenure at time 1 in analysis of physical health score and mental health score; controlling for sex, health (LLTI), marital status, highest qualification in analysis of social isolation. Physical health score is Physical Component of the Short-Form 12 Health Survey (SF12 PCS; range 4.62-75.48); lower score = worse physical health. Mental health score is Mental Component of the Short-Form 12 Health Survey (SF12 MCS; range 0-75.38); lower score = worse mental health. (1) Under State Pension Age only.

Discussion

The effects of providing unpaid care at higher care hours or within the household on carers' employment, earnings, and mental health is well-established in the literature and our study findings concur. However, our study adds to that body of evidence by showing that gender, ethnicity, SES, and age interact with care provision to amplify these effects. That is, that care and context contribute to outcomes (as postulated by Pearlin's stress process model (Pearlin et al., 1990)) and that social determinants also influence carers' outcomes. A further contribution of our paper is the finding that care provision at higher hours or within the household was associated with poorer physical health or greater social isolation; outcomes which are much less studied. Interaction effects were seen here as well leading to greater impacts for some population sub-groups.

The interaction of being female and providing higher hours of care or providing care within the household was associated with impacts in all life domains under study with the exception of employment status. Previous research shows a greater negative impact for female carers on employment (Carmichael and Charles, 2003; Heitmueller and Inglis, 2007; King and Pickard, 2013; Van Houtven et al., 2013), although only the King and Pickard study takes account of care intensity. Our findings of an earnings penalty for female carers are consistent with the few other studies, most not in the UK context, which found differential earnings effects by gender (Keating et al., 2014). The effect of higher hours of care provision and co-resident caring on earnings is likely due to the fact that these types of care are associated with lower likelihood of being in paid employment and higher likelihood of working reduced hours and/or in lower paid jobs (Keating et al., 2014; Brimblecombe, Fernandez, et al., 2018a). This is exacerbated for female carers by the gender pay gap whereby women earn on average 15% less than men in the UK (Office for National Statistics, 2020a). The amplifying effect of the interaction may be due to female carers being more likely to reduce their paid employment hours and/or to take a less well-paid job (Keating et al., 2014). There is evidence that strategies with regards to managing employment and care differ by gender, with men more likely to organise care around their work and women their work around care (Auth et al., 2019).

The types of care provided also may vary by gender. Women provided higher hours of care in our study and may also provide more personal care. Whilst this is part of the caring context *per se*, it is also related to the unequal gendered nature of caring and to gender roles and is therefore currently inextricably, but not irrevocably, linked with gender. We also observed an interaction effect of being female and providing care on mental and physical health and on social isolation. The care effect is likely to be due to the mental and physical stresses and strains of providing high level or within-household care and reduced time to spend on social participation. The interaction effect may be due to gender roles, differential access to resources (Solar and Irwin, 2010), and to the complex relationship between gender roles and coping strategies, agency, and gender differences in self-care (Zygouri et al., 2021). A recent review found that female carers found it harder to maintain a sense of self-agency and ‘felt socially restricted in pursuing their interests, personal needs and career ambitions’ (Zygouri et al., 2021). As with employment, differences in the type of care may also play a part, in particular women providing more emotional care as well as higher hours.

For ethnicity, the picture was more complex. Being Asian and providing higher hours or within-household care had negative effects on health and on earnings. The effect on earnings may be due to a combination of the negative effect of caring on employment and on earnings, the ethnic pay gap, and different strategies and pressure with regards to the balance of care and work. The effect on health is consistent with ethnicity being a social determinant of health (Solar and Irwin, 2010; Marmot and Bell, 2012) and the effect of care provision on health. Ethnicity was not associated with differences in care hours provided but there may be other differences in type of care provision for Asian carers that may contribute to the outcomes seen. The findings for mental health and Black ethnicity were unexpected. Despite a wealth of existing evidence on ethnicity and health leading us to expect poorer outcomes for Black participants compared to White (Bignall et al., 2019), the findings for Black carers and mental health score were non-significant in our study. Black participants in the UKHLS sample overall had higher mental health scores than White participants, indicating better mental health. This may be due to methodological issues. There is higher attrition among minority ethnic participants, for example, although attrition in the sample is unrelated to health status (Lynn and Borkowska, 2018), and a higher proportion of missingness for the mental health variable. Black participants in our sample were younger on average than White participants and a higher proportion were female. However, neither of these help explain our finding because women, and younger people, had poorer mental health in our study. Black participants also had higher educational qualifications, which is associated with better mental health.

SES, as measured by highest educational qualification, was on its own and in intersection with care provision associated with negative impacts in every domain. Lower qualifications are associated with lower earnings and employment rates (Office for National Statistics, 2020b) and are a major determinant of health (Solar and Irwin, 2010; Marmot and Bell, 2012). The interaction effect of care provision and qualification on employment and earnings may also be because higher qualified carers are more likely to have flexible work practices or be able to negotiate them (Spiess and Schneider, 2003). A further possible reason for the interaction effect of care provision and SES on mental and physical health may be the role of choice. Theories of, and evidence on, role captivity, role strain, and choice suggest that reduced choice about taking on care responsibilities negatively impacts on carers' wellbeing (Al-Janabi et al., 2018). Lower qualified people may have fewer resources available to them and therefore fewer alternatives to providing that care themselves. The stress process model also sets out how the resources available to carers can increase or decrease the impacts of caring on wellbeing (Pearlin et al., 1990). The choices available to lower qualified carers are not just due to their lower financial and other resources. Choice is also delineated by cultural and familial expectations and these may vary by SES. Expectations about who provides care also vary by ethnicity and gender (della Giusta et al., 2009; Parveen et al., 2011). Greater role captivity may thus also be a contributor to the interaction effect for female and Asian carers both because of the pressure of societal expectations and because women and ethnic minorities are less likely to seek or receive care services and thus to have fewer alternatives to providing that care themselves (Greenwood et al., 2014; Zygouri et al., 2021).

The effects of age and the interplay between age and care provision were striking. The combination of age and caring responsibilities means that younger carers had much worse mental health than older carers whereas older carers had poorer physical health. The interaction effect may be linked to a combination of younger people's and carers' poorer mental health in general. However, it may also result in part from care provision among younger carers being particularly linked to lack of alternatives (Olsen, 2000) and from their fewer emotional, financial, and other resources to mediate the effects of providing care (Aldridge, 2018). Carers aged 25-44 had similarly poorer mental health. This may also be due to role strain and need to juggle competing commitments of work and childcare; such factors exacerbate the stresses of care provision (Pearlin et al., 1990). That caring exacerbates mental ill health among younger carers and physical ill health among older carers is a cause for concern and for action. In our study the odds of younger people expressing being lonely was higher than older people and the combined effect of care and age was seen most in younger age groups for both higher care hour carers and co-resident carers. Care provision at higher hours will reduce the time available for social participation. Stigma and fear of being judged, particularly among younger carers, may cause concerns about bringing people home and/or disconnection from their non-carer peers (Becker, F. and Becker, 2008; Joseph et al., 2020).

Thus caring on its own was, in our study, associated with poorer outcomes one year later, both in domains where a wealth of evidence has already shown this (employment and mental health) and in domains where there has been a research gap (physical health; social isolation). However, some carers were doubly disadvantaged. Structural disadvantage, role captivity, choice, alternatives and opportunities, and financial and other resources may help to explain why. Social determinants of health frameworks model how social determinants might contribute to health outcomes in several key ways. Some authors have argued that because of the extensive effects of care provision on health and wellbeing, unpaid caring should also be considered a social determinant, as part of living and working conditions (Spiers, Liddle, Stow, et al., 2021).

Our study has some limitations. Whilst a strength is that we look at the interaction between care responsibilities and individual social determinants of health, because of sample sizes and the difficulties of interpretation we were unable to look at further interaction between, for example, caring, gender, and ethnicity. Clearly there will be variation within these broad sub-groups and further research would benefit from exploring some of these intersections, as also pointed out by Hengelaar et al. in their 2021 review of intersectionality and unpaid care. Even within the broad sub-groups used, there are small sample sizes for some groups, another limitation. There are a number of other limitations to our study. The earnings variable only includes earnings from paid employment, thereby excluding people in self-employment (4.8% of the sample). We sought to address possible selection bias in a number of ways – our regression models considered care provision at time 1 and outcomes at time 2, controlling for a number of factors suggested from previous research as likely to be associated with providing care and with the outcomes under study (e.g. Marmot and Bell, 2012; Pickard et al., 2018). Cost estimates were based on two-part models which have been shown to be robust to endogenous selection (e.g. Drukker, 2017). However, there is still the potential for some selection bias. The analytical tools that are commonly used for addressing any further bias were not suitable for this analysis. For example, fixed effects models would not have enabled us to consider the effect of characteristics that tend to remain the same in both waves, such as ethnicity and gender. Propensity score matching has disadvantages for this study because it only allows for analysis of carers new to caring at time 1. Care hours are much lower in a sample matched like this, a disadvantage when exploring higher intensity caring. This, plus the shorter duration of care provision, makes the matched sub-sample substantially different from carers more generally as well as reducing the sample size. Furthermore, we were not seeking to investigate causality, rather how care provision and people's socio-demographic characteristics interacted to affect outcomes, how experiences differed, and who experienced poorer outcomes. Our study has strengths, in particular that it is based on analysis of longitudinal data for a large, nationally-representative sample. This means, for example, that we had sufficient data on provision of care at one time-point, socio-demographic characteristics, and a wide range of consequences one year later.

Conclusion

In conclusion, we found that caring responsibilities interact with socio-demographic factors to affect carers differentially in a number of life domains, leading to, and exacerbating, key disadvantages and inequalities. Our findings reinforce the need for differentiation of carer support. One clear example is the need for mental health support and prevention for younger carers and physical health support and prevention for older carers. One of the pathways by which social factors determine health and other outcomes is by ability to access health, long-term care, and other services (Solar and Irwin, 2010) and there is evidence of differential access to care services among carers and the people they support (García-Gómez et al., 2015; Ilinca et al., 2017; Floridi et al., 2021). Thus, a further implication is the need to reduce or remove barriers to support for sub-groups of carers, examples being through targeting and/or making changes to charging regimes and other barriers. Because caring responsibilities are a contributory factor to poorer outcomes, good and targeted support for carers including services for the person they care for has an important role to play. However, support for carers is just one part of what is needed. For example, for female or ethnic minority carers, the gender or ethnic pay gap may be as much of an issue as their care responsibilities. Future qualitative research might fruitfully explore in depth some of the reasons for the sub-group differences seen in our study.

Chapter 4

Paper 2. Inequalities in receipt of long-term care services by disabled or older people and co-resident carer dyads in England

A version of this paper was published as ‘Brimblecombe, N. (2022). Inequalities in receipt of long-term care services by disabled or older people and co-resident carer dyads in England, Journal of Poverty and Social Justice, 30(3), 268-286.’
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Abstract

Internationally, many care recipients and unpaid carers are not receiving the services they need to live full and independent lives, representing substantial social injustice. I explored unmet need and inequalities in receipt of long-term care services in England. Methods comprised in-depth interviews and secondary analysis of UK Household Longitudinal Study dyad data from 2017/2019. I found widespread unmet need for services overall and inequalities by sex, ethnicity, income, and area deprivation. Aspects of long-term care policy, service delivery, people’s material resources, and constrained and unconstrained choice all played a role.

Introduction

Access to social rights such as health and long-term care (LTC) services is an important part of social justice. Inequalities in access is a key social injustice, both in itself and in its implications for other social injustices such as poorer health or limited independence or opportunities (WHO, 2002). There is currently substantial under-access and inequalities in access to LTC services. This has been observed across Europe (e.g. Rodrigues et al., 2014; García-Gómez et al., 2015; Albertini and Pavolini, 2017; Floridi et al., 2021) and in China (Wang et al., 2020). Whilst less research has been carried out in the English context, inequalities in receipt of LTC services have been found to occur by type or level of care need, ethnicity, gender, and income (Vlachantoni et al., 2015; Burchardt et al., 2018). Despite this, and whilst provision of LTC has been increasingly highlighted in social policy, the issues of inequality and unmet need have got much less of a mention.

Investigating who does and who does not receive services enables us to understand access, and equality of access, to public service-related civil and social rights, key aspects of social inclusion (Schulmann et al., 2019). In many care situations, an unpaid carer is also involved. However, research to date has tended to overlook carers when investigating gaps and inequalities in care. My study aims to bring carers back into the picture both theoretically and empirically. In this dyadic approach, services directed at the care recipient are also seen as a service for carers (Rand and Malley, 2014). This is the approach taken by current policy in England – the 2014 Care Act. The Act aimed to more widely recognise and address unpaid carers' need for support, including through provision of services to the person they care for (House of Commons, 2014 paragraph 152).

Provision of LTC services, sometimes termed social care in England, is the responsibility of local authorities. There can be variation in adequacy of funding and in provision across those authorities (Cromarty, 2019; Fernandez et al., 2020; O'Rourke et al., 2021). Publicly-funded LTC services are allocated according to both care need and financial eligibility criteria (Her Majesty's Government, 2014a). Where care needs do not meet the criteria or financial means are above the threshold, LTC services might be privately purchased by individuals, or not received at all. My study focuses on co-resident carers, who make up approximately half of all unpaid carers in the UK (Petrie and Kirkup, 2018), provide the most intense care, and experience the greatest negative impacts (Brimblecombe et al., 2018). Services for one member of the dyad can therefore potentially be more impactful on the other than in extra-resident caring situations. Unmet need can be defined and measured in a number of ways

(Vlachantoni et al., 2011). My study includes both non-receipt of any LTC services for a particular need – a minimum or baseline measure – and a subjective definition which enables the inclusion of other, user-defined, aspects of need not being met by services.

Studies of LTC service provision, and some conceptualisations of unmet need for care, emphasise the role of wider factors including care policy, shifting the emphasis from individual or within-dyad factors alone (Vlachantoni et al., 2011, 2015; Kröger, 2022). This paper draws on insights from these approaches. The paper is further conceptually framed by Andersen's Behavioral Model Of Health Service Use (BMHSU; Andersen and Newman, 2005; Andersen et al., 2013). The BMHSU was originally developed to assess and understand inequalities in health care use, for which it has been widely used (Lederle et al., 2021). It has also been used, although to a lesser extent, in studies of LTC services (e.g. Travers et al., 2020; Floridi et al., 2021). My paper is informed both by research extending the model to the study of LTC service use and more recent iterations and adaptions of the model which most fully incorporate contextual as well as individual factors. These later versions and applications also explicitly include and explore constraints – both contextual and individual – on service use. These have been termed inhibiting and impeding factors (Lederle et al., 2021). The main components of the model used in my paper are, first, contextual factors including what Andersen et al. (2013) term 'predisposing' factors (demographic, social, and beliefs) and enabling/inhibiting factors (policy, financing, and organisation). Second, individual factors, both predisposing and enabling/inhibiting and including the role of choice (as used in expanded versions of the model e.g. Travers et al., 2020). This individual-structural framework was used to assess and better understand extent, inequalities, and contextual and individual determinants of unmet need for services for the carer-care recipient dyad. Specifically, I sought to answer the research questions: (i) what is the extent and nature of unmet need for LTC services for disabled adults or older people who receive some support from co-resident unpaid carers? (ii) what are the inequalities in unmet need for LTC services by care recipient and carer characteristics and circumstances? and (iii) what are the perceived contextual and individual mechanisms for unmet need for services? I also aim to contribute to the debate on how best to measure unmet need for services, including inequalities in unmet need.

Methods

The research design for this study takes a mixed-methods approach, informed by a critical realist ontology (Bhaskar, 1989). Each method answered different aspects of the research questions. Quantitative methods were used to investigate patterns, extent of and inequalities in non-receipt of LTC services (research questions 1 and 2). By necessity, this used non-receipt of services (compared to receipt of services) as the definition of unmet need for services. Non-receipt was as perceived by the care recipient. The qualitative methods enabled me to explore other definitions and perceptions of unmet need for services, and to bring in carers' perceptions. This meant I could include a more nuanced definition of unmet need, both non-receipt and other aspects such as appropriateness, adequacy, and quality (research question 1). The ability to explore the reasons underlying unmet need for services and so gain a fuller understanding of why some people were less likely to receive services than others (research question 3) was another contribution of the qualitative component. Further, this component allowed me to investigate unmet need for services among a wider range of carers and care recipients, enabling me to include working age disabled people and their carers, a population that is growing in size and policy and practice importance. Thus, the functions of the mixed-methods research design in this paper most closely align with offset, explanation and enhancement in Bryman's (2006) typology. 'Offset' recognises that each method has different strengths and weaknesses; combining them allows weaknesses to be offset and the strengths of each maximised. The explanatory function is that findings from one can help explain the other. Enhancement is a process whereby the findings from each method augment the other, contributing in different ways to result in a better overall picture of unmet need for services among co-resident unpaid carers.

Quantitative methods

This paper uses data from Wave 9 of the UK Household Longitudinal Study (UKHLS), a large-scale, nationally-representative dataset (University of Essex Institute for Social and Economic Research, 2019). Sampling for UKHLS is based on a proportionately stratified, clustered sample of addresses selected by postcode, supplemented by specific additional samples added at subsequent waves (Knies, 2017). Wave 9 (collected 2017/2019) is selected because it is the most recent wave to contain a module on LTC service use in addition to questions on unpaid care provision and participant characteristics and circumstances. I first paired care recipient and co-resident carer panel members at Wave 9. Care recipients were aged 65 or older; carers were aged 16 and older. I confined the sample for this analysis to England because of the different LTC funding and provision context across the devolved nations of the UK. The resultant sample size is 1,141 dyads for whom there is information on care need and LTC service receipt (or non-receipt) at Wave 9. Ethical approval for the

UKHLS was obtained by the University of Essex Ethics Committee, which has approved all data collection on the UKHLS main study and innovation panel waves.

Measures

I first identified who had care needs. Need for care was based on questions in UKHLS that asked the care recipient about ability to perform specific Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) and includes inability to perform these tasks or only being able to perform these tasks with help. ADLs and IADLs are measures of functional abilities, have good reliability and validity (Edwards, 1990), and have been used extensively in studies of care need (Vlachantoni, 2019). ADLs include ability to manage stairs, get around the house, get in and out of bed, cut toenails, bathe, use the toilet, feed oneself (including cutting up food), wash own face and hands, get dressed and undressed, and take the right amount of medicines at the right times. IADLs include ability to walk down the road, do the shopping, do housework or laundry, and do paperwork or pay bills. Some of the latter are related to broader needs such as social participation and isolation, others to mobility.

Receipt of LTC services was derived from questions asked of the care recipient about whether services were received for help with their ADL and/or IADL care needs. Services asked about and included in this measure are: Home careworker/Home help/Personal Assistant; Reablement/intermediate care; Occupational therapist/Physiotherapist/Nurse; Cleaner; Other. I look firstly at service receipt if a care recipient has eligible care needs under current LTC policy in England (the 2014 Care Act). This was conservatively operationalised as difficulties with three or more ADLs. Investigating eligible care need as set out in current English adult LTC policy enables an understanding of the extent to which care needs are being met by services according to those criteria. However, in recognition that current eligibility criteria have become increasingly restrictive in practice, I additionally looked at service receipt if a person has care needs below the policy-defined eligibility threshold, defined as difficulties with less than three ADLs. I also looked separately at service receipt for any IADL care need.

Factors under consideration for their possible association with non-receipt of services were informed by the BMHSU conceptual framework, previous research (Rodrigues et al., 2014, 2018; Vlachantoni et al., 2015; Brown and Sondaal, 2016; Ilinca et al., 2017), the qualitative findings, and ability to be relevant to, and actionable in, policy and practice. They were also determined by data availability. ‘Predisposing’ factors include the care recipient’s and carer’s sex (male or female), ethnicity (White or ethnic minority), and geographical location type (urban or rural). Enabling factors, both contextual and individual, included care recipient's income (continuous variable), and the dyad's housing tenure (owner-occupied, social-rented, or privately rented), and locality's Index of Multiple Deprivation (IMD) quintile. Indices of Multiple Deprivation are measures of relative deprivation at small local area level across England (Ministry of Housing Communities & Local Government, 2019).

Descriptive statistics – frequencies, range and mean – were used to report the characteristics of the sample and receipt of services to meet the three levels of care need (eligible need; sub-threshold ADL need; IADL need). Tests of association (Chi2 and t-tests of means) were used to establish statistical significance of associations between each individual and contextual characteristic (described above) and unmet need for services. The descriptive analysis used in this paper cannot, nor is intended to, identify causal processes but instead to indicate inequalities and extent of unmet need and so provide critical information for service providers and policy makers about who is and who is not receiving services. People have overlapping characteristics and thus any bivariate associations observed between, for example, ethnicity and unmet need for services could be explained by a combination of individual and contextual factors that make up the experiences and circumstances of being an ethnic minority carer or care recipient in England. Bivariate analysis enabled this complexity to be preserved, and inequalities and extent of unmet need to be described among the population as it exists in reality. However, in order to explore this further, where sample size allowed and preliminary analysis showed a link between characteristics, I carried out further exploratory analysis. Information on the reasons for inequalities in unmet need, and hence the potentially modifiable factors for policy and practice, were explored in the qualitative analysis.

Qualitative methods

One-to-one in-depth telephone interviews were carried out between February and May 2020 with 26 adult co-resident carers caring for adults aged 16 or older living in England. Within these criteria, sampling was purposive maximum variant (Patton, 2014) aiming to cover a range of experiences and circumstances. Recruitment took place through local and national carer and non-carer organisations and networks and from amongst the general public. This was in order to recruit people with caring responsibilities who identified as carers and those who did not, as well as to recruit a diverse interview sample. Participants were sent information sheets beforehand explaining the purpose and nature of the research; what taking part involved; the potential benefits, risks, and burdens; confidentiality and limits to confidentiality; anonymisation of data; and the voluntary nature of participation. Consent was discussed with participants before the interview began, taken verbally and recorded on a paper version of the consent form. Ethical approval for the interviews was granted by the Social Care Research Ethics Committee in October 2019 (Ref: 19/IEC08/0046). Interviews were semi-structured and followed a topic guide, structured around the research questions. Similarly to previous research (García-Gómez et al., 2015), the definition of unmet need for services in the interviews was based on questions that first ascertained if the carer perceived that the care recipient had care needs, and then reported not having received any or adequate LTC services to meet those needs. This enabled me to explore the nature as well as the extent of unmet need. I used probes as needed to explore aspects of perceived unmet need for LTC services (probes included affordability, availability, amount received, and so on). Further questions, and probes as needed, explored the reasons why some dyads were less likely to receive the services they needed than others. Probes included choice/preference, affordability, accessibility, availability, and suitability.

Interviews were audio-recorded with the interviewee's permission and transcribed in full. Analysis took place in NVivo. The overall approach to the qualitative analysis was thematic analysis (Braun and Clarke, 2006). Analysis started with familiarisation with the data and then proceeded as follows: generation of initial codes; review and adjustment of codes; collation of codes into potential themes; gathering of all data relevant to each potential theme; and review of themes including re-examining data for evidence related to the theme. Deductive reasoning was used to structure the initial themes around the research questions and informed by the literature and the conceptual framework (Andersen and Newman, 2005; Andersen et al., 2013) to include contextual and individual predisposing, enabling, and inhibiting/impeding factors. Codes were also developed in response to the data, resulting in an additional set of themes. When new codes were added, previously coded transcripts were revisited to consider the relevance of the new code. In order to further minimise analysis bias, NVivo was used to check for text that had not been coded to that theme, counter-examples, and exceptions.

Results

In the following section, I first describe the quantitative and qualitative samples. I then present the quantitative and qualitative findings on extent of, and inequalities in, unmet need for LTC services looking at (a) non-receipt of services for eligible care needs; (b) non-receipt of services for ineligible ADL care needs; (c) non-receipt of services for IADL care need; and (d) a wider conceptualisation of unmet need for services that includes non-receipt and care needs not being met by services in other ways such as adequacy of amount, or appropriateness to care needs. Third, I present qualitative findings on reasons for unmet need for services and why some people may be less likely to receive the services they need than others.

Samples

Table 5 shows that approximately half of the care recipients were male (47%) and half female (53%). Seventeen percent were from a minority ethnic group. The majority (83%) lived in owner-occupied housing, and just under a quarter (23%) lived in a rural geographical area. Participants came from all regions of England, covering a number of different local authority areas.

Table 5. Sample descriptives

N=1,141	**% (N)**
Care recipient is female	53.5 (610)
Carer is female	52.6 (600)
Care recipient is from ethnic minority background	16.7 (190)
Carer is from ethnic minority background	16.8 (192)
Dyad live in rural area	22.7 (259)
	Mean
Care recipient monthly income (£)	1256.69
Household housing tenure	**% (N)**
Owner-occupied	83.0 (930)
Social-rented	13.0 (145)
Private-rented	4.0 (45)
Index of Multiple Deprivation quintile	
1 (most deprived)	19.3 (216)
2	19.0 (213)
3	21.3 (239)
4	22.6 (253)
5 (least deprived)	17.8 (199)
Care recipient care need	**% (N)**
Care recipient has eligible care needs	28.3 (323)
Care recipient has sub-threshold ADL care needs	71.7 (818)
Care recipient has any IADL need	88.7 (1,007)
Service receipt	
Care recipient has eligible care needs and receives no services	69.0 (223)
Care recipient has sub-threshold ADL care needs and receives no services	69.3 (338)
Care recipient receives no services for IADL need	90.6 (910)

The interview sample comprised 26 unpaid carers. Six were male and twenty female; they were aged 19 to 85 with five being retired, nine full-time carers and/or stay at home parents, three unemployed and nine in full- or part-time employment. Seven described themselves as being minority ethnic, twelve as White, and the others did not say. Interviewees were from a wide range of socio-economic backgrounds and geographical areas and types (e.g. urban/rural) within England, again covering a number of different local authority areas. Eight provided spousal care, nine provided care for their parent, and nine for another adult relative.

Extent of unmet need for services

The majority of the dyads in my study experienced unmet need for LTC services whether looking at non-receipt of services or other aspects. In the survey data, two thirds of dyads where the care recipient had eligible care needs according to current care policy had unmet need for services. Figures were even higher for people with IADL needs (Table 5). In the qualitative data, 23 out of 26 interviewees reported unmet need for services. This included non-receipt (N=14) and services received but not meeting care needs (N=9). Other ways in which services reportedly did not meet care need included timing, amount, quality, and appropriateness to care needs and the way people wanted to live their lives.

Inequalities in unmet need for LTC services

In both the survey data and qualitative interviews, male care recipients were less likely to receive services for non-eligible care needs (

Table ***6***) and to experience other ways of services not meeting needs. Ethnic minority care recipients were less likely to receive services for non-eligible needs (survey data). Lack of appropriateness of services was also reported more often in interviews when the care recipient was from an ethnic minority. Exploring the association between ethnicity and non-receipt of services seen in the quantitative data further, whilst ethnic minority care recipients had significantly lower income than White care recipients, the association between ethnicity and unmet need for services still remained significant when controlling for income, suggesting that both income and ethnicity contribute to the inequality seen. Ethnic minority care recipients were more likely to live in areas with higher deprivation and, in this case, the association between ethnicity and unmet need for services was not significant when controlling for local area deprivation (IMD quintile).

Housing tenure was not significantly associated with non-receipt of services (survey data;

Table ***6***). There was an association between living in an urban area and non-receipt of services in the quantitative data, although in interviews people living in rural areas reported difficulties accessing appropriate services. In the quantitative analysis, unmet need for services for both eligible and non-eligible needs was highest amongst those living in the most deprived local areas.

Table 6. Composition of service recipients and non-recipients

	Care recipient has eligible care need		**Care recipient has non-eligible ADL need**		**Care recipient has IADL need**	
N=1,141	**No services received**	**Services received**	**No services received**	**Services received**	**No services received**	**Services received**
Male care recipient (%)	67.9 ns	32.1 ns	**74.8***	**25.2***	91.5 ns	8.5 ns
Female care recipient (%)	70.1 ns	29.9 ns	**65.3***	**34.7***	89.8 ns	10.2 ns
Male carer (%)	69.2 ns	30.8 ns	65.6 ns	34.4 ns	90.1 ns	9.9 ns
Female carer (%)	69.0 ns	31.0 ns	72.4 ns	27.6 ns	90.8 ns	9.2 ns
Ethnic minority care recipient (%)	75.4 ns	24.6 ns	**81.8***	**18.2***	92.8 ns	7.2 ns
White care recipient (%)	67.4 ns	32.6 ns	**67.7***	**32.3***	90.1 ns	9.9 ns
Ethnic minority carer (%)	73.4 ns	26.6 ns	77.6 ns	22.4 ns	92.5 ns	7.5 ns
White carer (%)	68.0 ns	32.0 ns	68.1 ns	31.9 ns	90.2 ns	9.8 ns
Dyad live in urban area (%)	**71.4~**	**28.6~**	71.1 ns	28.9	**91.9***	**8.1***
Dyad live in rural area (%)	**60.3~**	**39.7~**	63.1 ns	36.9	**85.9***	**14.1***
Care recipient monthly income (mean, £)	1453.64 ns	1286.09 ns	1219.75 ns	1103.02 ns	**1198.42***	**1660.46***
Owner-occupied housing (%)	66.7 ns	33.3 ns	70.6 ns	29.4 ns	90.4 ns	9.6 ns
Social-rented housing (%)	79.3 ns	20.7 ns	63.1 ns	36.9 ns	90.8 ns	9.2 ns
Private-rented housing (%)	81.8 ns	18.2 ns	70.0 ns	30.0 ns	90.0 ns	10.0 ns
IMD quintile 1 (most deprived)	**81.3***	**18.7***	**81.8***	**18.2***	93.6 ns	6.4 ns
IMD quintile 2	**77.1***	**22.9***	**65.6***	**34.4***	91.1 ns	8.9 ns
IMD quintile 3	**59.7***	**40.3***	**67.8***	**32.2***	92.0 ns	8.0 ns
IMD quintile 4	**62.9***	**37.1***	**73.2***	**26.8***	88.4 ns	11.6 ns

IMD quintile 5 (least deprived)	**57.8***	**42.2***	**60.0***	**40.0***	88.4 ns	11.6 ns

*= p <0.05; ~ = p<0.10. Statistically significant results in bold. IMD= Index of Multiple Deprivation

Reasons for unmet need for services

Using Andersen's (2013) BMHSU framework, the following section presents qualitative findings on mechanisms for unmet need for services (non-receipt and services not meeting needs in other ways). Themes were grouped under, first, contextual enabling and impeding determinants of unmet need for services (LTC policy, financing, and organisation including availability) and, second, individual determinants both enabling and impeding (financial and material circumstances/financing and affordability, and psychosocial factors such as the role of choice) (Travers et al., 2020).

Contextual enabling and impeding factors: LTC care policy, financing, and organisation

Eligibility

LTC policy determines what constitutes eligible level of care need. Not meeting those criteria was a reason for unmet need for services, in particular non-receipt:

> *C2. 'I think it's partially funding. And the criteria to get the kind of the care you need, you have to be desperate for it really, I think that's part of the issue.' (Carer for parent with long-term condition.)*

In many cases, eligibility was also decided on the basis of there being an unpaid carer, or potential carer, as well as care need:

> *C24. 'It just seemed like they were overloaded and because he had such a support system already, they don't really feel like he needs it, but I think he needs independent carers. I think he needs to have that in place.' (Carer for grandparent with dementia.)*

> *C18. '[Social services have] come to my home, seen where she was sleeping, spoke to her and really, we've not had much contact with them since. I think it was because I said I had [siblings] so they thought, well she's pretty much got it in hand. We do need this assessment for me and then I can put my side, because when they did [care recipient], they sort of didn't want to hear what I had to say.' (Carer for older relative with dementia.)*

Financial eligibility rules were also a factor. Under the current financing system in England, if services are not paid for by local councils, the cost of services falls to the care recipient, even if the service is intended to meet the carer's needs. As a result, carers were sometimes reluctant to accept these services:

> *C7. 'I won't take respite if it's at her expense because I don't think that's right.' (Carer for older relative with dementia.)*

Availability

Lack of availability was another contextual factor underlying unmet need for services. This was mentioned by the majority of the carers interviewed. Either the service needed did not exist at all:

> *C11. 'We have been to the local council with regards to help [supported employment], and they couldn't help in any way.' (Carer for adult child with autism.)*

> *C18. 'We have a nurse come in once a fortnight for the arthritis, but as for the dementia, nothing. There doesn't seem to be any support.' (Carer for older relative with dementia.)*

Or the support available did not appropriately meet the person's needs:

> *C23. 'There's a day centre that I know of that's not too far, but some of them are aimed at specific types of people. He is in his late fifties and a lot of the people at day centres, they're a bit older, seventy to eighty, that type of thing. He's still quite a young outgoing person, it's not that he wouldn't talk to elderly people, but it's just….It seems to be set up more for older people, so it puts slightly younger people off a bit.' (Carer for spouse with multiple long-term conditions and limited mobility.)*

Lack of availability also meant long waiting times, another reason why services were not being received:

> *C6. 'He hasn't been out since he lost his mobility. We have got a wheelchair but it's not suitable because there's such a long wait. I'm on a*

> *waiting list for one to be made for him, but there's a six months' waiting list to be seen.' (Carer for spouse with dementia.)*

> *C13. 'They tried to discourage me from that because of the waiting list, but to me, I preferred mum to go somewhere where she's going to get help and they kept coming in and discouraging me, and eventually I thought you know what, let me just take my mum home. I haven't got the energy for this, I'll just look after her at home. And that's what I did.' (Carer for parent with dementia and multiple long-term conditions.)*

National policy on LTC financing at local level also meant that people living in some areas were at higher risk of unmet need for services than those living in areas that had more funding for LTC services, as the following quote highlights:

> *C11. 'There's nothing – yeah, really bad. If you're a disabled person I'm afraid you are not looked after the way you should be looked after at all. There's just no support. And you have to fight for support. It's very difficult…They need more money… they're desperate for funding, for all sorts of things – infrastructure and what have you. It's a continual fight….' (Carer for adult child with autism.)*

Organisation

Organisation of LTC service delivery systems was another contextual determinant of unmet need for services. Sub-themes included working practices, fragmentation of systems, and relationships.

Fragmentation of LTC provision, such as multiple providers and agencies, meant it was difficult to find out about or access services:

> *C17. 'I just think there should be a way of checking in and that person can direct you to social services, direct you to mental maybe, or have like a referral. Because everything's just becoming more and more of a palaver. We wanted to get a walk-in bath, so we emailed the council and the palaver to get one, you've got to go through social services, they've got to come round and assess you. Then even if they do assess you, the council stick you on a list….Nothing's easy, everything's a drama. And then you think, do you know what? I can't be bothered. I'll give up because everything is such*

> *a pain.' (Carer for spouse with mental ill health and physical long-term conditions.)*

Quality of relationship between careworker and care recipient and carer was important to whether appropriate services were received. Care providers' working practices – in particular caseload and length of visits – affected ability to develop good relationships:

> *C23. 'It does make a big difference [whether it is the same people]. There's like a regular group that come fairly often that would know most of his requirements or the way he likes things…Some of them just sort of come in the door and run in and literally start straight away, they don't say, oh, good morning, how are you? Yeah, it's just taking a little bit of interest really. We don't blame any of them for rushing, we know they've got like eight [morning] calls to get through and they're leaving us at say, ten o'clock in the morning.' (Carer for spouse with multiple long-term conditions and limited mobility.)*

Working practices of care providers were a mechanism for how appropriately services met care needs. For example, a carer of their spouse with dementia explained how the careworkers could not come at the times needed because of the number of visits they had to do and the large area they covered.

Lack of specialist training for careworkers was a further systems factor that affected people with some health conditions, in particular advanced dementia, much more than others. The following quote illustrates how both these mechanisms resulted in no respite care for carer and care recipient:

> *C26. 'I wouldn't feel confident to put him in a home for respite…I don't think these care homes will be able to look after him. Because he's got advanced dementia and you need different techniques to feed him….Because I think many people at his advanced stage – many of them who go into care homes they will die within weeks. They're looking after so many people and so obviously he's not going to get the care that he needs….Carers aren't trained to look after people like my dad, with advanced dementia like his. They don't know what to look out for, they don't know about the dangers and all the little things they need to look out for.' (Carer for parent with dementia.)*

Individual enabling and impeding factors

Financial resources and affordability

Individual financial resources and affordability are, in the BMHSU, influenced and delineated by financing of LTC and care policy at a contextual level. In the survey analysis, people with lower income were less likely to receive services for IADL needs (Table 6). In interviews, financial resources and, relatedly, affordability were associated with other aspects of unmet need such as lack of appropriate services.

Cost of services and lack of financial resources acted as impeding factors. This meant less ability to circumvent the service package offered so either this offer was declined, resulting in non-receipt, or as in the following case, was accepted even though it was felt to be not adequately meeting needs:

> *C8. 'She goes to the day centre twice a week, she has to pay out half for that, so I'm not sure if [the council] would [pay half] for someone coming in [the dyad's preference]….She gets the DLA [Disability Living Allowance], but then she has to pay this money out, do you see what I mean?' (Carer for parent with dementia and physical health conditions.)*

Individual financial circumstances also interacted with contextual factors such as eligibility criteria:

> *C24. 'What he needed was more than what they were offering, than they could offer. So, we just said, we'll just handle it until it gets to a point that we can't…. I'm in the midst of fighting for that at the moment….Because of them denying us the social care we would have to pay for it, but we are looking to recruit some money together as a family and probably put him into a private care home and use some of what he's got and see how we can manage…so, it seems expensive, but I think we could manage it. [He has some savings but] not enough to put six months to a year.' (Carer for older relative with dementia.)*

Conversely, as can also be seen from the above example, having adequate financial resources enabled people to access services or services that better met their needs, at least in the short term. There were other examples of this in the interviews.

Role of choice

One reason for not receiving services was choice. This was a factor for about half the interviewees. In most of those cases choice was not the only factor. It interacted with, and was influenced by, enabling/impeding factors such as quality of care, and psychosocial factors such as (mis)trust of services:

> *C4. 'I think for me it's also trust. Obviously there are good services out there but I've heard some horror stories, and I just think if I'm capable of doing it I don't see why I should hand it over to a complete stranger.' (Carer for parent with long-term condition and problems with memory and mobility.)*

> *C13. 'I wouldn't have anybody take my mum out because my mum's mobility is poor. And I don't trust anybody.' (Carer for parent with dementia and multiple long-term conditions.)*

However, feelings of reciprocity and love also influenced choice about how care needs were met:

> *C21. 'She's my mother at the end of the day, she raised us, I just want to be able to give back what she gave to us.' (Carer for parent with problems with mobility and low mood.)*

> *C7. 'She cared for me and got me through tough times, so when it came to going into care I said look, if the family are happy, we will move in with her…I just didn't want her in a care home. No way. It's literally over my dead body would she go into care. I can't – no – and I love her. It's really blinking hard but I love her to bits.' (Carer for older relative with dementia.)*

Discussion

My study found a widespread gap between care needs and LTC service receipt among co-resident carers and care recipients in England, even when the care recipient had care needs that made them eligible for services under current policy. The majority of people with care needs did not receive any services at all. For those who did receive services, issues with quality, amount, and ability to appropriately meet care needs resulted in a further gap between care need and the extent to which needs were met by LTC services. There were inequalities in unmet need for services by sex, ethnicity, income, local area deprivation, and geographical type.

Using Andersen’s BMHSU and recent adaptions and additions to it, several themes were associated with the extent and inequalities in unmet need for LTC services seen in my study. Contextual determinants of service (non-)receipt included government policy on eligible care need and financial means. In conjunction with financing decisions and funding constraints, this meant a concentration on certain levels and types of care need, reflected in my finding of lower receipt of services for non-eligible care needs than for eligible care needs. However, in my study, people with care needs that fell outside the criteria defined in policy still had substantial limitations on their daily life when unsupported.

A further aspect of eligibility criteria is the extent to which the presence of an unpaid carer or potential carer is considered a criterion for providing, or not providing, LTC services. In current English policy, because a carer’s needs can be met or prevented by providing services to the person they care for, the presence of a carer is part of the criteria for receiving LTC services (House of Commons, 2014 paragraph 152). However, LTC policy in England also says that ‘local authorities are not required to meet any eligible needs which are being met by a carer’ (Her Majesty’s Government 2014: Section 6.115). This apparent contradiction may lie in the space whereby a carer is providing care but is not perceived as having needs as defined in the legislation, although in my study, where LTC services had been refused on the grounds of there being a *potential* family carer, the carers did appear to have eligible needs and/or risk of poorer outcomes. The contradiction may instead, or as well, lie with resource constraints. The extent to which a family member is expected to take on unpaid care may be influenced by highly-gendered societal expectations about who provides care, thus affecting some dyads more than others. In my interviews, the expectation came from the care practitioners carrying out care need assessments. However, expectations may also come from within the family and/or from the carer themselves (Broese van Groenou and de Boer, 2016). This ‘carer as resource’ approach by practitioners sometimes resulted in inadequate or inappropriate service provision, potentially impacting on both carer and care recipient, as well as equity issues. Expectation that a carer or potential carer will provide care without alternatives offered reduces choice. As reduced choice to provide care is associated with poorer carer outcomes (Al-Janabi et al., 2018), this is not without consequence.

Under-availability of LTC services – either any services or services that adequately met care need – also resulted in unmet need for services, both non-receipt and other mismatches between care need and LTC service provision. Availability is affected by, among other things, LTC financing policy. This includes overall amount, how that amount is raised, and the ways in which funding is allocated to individuals and across the country. In England, current policy on budget allocations to local government and the systems available for local government to raise additional funds to pay for LTC services has resulted in more deprived local authorities having larger shortfalls than less deprived areas (Foster, 2022) and potentially lower availability of services. This may help explain the study finding that local area deprivation was a key factor underlying inequality in non-receipt of services.

Individual financial resources were also associated with service use in my study. This was despite the likely redistributive effect of the financial means test. Research on unmet need for LTC in England has found similarly that means-tested public entitlements 'ameliorate but do not remove the increased risk among people in low-income households' (Burchardt et al., 2018, p. 1). The finding that ethnic minority care recipient-carer dyads were less likely to receive services for non-eligible needs, and less likely to receive services appropriate to their needs, is consistent with previous research on barriers to access of LTC (Moriarty, 2008; Greenwood et al., 2014). Lower material resources among some ethnic minorities in England, may mean that enabling and impeding factors such as availability and affordability are more pertinent for ethnic minority care recipient-carer dyads. My study also showed how lack of appropriate services, a particular barrier for ethnic minority care recipients (Greenwood et al., 2014), was exacerbated by lack of financial resources.

My study showed that choice may play a part in explaining lack of services. In some cases, this appeared to be an unconstrained choice and one that it is important to recognise and support. However, in this study, and in other research, choice was influenced and constrained by contextual factors related to LTC provision, in particular perceived quality, affordability, and acceptability of services (Yeandle and Buckner, 2007; Brimblecombe, Pickard, et al., 2018) For choice over service receipt to be completely unconstrained, appropriate and adequate services would need to be readily available. The carer would also need to not feel obligated to provide care for any other reasons, nor the care recipient to receive it.

Strengths and limitations

There are a number of limitations to the study. Service receipt in the quantitative analysis is derived from a question asked to care recipients about receipt of services to help with their

ADL and/or IADL care needs and therefore will not include services that the care recipient perceived as services for the carer rather than themselves. Some of the interviews took place during the COVID-19 lockdown measures in England which resulted in cessation or reduction in usual service provision for many people (Carers UK, 2020). Unmet need may therefore have been higher than pre-COVID-19. The survey data is limited to care recipients aged 65 and older and does not therefore include working age disabled people and the people caring for them. However, the interview sample expanded this to all adults with care needs and their co-resident adult carers, giving a broader view. Interviewees were recruited from a range of regions and hence a range of local authorities – a strength. However, as not all local authorities were covered, reasons for non-access may potentially differ among dyads from other authorities, although many of the reasons seen in my study are issues across the LTC sector as a whole (Association of Directors of Adult Social Services, 2019). My study focuses on co-resident carers only; extra-resident carers may have different experiences and factors associated with unmet need for services. Finally, because of small sample sizes for the quantitative analysis, some characteristics such as ethnicity have been treated as binary variables for the purposes of analysis. Clearly, these broad categories incorporate many different ethnicities and experiences and more nuanced inequalities in receipt of care services may therefore have been masked. The analysis thus lacks an intersectional approach and understanding. Future research could benefit from exploring intersectional associations with unmet need for LTC services.

Implications for policy, practice, and measurement

The extent of unmet need for services for care recipients and their co-resident carers shown in this study, and the inequalities observed, indicate failures within current care policy, and/or the ability to implement that policy in practice. Others have documented the swingeing cuts to LTC budgets in England which have increased the gap between care need and LTC service provision (Bottery and Babalola, 2020), a gap that disproportionately affects ethnic minority care recipient-carer dyads, those with lower financial resources, and those from more deprived areas. Whilst funding for care has recently been increased, this will not be by enough to close the gap nor ameliorate inequalities. Furthermore, this extra funding will be derived from a regressive taxation change, thereby entrenching wider inequalities in society (Simpson, 2021).

Amount of funding is, however, not the only concern; distribution of funds is also important. Attention could be given to a rethink of the care funding system at local level in England which has resulted in geographical inequalities in funding and availability and a mismatch between local funds and local needs (Foster, 2022). Some sub-groups of care recipients and carers, for example those from ethnic minorities, are more likely to live in deprived areas. This leads to further disadvantage with regards to access to social rights and gives further impetus to the need to equalise the situation geographically. Consideration should also be given to the nature and level of eligibility criteria. There are promising signs in the ongoing drive towards preventative services (House of Commons, 2014). However, lack of resources has somewhat hampered the preventative agenda in LTC (Association of Directors of Adult Social Services, 2019).

How unmet need for services is defined is a key question for policy and practice because those definitions determine who does and who does not receive publicly-funded care and who experiences the consequences. Eligibility criteria – the state definition of care need – change over time and vary across countries. With those changes comes a refocusing not only of what care need is but also what help should be provided and to whom. Definitions and measurements are also a key issue for data collection if we are to understand the extent of under-utilisation of care services and who is most disadvantaged (Vlachantoni, 2019). Who is or is not receiving services is a useful starting point as it illustrates extent and inequalities in receipt based on current eligibility criteria, and thus access, and equality of access, to civil and social rights (Schulmann et al., 2019). It is also useful to inform policy and practice action. However, receipt of services is not the only relevant aspect of having care needs met by services, and measuring this alone could underestimate the extent of unmet need and give an incomplete picture of inequalities in access to social rights. These other aspects of having care needs met by services are also important to individuals. Any measurement of met or unmet need for services should thus ideally include indications of appropriateness, acceptability, amount, and quality as well as receipt or otherwise.

Chapter 5

Paper 3. The consequences for unpaid carers of unmet need for long-term care services in England

The following chapter presents a version of a paper published as ‘Brimblecombe (2022). The consequences for unpaid carers of unmet need for long-term care services in England. *International Journal of Care and Caring*. doi.org/10.1332/.’

The paper below answers qualitatively the research question: What are the consequences of unmet need for social care services for unpaid carers and how do these vary? Initially, the plan was to write two papers to answer this research question, one based on secondary analysis of the quantitative data and one based on analysis of the qualitative interviews. However, preliminary analysis of the associations between consequences for unpaid carers and unmet need for services using the binary variable available in UKHLS (receipt of services for ADL or IADL care needs or non-receipt) illustrated the difficulties with using a quantitative approach to answer this research question. This binary measure has merits for looking at extent of unmet need (see also Paper 2), although is not currently sufficient on its own to fully do so. However, it is not fine grained enough to look at the relationship with carer outcomes because it does not take into account aspects such as type, adequacy, appropriateness or quality of services received. Thus a qualitative-only methodological approach was needed in this instance as the interviews did capture those aspects (see Paper 3 for more detail). The now-recurrent themes of what unmet need for care is and how to conceptualise and measure it, highlighted again by this preparation work for Paper 3, will be returned to in the thesis discussion.

Abstract

Under-provision of long-term care services for people with support needs may have consequences both for them and for their unpaid carers. Using in-depth interviews with 23 co-resident carers living in England, my study aimed to explore the impacts of unmet need on unpaid carers and how such impacts occur. Unmet need for services – services not being received or gaps between provision and need – had multidimensional impacts on carers. Key mechanisms were constrained opportunities through limited time or emotional resources, and constrained choices about whether and how to provide care and over multiple other aspects of their lives.

Introduction

How best to meet the care needs of the population has long been a societal and policy concern. With insufficient funding to adequately meet care needs, as in the UK currently, long-term care services may be restricted through both deliberate and unintended mechanisms. Recent evidence suggests that many people are not getting their care needs met, either at all (Institute of Fiscal Studies, 2017; Age UK, 2019), or by formal care services (Rodrigues et al., 2018), with evidence of inequalities in receipt of services by income and wealth (Vlachantoni et al., 2015; Ilinca et al., 2017). Despite substantial unmet need for services, little research has been carried out on the consequences, although population-level studies suggest higher mortality among care recipients as a result of unmet need for health or care services (Watkins et al., 2017). Care services for the person with care needs are often seen as simultaneously a service for the unpaid carer. This is the approach taken in English care policy (Her Majesty’s Government, 2014a); some studies of care services (Pickard, 2004; Rand and Malley, 2014); and this paper. In England, carers are entitled to an assessment of their own needs and as a result, services for the care recipient can be provided explicitly to meet the needs of the carer (Her Majesty’s Government, 2014a). Given the dyadic nature of the caring relationship, it might be expected that there would also be consequences for carers of unmet need for services, especially for co-resident carers who are the focus of my study. Co-resident carers make up approximately half of all unpaid carers in the UK (Petrie and Kirkup, 2018), provide the most intense care, and experience the greatest negative impacts of care provision (Brimblecombe, Fernandez, et al., 2018a).

Unmet need for care services, can be and often is conceptualised as lack of services to meet particular or any care needs (Vlachantoni, 2019). However, this is only part of the picture (Vlachantoni, 2019; Brimblecombe, 2022a). Gaps between care need and care provision can occur for other reasons and even when services are being received. Aspects such as adequacy, appropriateness, and quality are key parts of this type of unmet need. This paper thus conceptualises unmet need for services as formal care services for the person with care and support needs not adequately meeting their care needs whether because no services are received or because services received did not adequately meet care needs in other ways. With the notable exception of studies using multidimensional measures or approaches such as the Adult Social Care Outcome Toolkit for Carers (ASCOT-Carer) (Rand et al., 2020b), studies on outcomes for carers of unmet, or met, need for services, have tended to focus on single outcomes, usually carers’ employment (Heger, 2014; Geyer and Korfhage, 2015; Pickard et al., 2015). My study instead looks at multiple outcomes, both singly and in combination, and including the relationship between outcomes. Multidimensional approaches argue that to lead a flourishing life, a person should have the ability to achieve positive outcomes in several domains that are important to them (Sen, 1985a). This is the stance of long-term care policy in England that aims to support unpaid carers (Her Majesty's Government, 2014a)

My study investigates whether, and in what ways, unmet need for services constrains the freedoms carers have to achieve positive outcomes in multiple aspects of their lives, including their preferred outcomes or agency goals (Sen, 2009). I use a conceptual framework that includes three key elements: a multidimensional approach to outcomes and the interplay between them (Sen, 1985a; Hrast et al., 2013); choice and constraints (Sen, 1985a; Al-Janabi et al., 2018); and the dialectical relationship between individual and structural factors that frame choice and opportunities and thus the complexities inherent in expressed choice (Sen, 1992; Abel and Frohlich, 2012; Robeyns, 2016). This last has much in common with a social determinants of health approach (Dahlgren and Whitehead, 1991; Solar and Irwin, 2010).

Using qualitative methods, my study aimed to explore (a) the effects on co-resident carers in multiple domains of their lives of unmet need for services; and (b) the ways by which any effects occur.

Methods and sample

One-to-one in-depth semi-structured interviews were carried out between February and May 2020. The inclusion criteria were adult co-resident carers caring for adults aged 16 or older living in England. Sampling was purposive maximum variant (Patton, 2014), aiming to cover a range of carer experiences and circumstances. The selection criteria did not include whether the participant experienced unmet need for services or not. This was because, firstly, I did not want to impose a particular and maybe restrictive definition *a priori*, but rather wanted to explore the nuances of unmet need in the interviews. Secondly, I wanted to include people who perceived that their need for services was met. Recruitment took place through local and national carer organisations and networks and from among the general public, the latter through a specialist research recruitment agency. In both cases, I used phrases such as 'do you help support an adult with long-term physical or mental ill health, disability, or other difficulties?' as well as 'carer'. This was in order to recruit people with caring responsibilities who identified as carers and those who did not, as well as to recruit a diverse interview sample. Participants were sent information about the purpose and nature of the research; what taking part involved; the potential benefits, risks, and burdens; confidentiality and limits to confidentiality; anonymisation of data; and the voluntary nature of participation. Consent was discussed with participants before the interview began and taken verbally and recorded in writing. Ethical approval for conducting the interviews was granted by the Social Care Research Ethics Committee in October 2019 (Ref: 19/IEC08/0046).

The interview sample comprised 26 unpaid carers. Six were male and twenty female; they were aged 19 to 85: five were retired; seven described themselves as full-time carers; three were unemployed; and nine were in full- or part-time paid employment. Seven described their ethnicity as Black or Asian, twelve as White British, and seven did not specify. Interviewees were from a wide range of socio-economic backgrounds and geographical areas, including both urban and rural. Eight provided spousal care, nine provided care for their parent, and nine for another adult relative. Care needs included dementia, long-term conditions, mental ill health, learning disability, autism, and mobility difficulties. Multi- or co-morbidity was common. All were main carers, 14 were sole carers, three had regular input from other unpaid carers, and a further nine had very occasional input. Twenty-three of the twenty-six experienced unmet need for services: either services were not received (N=14) or, in the view of the carer, there were gaps between services received and the care need of the person they cared for (N=9). The analysis below includes the sub-sample (N=23) with unmet needs for services only.

Unmet need for services was defined in this research as long-term care services not adequately meeting the care needs of the care recipient in the subjective view of the carer. This could be because no services were received at all or because of a mismatch between services received and care need. Subjective unmet need is well-used in studies of unmet need and/or inequity in formal care (Hernández-Quevedo et al., 2010; García-Gómez et al., 2015); the definition used in this analysis was based on questions that first ascertained if the carer perceived that the person they cared for had care needs, and then reported not having received any or adequate services to meet those needs. Asking about subjective unmet need enabled me to explore experiences, preferences, and choices as well as access. If the carer perceived unmet need for services, I explored any effects this had on their lives, with probes covering several life domains established from other multidimensional outcome frameworks (Rand et al., 2012; McKnight et al., 2019) including health and wellbeing; employment or education; social and community participation, isolation, and personal and family relationships; financial impacts; and preferred outcomes. I also explored reasons for care needs not being (fully) met by services with probes including affordability, availability, choice, and preference of both carer and person with care and support needs.

In March 2020, public health measures to contain the spread of COVID-19 were implemented across England (Her Majesty's Government, 2020). These measures included closure of long-term care services provided by the private, public, and voluntary sectors and the 'relaxation' of existing legal duties around the provision of care and support (Department of Health & Social Care, 2020). Concerns about exposure to risk of infection from paid careworkers, compounded by absence of infection protection equipment for those workers, was an additional reason for cessation of usual care services (Carers UK, 2020; Giebel et al., 2020). Nineteen carers were interviewed during the COVID-19 period and seven before. This enabled me to explore cases of unmet need for services pre-COVID-19 and newly unmet need for services during the pandemic. In the interviews conducted during COVID-19 measures, participants were asked separately about pre-existing and newly unmet need for services. The analysis also differentiated these.

All but one interview took place by telephone. All were audio-recorded with the interviewee's permission and transcribed in full. Thematic analysis, aided by NVivo 12 software (QSR International Pty Ltd., 2018), aimed to identify, analyse, report, and interpret patterns of meaning within the data (Braun and Clarke, 2006, 2019). Analysis began with the researcher familiarising themselves with the data and generating initial codes. Codes were collated into themes, and themes were re-examined and recoded to reflect developing interpretations of the data and to check for counter-examples and exceptions. The analysis began deductively, with initial themes and codes structured around the research questions and informed by the literature and the conceptual framework described above. Codes and themes were also drawn inductively from the data and, in an iterative process, transcripts were recoded to reflect newly-generated codes and themes.

In presenting the results below, I use pseudonyms and have further anonymised the results by removing potentially identifying information.

Results

Consequences of unmet need for services

This section reports on consequences for carers of unmet need for services, both the effect of withdrawal of services during COVID-19 restrictions and non-receipt of services that predated those restrictions. Unmet need includes both no services and services that did not meet care needs in other ways, because of a mismatch between the amount, type, or quality of services and care needs. For some outcomes, I looked only at effects pre-COVID-19. For example, restrictions on social participation for the entire population during COVID-19 measures meant it was not possible to differentiate the effects of newly unmet need for services on social participation. One consequence was a negative effect on the relationship between carer and care recipient. A common theme was that the relationship had been strained and had changed from the relationship they had previously and which the carer very much wanted to regain. This was seen with both new and existing unmet need for services, as shown below in the presentation of findings on choice and on relationship with the person with care needs.

Twenty of the twenty-three interviewees with unmet need for services expressed an impact on their social and community participation and ability to develop or maintain social, personal, and family relationships. The following comments all pertained to pre-pandemic times; social and community participation was curtailed during COVID-19 lockdown measures so it is difficult to disentangle the effects of lack of services. Pre-pandemic, lack of services and the need to provide alternative provision meant that carers had less time to spend with friends and family, and in some cases, were unable to leave the house to participate socially or in the community. The following comments illustrate both aspects:

> *Daisy: 'Well, I don't go out – I haven't been out for a few years now – cos you don't, because you just worry that if somebody needs you, then you can't do anything. There's nothing there really – there's no back-up for me. So, no, I don't go out. I don't really do anything to be honest. I'm just in limbo. Your life's just put on hold.' (Provided care for adult son/daughter; no care services received.)*

> *Diane: 'I could do with a bit more time with my friends and work colleagues….There are certain things I just don't do….Because I thought, well, you know, what if he needs me?' (Provided care for parent; no care services received.)*

For Carol, the situation had improved slightly since formal care was provided:

> *Carol: 'I sometimes have been very stuck at home, unable to get out with insufficient help. You know, I can't leave him. That has eased a bit this year*

> *[now we have got care visits]. I think it had become so difficult one way and another, it was obvious that I needed more help.' (Provided care for partner receiving paid careworker visits and attending a day centre, but in need of more support/services.)*

In the absence of (sufficient) services, carers prioritised supporting the person with care needs, often at the expense of other family members or friends. This was not by choice. More services would mean ability to spend more time with young children and prioritise their needs:

> *Paula: 'The kids can have their bit of time, without everything aimed at [care recipient] all the time. Because they must feel a bit pushed out, I know they do, it's like the whole world's been turned upside down.' (Provided care for other relative and provided with a short break service once a month; needed more short breaks and regular home care; interviewed during COVID-19.)*

Unmet need for services negatively affected participation in leisure activities, accessing community resources, and community participation. Leisure and community services were closed during COVID-19 measures in England, and restrictions placed on movement and social interaction. Therefore, analysis on the relationship between unmet need for services and community participation was restricted to interviews carried out pre-COVID-19. The following comment illustrates this relationship:

> *Chu: 'I'm just confined to the house, that's the biggest thing....Because before, when I had [services], I could ask them to do overtime. So, for example, if I had something in the evening, if I'm meeting up with somebody or if I have a class or something, I can ask them to come and sit during those hours and they would do that.' (Provided care for parent who received two care visits a day; perceived need for more visits, more specialist carers, and some short breaks.)*

Lack of community participation potentially had impacts on the community itself as well as the carer. A number of carers interviewed ran community groups and/or supported others in the community. They reported being less able to do this because of the time spent providing care, and reduced ability to prioritise community participation and/or their own needs.

Attending to their own needs and time for themselves was a theme expressed by a majority of carers in my study.

Unmet need for services had also led to stress, tiredness, and negative effects on wellbeing and mental health. This was evident in cases of newly unmet need as a result of COVID-19 lockdown measures:

> *Carol: 'What has been quite difficult, particularly for me, is he was going to a day centre, five days a week. This is an absolute godsend really. They run it beautifully, it's all kind and lovely, and he really enjoys it down there. He likes getting in the bus and going off with his mates – just like going to work….I can't [have a break] now, it's a little bit trying at the moment really.' (Provided care for partner who had careworker visits and attended day centre pre-COVID-19. Both had halted during the pandemic.)*

Stress, tiredness, mental health and wellbeing were also experienced by carers reporting ongoing, pre-COVID-19 unmet need. Stress and tiredness, including exhaustion, were recurrent themes:

> *Becky: 'I think respite wouldn't be a bad thing for us….It's quite frustrating at times, very stressful. And it can be quite hard to focus on, like uni work and that sort of thing….Outside help wise, the main thing is potentially getting a bit more respite for us, so that then, obviously, we can be better carers in the way of, we have that kind of stress release, so that we don't get so stressed at home and stuff.' (Provided care for parent; no care services received.)*

In the absence of alternatives, Paula was providing more care for an older relative than she wanted or felt able to and described how she was not coping:

> *Paula: 'I'm tired all the time. Just run ragged to be honest with you….It's just really hard. Really hard. It's been one of the hardest things I've done in my life.' (Carer for other relative who attended short breaks once a month; needed more short breaks and regular home care; interview conducted during COVID-19.)*

Chu's situation also exemplified how even when services were received, inappropriate or poor quality services could affect a carer's health and exacerbate existing health issues:

> *Chu: 'It's the stress and frustration that cause me shortness of breath….Because I suffer from anxiety as well, so the more I wait [for the careworkers] the more anxious I get.'* (Provided care for parent who received two care visits a day; needed more visits, more reliable and specialist trained careworkers, and some short breaks; interview conducted pre-COVID-19.)

Impacts on health could be cumulative. Gillian had increasingly been providing more care hours and personal care than she wanted or felt able to, as a direct result of no services being received by the person she supported. This had been a long-term situation and her grandparent's care needs had increased over that period:

> *Gillian: 'I care, and I've cared for all these years. I'm knackered….It impacts my health I presume because I'm shattered….It's back-breaking, my shoulder and my back hurt, because she leans on me really heavily.'* (Provided care for grandparent; no care services received; interviewed pre-COVID-19.)

Carers' paid employment, voluntary work, or education was also affected by services not being received or care needs being unmet because services received were, for example, of insufficient amount and/or inappropriate to needs. Carers reported leaving their employment or taking early retirement; not being able to start or return to work; not working as many hours as they wanted or needed to; and restrictions on their type of job, employer, or educational establishment. Some carers who had to give up work when they started caring were struggling to return to work, even when care needs were met well enough by services for that to happen.

Leaving work, restrictions on paid employment hours or type of job, and being unable to return to work had financial implications, both for regular income, and for wealth accumulation such as savings and pensions. Kate stopped work when the person she cared for had no services. This impacted on her savings. Although some services were subsequently received, and Kate returned to paid employment, she had been unable to recoup her savings. In part this was because her ongoing caring responsibilities meant she could not pursue options for better paid work:

> *Kate: 'So I stopped work for two years. I lived off my savings. I did ask — there was something called direct payments that you could get to look after*

> *a loved one, but they wouldn't give me it and I thought, oh, I'm not going to argue. So, yeah, all my finances went. I was broke. I didn't want to [claim state benefits] — my pride.…My savings have never come back….I feel really cheesed off because that would have really helped me.' (Provided care for parent who received some home care visits; needed more support, but unable to find appropriate services; interviewed pre-COVID-19.)*

Impacts on employment as a result of services being withdrawn during COVID-19 were less reported by carers in my study. This may be because when the interviews took place, COVID-related cessation of services had only been in place for a few months and any detrimental employment effects usually occur over longer timeframes than that (Arksey & Glendinning, 2008). However, the ability to balance work and care was also related to an increase in flexible working and working from home during COVID-19 experienced by some carers in my study (and in other surveys during COVID-19 (Bennett et al., 2020; Carers UK, 2020)). Some carers also were on paid temporary leave of absence due to a UK government furlong scheme, paid at 80% of wages, during the COVID-19 pandemic. This did, however, bring its own strains: not being at work increased social isolation and removed an important source of respite from caring.

Carers experienced outcomes in a number of life domains as described above. All but one carer experienced impacts in multiple domains. Theoretically, there are two main ways in which unmet need could impact the multiple areas of carers' lives. One is the process of trade-offs, whereby (in the absence of adequate services) carers may prioritise, or have to prioritise, good outcomes in one life domain to the detriment of another. This may be an active and deliberate strategy, for example a carer making a choice, among the limited options available, to take a different job or educational route to preserve their health and energy. The following comment provides one example:

> *Becky: '[Studying at home] is partially from wanting to stay at home to be able to carry on helping out, because I know that if I were to be going back and forth to [university in another city] every day, I wouldn't have the good health left in me to carry on with my caring role.' (Provided care for parent; no care services received; interviewed pre-COVID-19.)*

However, in my study, the main driver of a gain in one area but a penalty in another was lack of choice. Unmet need for services meant Kate had to provide more care than she wanted.

However, as she wanted and needed to be in paid employment, she had to prioritise this at a cost to her health:

> *Kate. 'That's me, caring responsibility and work, have to keep going….That's the main – exhaustion….I'm physically exhausted.' (Provided care for parent receiving some home care visits; needed more but unable to find appropriate services; interviewed pre-COVID-19.)*

Some carers maintained paid work at the expense of personal relationships and social interaction. However, being in paid work could partly ameliorate these negative effects by reducing social isolation. Ursula's social participation was affected because no services were received outside her working hours, but services received during her working hours enabled her to work, reducing her social isolation:

> *Ursula: 'For me, working has always been a really important part of balancing the caring responsibilities with everything else. Much as there are lots of things I'd like to get involved in and do, that I can't do, working is also what prevents me, I think, from becoming much more isolated than I would otherwise be.' (Provided care for adult son/daughter; interviewed pre-COVID-19.)*

Unmet need for services could simultaneously have a negative impact on multiple domains in a carer's life, however. I saw both multiple impacts and trade-offs in my study. For example, in order to remain in employment, carers had to make decisions to stay in, or change to, a less well-paid job that fitted better around caring, with implications for income, pensions and savings:

> *Daisy: 'I've had to adapt my work. I've had to leave a job to go into another job to do other [part-time] hours…because I can't leave for too long, and I can't be away. So now I work an hour and three quarters every day, to try and fit everything in.' This had affected her income. (Provided care for adult son/daughter; no care services received; interviewed pre-COVID-19.)*

Not working could either increase opportunities for social activities in my study – a trade-off – or increase isolation because of non-interaction with work colleagues – a combination. Vivian, for example, described how, before services were provided, she had to leave a job she really enjoyed when her husband's needs increased. This had left her feeling isolated: '*You* *don't really see other people, just to have a chat to or anything really, it does make a difference.'* Being in employment helped her feel less isolated. Multiple impacts such as this were the most common experience in my study: lack of services led to impacts on work, finances, personal relationships, social participation, and mental health, stress, and/or tiredness. As one carer put it, '*you miss out on life really'*.

Mechanisms

There were a number of ways by which unmet need for services led to poorer outcomes, within an overarching theme of constrained choices and opportunities. One mechanism for poorer outcomes was an increase, or no reduction, in unpaid care provided. In the absence of appropriate, adequate, or any services, carers had to, or opted to, step into the gap. Providing a high level of care (for example, higher care hours) constrained choices and opportunities for employment and social participation by reducing the time carers had available to spend on these activities. Over and above hours of care provided, and a key mechanism, was the experience of 'constancy': the unrelenting nature, both practical and emotional, of caring when no services were provided. This mechanism mainly affected health and wellbeing, and in the study was seen during COVID-19 pandemic withdrawal of services:

> *Heidi: 'She goes to the day centre twice a week…but of course that's not happening now [because the day centre is closed]….It gives us both a break from each other.' (Provided care for parent who attended day centre twice a week pre-COVID-19 and needed more services; no services received during COVID-19.)*

> *Florence: 'It's the constant, it's the constant, you know, you can't park it.' (Provided care for partner, usual care visits at home withdrawn during COVID-19. Even pre-COVID-19, needed more, differently-timed care visits and additional services).*

Non-receipt of services, the ensuing constancy and impact of that on wellbeing was a theme pre-COVID-19 as well:

> *Sade: 'I think more support for him would support me. I'm in the middle, but the real person is more him, because the more I get for him, the more relief I'll get for myself.' (Provided care for parent; no care services received.)*

Restricted choices over receipt or non-receipt of services, as well as other aspects like amount and type received and, relatedly, restricted choices over extent of unpaid care provided, appeared to be a key mechanism for some negative outcomes, in particular mental health and wellbeing. Analysis of the associations between sub-themes (outcomes and mechanisms) showed that when lack of services was not by choice carers experienced greater impacts in some domains. For example, all carers for whom lack of services was not by choice reported feeling socially isolated, whereas no carer for whom lack of services was by choice did so. Similarly, the majority of carers who reported lack of choice also reported mental health impacts. Among those who perceived there was a choice, the minority reported these impacts.

The following comments illustrate the relationship between lack of choice and impacts on the carer. Heidi had moved in to her mother's home to provide care. Her mother did not have enough services to meet her care needs. Heidi explained how this had been detrimental to their relationship and that she would like more services for her mother so she could move out again:

> *Heidi: 'I would like to, definitely. It's for my mental health as well and for our relationship as mother and daughter. I said to the doctor, "That's pretty much gone, as mother and daughter, it ruined that.''' (Provided care for parent who attended day centre twice a week pre-COVID-19 and needed more services; no services received during COVID-19.)*

Lack of choice over hours or type of unpaid care provided, and received, negatively affected the caring relationship:

> *Gillian: 'I've just recently started looking into someone coming in…because I don't want to ruin my grandmother/granddaughter relationship. I want to keep that….She sometimes gets upset that I'm around and that would disassociate me from those parts of the job. It means that I can go back to companionship, love, getting her meals, eating with her. It's becoming that thing where the personal care is affecting the relationship between us….She's my grandmother, I need to just be her granddaughter, and I shouldn't be doing those things.' (Provided care for grandparent; no care services received; interviewed pre-COVID-19.)*

Analysis of associations between sub-themes further suggested that newly unmet need that was not by choice was particularly detrimental to caring relationships, and to the carer's mental health, wellbeing, and feelings of isolation (as shown, for example, in Carol's comments above). Carers' expressed choice over unmet need for services varied from constrained, through partially constrained, to completely unconstrained. A common theme expressed by carers was that they wanted, or were willing, to provide some types or levels of care, but wanted other care needs to be met by paid careworkers.

In other cases, carers freely chose not to seek services and to provide care themselves:

> *Irene: 'We've just got into our own routine and I just look after him, and to be truthful, nobody's ever offered it to him.' When asked if her partner needed support from external agencies, Irene replied, 'No, we're okay. We've got into a routine and it all sort of works for us, you know?' (Provided care for partner; no care services received.)*

Lack of services could result in an increase, or no improvement, in care need. This was reported as a result of newly unmet need during COVID-19 measures: deterioration in the health of the person with care needs led to short-term increases in unpaid care with implications for the longer term, for both unpaid and/or formal care provision:

> *Heidi: 'Well, she likes it all [the day centre], and I'm noticing already, because that's only been a week, you know, and I'm noticing her mood's gone down already.' (Provided care for parent who attended day centre twice a week pre-COVID-19 and needed more services; no services received during COVID-19.)*

Lack of services could also have direct emotional effects on the carer, for example because of experiencing the person they cared having their needs unmet, or inappropriately met, and/or because of the stress of trying to get adequate and appropriate services. Some carers were happy with the level of care they provided but felt additional or different support from formal services would benefit the person they cared for.

Discussion

My study found that unmet need for services – services not adequately meeting care needs – was associated with impacts on carers in a number of life domains: paid and voluntary employment; health; social and family relationships; social and community participation; and leisure activities. This is consistent with previous research in the United States which found effects of unmet need for services on work, depressive symptoms, and social isolation (Robison et al., 2009), and in Switzerland which found effects on health, social participation, and social relationships (Tough et al., 2019). My study shows that impacts on carers resulted from newly unmet need for services, brought about by COVID-19 restrictions in the UK, and ongoing, or previous, unmet need. Even when services were received and need met, effects of previously unmet need, such as difficulty returning to work, ill health, and financial impacts, continued in some cases, showing the importance of early intervention and prevention in long-term care delivery for carers as well as for people with care and support needs. Care recipient and carer needs change over time, in response to changing health and individual, family, and wider circumstances and external societal forces (Henwood et al., 2017). Prevention and early intervention therefore needs to be an ongoing process.

Newly unmet need appeared to be more detrimental than ongoing unmet need for some outcomes; however, duration of unmet need may also have played a part and/or be more important for other outcomes (Hirst, 2004; Vlachantoni et al., 2013). The effect of newly unmet need for care services suggests the presence of ‘conditioned expectations’ or ‘adaptive preferences.’ This is where people adapt their preferences to their material, social, and cultural circumstances (Sen, 1985b; Nussbaum, 2001). Applying this concept to my findings, lack of adequate or any services might, over time, lead carers to adjust their preferences in order to make their situation more psychologically bearable (Sen, 1985a; Au et al., 2010). For newly unmet need, that process has not (yet) happened.

Unmet need for care services constrained carers’ choices and opportunities if they provided that care themselves instead by reducing the time they had available to spend on other activities (such as employment) and/or diverting their emotional resources through a shift in priorities, including away from the carer’s own health and other needs (see also Rand et al., 2020a). The needs of the person cared for often had to take priority over the carer’s preferred outcomes (or in Sen’s terminology, agency goals) such as spending time with other family members or friends (Sen, 1985c). Self-actualisation goals – social interaction, relationships, leisure and community activities, and time for their own needs – were important to carers. Most carers in my study experienced constraints to choice and opportunities in multiple domains. This has implications for long-term care practice. In particular, support for carers may need to come from multiple agencies and incorporate both prevention and mitigation of negative outcomes.

One way in which formal care services could help prevent negative outcomes for carers is by improving outcomes for those they care for. There is potential for services and other support to prevent care needs from increasing and/or to assist people with support needs to live more full and independent lives, both with and without the unpaid carer. Better services are not the only solution, however. Disabling structures and attitudes in society affect disabled people (e.g. Oliver and Barnes, 2012; Hackett et al., 2020) and their unpaid carers (Aldridge and Becker, 1999; Dowling and Dolan, 2001). Wider inclusion and anti-discrimination strategies could have additional positive dyadic effects.

Lack of choice over whether or not services were received was associated with greater negative impacts on carers' mental health, relationships with the people they cared for, and social connectedness. In this study, choice in receiving services was less of a factor for employment and financial outcomes – whether by choice or not, lack of formal care meant carers were less able to pursue paid employment or voluntary work. The extent to which people have chosen to take on caring responsibilities in the first place and the extent to which they have chosen to take them on at that intensity or type has also been shown to affect carer wellbeing (Brouwer et al., 2005; Schulz et al., 2012; Al-Janabi et al., 2018). Lack of choice over type and levels of care provided can also impact detrimentally on the caring relationships (Lawrence et al., 1998).

While perception of choice is affected by the objective care situation (level of care needed or intensity of care provision, for example), it is additional to it (e.g. Del Pino-Casado et al., 2019) and thus operates as an independent risk factor for poorer outcomes (Schulz et al., 2012). In my study, as in others, perceived choice, and the meaning a person attached to their objective caring situation, were important explanatory factors for carers' mental health, wellbeing, and personal and social relationships. There are two key implications of my findings for policy and practice. One is that impacts on carers are not only related to the care they provide: lack of choice and lack of alternative care options is an important and independent contributor to poorer outcomes for carers. Carers therefore need to be given choice whether to provide all, some, or no care through improved access to alternative care provision that is readily available and of good quality. Where lack of services is by choice, policies are still needed to mitigate any ensuing effects of caring on the carer's current and/or future employment and finances. This might include (re)training, flexible working conditions, better short- and long-term financial protection, and/or more flexibility in welfare benefit provision, including carer-specific welfare benefits.

The role of choice over receipt of services in outcomes for carers in my study also raises the question of whether need for services can be said to be ‘unmet’ if not accessing services is by choice, or if a more nuanced definition and approach to unmet need is required. Gibson and colleagues, for example, argue that knowing about a care need but choosing not to seek services should be treated as categorically different from ‘not chosen’ unmet need for services (Gibson et al., 2019). In deprivation research more widely, ‘simple lack’ – people not having a necessary item whether they want it or not – is differentiated from ‘enforced lack’, wanting an item but being unable to obtain it, either through lack of availability or affordability (Mack and Lansley, 1985; Guio et al., 2016). Two important points should be borne in mind, however, in drawing any conclusions about implications for formal care and measurement of unmet need. First, the complexities of people’s situations means they may simultaneously experience ‘enforced’ and ‘unenforced’ lack of services: people may have a degree of choice over some aspects but not others. Second, there are a number of structural and individual reasons why people do not receive services including eligibility, affordability, availability, and acceptability (Yeandle et al., 2007). Choice is one of them and it too is shaped and delineated by structural and/or internal factors, such as economic concerns or familial, cultural, and/or societal norms, meaning that the measurement of enforced lack is complex.

Strengths and limitations

Some of the interviews took place during the COVID-19 lockdown measures in England which resulted in cessation or reduction in usual care service provision for many people (Carers UK, 2020; Giebel et al., 2020). The extent of unmet need for services in my study may thus have been higher than unmet need pre-COVID-19, although evidence from pre-COVID-19 shows generally high levels of service under-provision (Yeandle et al., 2007; Brimblecombe et al., 2016). This is a strength, in that I was able to explore newly unmet need during the pandemic, but a possible limitation, as my findings do not necessarily reflect ‘usual’ levels of unmet need for services. The diversity of the sample of carers interviewed is a further strength, but the relatively small sample size and sampling strategy mean I cannot generalise my findings to the wider population of carers in England, and in this paper could not investigate in depth the ways in which some variation in the sample with regard to carers’ or caring circumstances may have led to variation in the impact of unmet need for services.

Conclusion

While lack of long-term care services may only be one of the reasons why some carers experience difficulties with employment, finances, and health, the evidence in this paper shows how detrimental it can be for carers when the services which they and the person they support rely on are withdrawn, inadequate, or not provided in the first place. Societies worldwide rely on unpaid care of various forms (OECD, 2019), and care provided to others is an important part of society. Therefore, both morally and, because these consequences have economic costs (Rodrigues et al., 2013), policy and action should address or prevent negative consequences for unpaid carers of unmet need for services. Addressing this requires changes to conceptualisation and measurement of unmet need for services and to the funding and delivery of long-term care. In recognising that care services for people with support needs are also a service for carers, current care policy in England goes some way towards taking into account the interdependence of their outcomes, although these rights need implementation in practice. It is also important to take choice into account, whilst bearing in mind that expressed choice not to receive services may reflect internalised constraints, such as insufficient information, concerns about or experiences of poor quality services, or concerns about cost (Brimblecombe, Pickard, et al., 2018). Some of these internalised constraints can be alleviated by addressing the external constraints that give rise to them via, for example, better information and better quality services.

Chapter 6

Paper 4. What are the individual and structural determinants of unpaid carers' mental health and wellbeing?

A version of the paper presented in this chapter was submitted to *Social Policy & Administration* in January 2023 and subsequently revised following comments and suggestions by the peer reviewers in June 2023.

Abstract

This paper aimed to investigate the multi-level determinants of unpaid carers' mental health and wellbeing using a social determinants framework and stress process model. Methods comprised secondary analysis of data from two waves of the UK Household Longitudinal Study (N=1,120 carer-care recipient dyads); and in-depth qualitative interviews with 26 carers. I found that carers' mental health and wellbeing are associated with the individual, community, financial, and living condition context in which they provide care. Individual and structural determinants of carers' mental health and wellbeing include their gender, ethnicity, financial situation, housing tenure, neighbourhood, community resources, and social support. Additional formal or informal support for the care recipient was also beneficial to carers' wellbeing in some circumstances.

Introduction

The majority of care received by older people is unpaid care (Verbeek-Oudijk et al., 2014a). An extensive body of evidence shows that at higher care hours, unpaid carers' outcomes tend to be worse than non-carers. This includes their mental health, wellbeing, and quality of life (e.g. Kaschowitz & Brandt, 2017; Bom et al., 2019; Ervin et al., 2022), and their employment (e.g. Keating et al., 2014; Nguyen and Connelly, 2014; Carmichael and Ercolani, 2016; Gomez-Leon et al., 2019). Some studies have also found negative effects on carers' physical health (e.g. Bauer & Sousa-Poza, 2015), although the findings on this are mixed. There is also some evidence of sub-group variation in carers' outcomes (Bom et al., 2019; Brimblecombe & Cartagena Farias, 2022). Much less is known about how best to support carers and reduce or prevent any negative effects of higher levels of care provision, despite this being a policy concern in many countries and a concern of carers themselves. Most research to date on support for carers has looked either at individual types of direct support such as counselling, training and education, or support groups (e.g. Thomas et al., 2017), or indirect carer support via long-term care (LTC) services for the care recipient in order to reduce the care that the unpaid carer provides (e.g. Heger, 2014; Rand & Malley, 2014). However, caring takes place in a broader context which policy and practice on support for carers should take into account.

My paper aims to better understand this broader context and the multidimensional and multi-level factors that might contribute to better mental health and wellbeing for carers and hence what would best support them. The study is informed by a social determinants of health conceptual framework, in particular the version developed by the Commission on Social Determinants of Health (CSDH; Solar & Irwin, 2010). It also draws on the caregiver stress process model (CSPM; Pearlin et al., 1990). The CSDH postulates that individual and structural determinants influence a person's health and wellbeing. Determinants in the CSDH include individual determinants (gender, ethnicity, social class, education); material circumstances; living and working conditions; psychosocial factors; and health and care systems. Overarching all these factors is the socio-economic and political context in which they operate: social and public policies, governance, and societal values.

Pearlin's (1990) CSPM also takes an individual-structural perspective, although the structural elements are more limited than the CSDH. However, an advantage for my study is that the model was developed specifically for studying impacts on unpaid carers and thus includes care need and care provided as well as direct and indirect support for carers. The model postulates that carers' outcomes are affected by the broader context in which they provide care, such as their social and economic characteristics, immediate environment, and social and economic resources. My study focuses on carers' mental health and wellbeing. In England, the setting for my study, supporting carers' health and wellbeing is a key principle of current LTC legislation and plans for reform (e.g. Her Majesty's Government, 2014a; Department of Health & Social Care, 2021b). Reducing health inequalities is also a stated policy aim (NHS, 2019; Her Majesty's Government, 2022). These health inequalities could be between carers and non-carers and/or among carers.

Framed by the theoretical approaches outlined above and the policy context, my research question was: 'What are the individual and structural determinants of carers' mental health and wellbeing?'

Methods

I used a mixed-methods research design informed by a critical realist ontological approach (Bhaskar, 1989). A critical realist approach and mixed-methods research design are well suited for exploring individual and structural determinants and for exploring both patterns and subjective experiences of those determinants (Becker et al., 2012). Specifically, I used a 'complementarity' and 'expansion' mixed-methods research design (Greene et al., 1989), using both secondary analysis of large-scale quantitative data and primary interview data. Each method also offset the weaknesses and drew on the strengths of the other (Bryman, 2006). The mixed-methods design enabled me to consider a wider range of determinants than one method alone. Where one method was not suited to or did not have information on a particular determinant, findings from the other method could be used to augment and enhance the overall picture. For example, the larger survey sample size meant that the quantitative analysis was best suited in this study to examining associations between individual determinants and carers' outcomes. Community resources were not asked about in the survey data but could be explored in the qualitative interviews and analysis. The mixed-methods design also enabled me to investigate different aspects of the determinants under study. For example, for material resources, household income and savings data were collected in the quantitative survey; financial security and concerns about future finances were sub-themes identified in the qualitative data. Another example is social support where the survey asked about number of close friends whereas the qualitative analysis explored the nature of social support. Synthesis and integration of quantitative and qualitative results took place during the interpretation phase of the study (Creswell & Clark, 2017).

Quantitative data

My study used data from Waves 9 (2017/19) and 10 (2018/20) of the UK Household Longitudinal Study (UKHLS) (University of Essex Institute for Social and Economic Research, 2021). The UKHLS is a large-scale annual survey of a nationally-representative sample of household members aged 10 or older living in the UK. Sampling is based on a proportionately stratified, clustered sample of addresses selected by postcode, supplemented by Ethnic Minority and Immigrant and Ethnic Minority booster samples (Knies, 2017). Information is collected longitudinally on a wide range of topics including on caring responsibilities for study members aged 10 and older and on care needs and LTC receipt from participants aged 65 and older. The sample for my analysis comprised co-resident unpaid carers aged 16 and older caring for people aged 65 and older (N=1,120). Identification of unpaid carers was derived from questions asked of the care recipient about who helped them with their care needs. I confined the sample for this analysis to England because of different LTC funding, provision, and regulatory contexts across the four nations of the UK. Data on possible determinants were collected at Wave 9 (2017/19; hereafter time 1) and outcome data at Wave 10 (2018/20; hereafter time 2). Ethical approval for the UKHLS was obtained by the University of Essex Ethics Committee.

Measures

All carers were co-resident. Carer characteristics, reported by carers themselves at time 1, were gender (male=0; female=1); ethnicity (White=0; ethnic minority=1); highest educational qualification (degree or higher degree=0; primary, secondary or no formal qualifications=1) as a measure of socio-economic status; and partnership status (not in partnership=0; in partnership=1). Ethnicity was categorised into only two categories because of very low sample sizes for some sub-groups. Highest educational qualification is an established measure of socio-economic status and was used in my study because it has a good response rate, is easy to measure, and, unlike measures of social class, includes people who are unemployed.

Material circumstances included equivalised household income quintile group and non-housing wealth quintile group. Equivalised household income is a measure of household income that takes account of differences in households' size and composition. Total savings, the measure of non-housing wealth in my study, was most recently asked at Wave 8 so is from an earlier wave than other time 1 variables. Following Solar and Irwin's (2010) CSDH model, living conditions included housing tenure (owner-occupied, social-rented, or privately rented); neighbourhood cohesion (Buckner's Neighbourhood Cohesion Index (Buckner, 1988)); and locality's Index of Multiple Deprivation (IMD) quintile group. Indices of Multiple Deprivation are measures of relative deprivation at small local area level across England (Ministry of Housing Communities & Local Government, 2019).

Care provision included the care need of the care recipient, as measured by (i) total number of Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) combined; and (ii) care recipient's mental health. Total number of ADLs and IADLs is a measure with good reliability and validity (Edwards, 1990) used extensively in studies of care need (Vlachantoni, 2019). ADL and IADL need variables were based on questions in UKHLS that asked the care recipient about their ability to carry out specific tasks and include inability to carry out these tasks or only being able to perform these tasks with help. ADLs include aspects of daily living such as ability to get around the house, bathe, or dress. IADLs include ability to walk down the road, shop, and do housework, laundry, paperwork, and bills. Care recipient's mental health was measured by the Mental Component Score of the Short-Form 12 Health Survey (SF12 MCS). The SF12 MCS has been validated for use in the general population (Ware et al., 1996). Unpaid care provision was derived from a question asking about number of care hours provided per week. Response options were categorical and were coded as 1-4, 5-9, 10-19, 20-34, 35-49, 50-99, and 100+ hours a week. Support received included from formal LTC services such as home care and/or from other unpaid co- or extra-resident carers. The measure of social support used was reported number of close friends.

Carers' life domains at time 2 (Wave 10) were (i) mental health (SF12 MCS score, as above); and (ii) wellbeing (Warwick Edinburgh Mental Wellbeing Scale (WEMWBS); Tennant et al., 2007).

Quantitative analysis

Quantitative analysis was structured according to the CSDH domains of individual determinants, material resources, living conditions (housing tenure, area IMD, neighbourhood cohesion), and psychosocial factors (social support). There were two carer-specific determinants. The first was level of unpaid care provision, a key determinant of carer outcomes in the CSPM (Pearlin et al., 1990). Unpaid work can also be considered part of working conditions in the social determinants frameworks (Spiers et al., 2021). The second carer-specific determinant was formal and informal (from other unpaid carers) support for the care recipient, again a key component of the CSPM (Pearlin et al., 1990). All determinants were first considered in bivariate linear regression analysis. Multivariate linear regression analysis was then carried out. Each multivariate regression model included all variables found to be statistically significant in the bivariate analysis. I report regression coefficients for the bivariate and multivariate analysis and standardised coefficients (beta) for the multivariate regression analysis. Adjusted R-squared, a measure of goodness of fit, is also reported for each multivariate model. I conducted analysis using Stata 14.2 (StataCorp, 2015).

Qualitative data

One-to-one in-depth telephone interviews were carried out between February and May 2020 with 26 adult co-resident carers caring for people aged 16 or older living in England. Adopting these criteria, sampling was purposive maximum variant (Patton, 2014) aiming to cover a range of caring circumstances and carers' characteristics (gender, ethnicity, housing tenure, and geographical type (urban or rural)). Recruitment took place through carer organisations and networks and from among the general public. This was in order to recruit people with caring responsibilities who identified as carers and those who did not and to recruit a diverse interview sample. Ethical approval for the interviews was granted by the Social Care Research Ethics Committee in October 2019 (Ref: 19/IEC08/0046). Interviews were semi-structured and followed a topic guide, structured around the research question – what are the individual and structural determinants of carers' mental health and wellbeing? – and the theoretical frameworks. Topics thus included effects on carers' lives of the caring situation; support received for the care recipient; support from family and friends; community resources; financial constraints and resources; and other aspects identified as important by the carer.

Qualitative analysis

The methodological approach for the qualitative analysis was primarily deductive or 'theoretical' thematic analysis (Braun and Clarke, 2021). After initial familiarisation with the data, an initial coding framework was developed, structured around the theoretical frameworks resulting in the following initial themes: material resources; living conditions; community resources; social support; and support with caring. I then gathered all data relevant to each theme, including counter-examples and exceptions. I subsequently used both deductive and inductive analysis to identify sub-themes within these main domains. For example, the initial coding frame included 'material resources' as a theme; sub-themes drawn from the data included sense of current and future financial security and concerns about welfare benefits. In an iterative process, I reviewed the themes and sub-themes in relation to the extracts coded and not-coded to each theme or sub-theme. Analysis took place in NVivo 12 (QSR International Pty Ltd., 2018).

Results

Sample descriptions for the quantitative analysis are shown in Table 7. Just over half the carers were female, 17% were from an ethnic minority, 87% were in a partnership, and a third had a degree or higher qualification. Most (83%) owned their home. A fifth provided care for 100 or more hours a week; a third for less than 10 hours a week. A quarter of the dyads received other formal help (LTC services) and over half (58%) received help from other unpaid carers. The interview sample comprised six male and twenty female carers aged 19 to 85. Seven described their ethnicity as Black or Asian, twelve as White British, and seven did not specify. Interviewees were from a wide range of socio-economic backgrounds and geographical areas and types. The majority cared for older people (parent, grandparent, or partner).

Table 7. Sample descriptives

INDIVIDUAL DETERMINANTS	**% (N)**
Male	47.9 (536)
Female	52.1 (584)
White	83.5 (935)
Ethnic minority	16.5 (185)
Highest qualification: degree or higher	33.3 (303)
Highest qualification: primary, secondary, or no formal	66.7 (608)
In partnership	86.8 (971)
Not in partnership	13.2(148)
LIVING CONDITIONS	**% (N)**
Household housing tenure	
Owner-occupied	83.0 (912)
Social-rented	12.9 (142)
Private-rented	4.1 (45)
	Mean (range)
Neighbourhood cohesion score	3.71 (1-5)
LONG-TERM CARE SUPPORT RECEIVED	**% (N)**
Long-term care services received	25.8 (288)
Long-term care services not received	74.2 (830)
Other unpaid carers	57.5 (643)
No other unpaid carers	42.5 (476)
PSYCHOSOCIAL FACTORS: SOCIAL SUPPORT	**Mean (range)**
Number of close friends	6.01 (0, 110)
OUTCOMES	**Mean (range)**
Mental health (MCS) score	50.3 (12.7,70.5)
Wellbeing (WEMWBS) score	25.2(7,35)

The next section presents quantitative and qualitative findings on the individual and structural determinants of carers' mental health and wellbeing, with synthesis of findings from the two methods continuing in the discussion. As described above, some determinant levels use just quantitative or just qualitative data, some both. Pseudonyms are used to indicate interviewees.

The overarching, 'global' theme was that carers' outcomes are associated with the care they provide and the multidimensional context in which they provide it. Within that, there were five themes each with sub-themes. The five themes were: (i) carers' outcomes are associated with their individual characteristics; (ii) carers' outcomes are associated with their material circumstances; (iii) carers' outcomes are associated with their living conditions; (iv) carers' outcomes are associated with their social support networks; and (v) carers' outcomes are associated with other support received by the care recipient.

Carers' outcomes are associated with their individual characteristics

Analysis of the associations between individual determinants and carers' outcomes used quantitative data only with the exception of carers' health. As Table 8 shows, all the carer individual characteristics under study were associated with their mental health. Being female, in an ethnic minority, or not having a partner was associated with poorer mental health for the carer (Table 8). Carers' wellbeing was associated with their partnership status (Table 9).

Table 8. Factors associated with carers' mental health: bivariate and regression multivariate regression analysis models

	Mental health score (MCS)		
	Bivariate linear regression	**Multivariate linear regression**	
	Coefficient (95% Confidence Interval)	**Coefficient** (95% Confidence Interval)	**Standardised coefficient (beta)**
INDIVIDUAL DETERMINANTS (CARER)			
Female	**-1.15~** (-2.35, 0.05)	-0.61 ns (-2.68, 1.45)	-0.03
Ethnic minority	**-3.62*** (-5.31, -1.93)	**-3.81*** (-7.40, -0.22)	-0.12
Highest qualification: degree or higher	0.04ns (-1.39, 1.47)	-	-
In partnership	**4.62*** (2.79, 6.45)	1.79 ns (-1.60, 5.19)	0.06
CARE PROVIDED			
Total ADL + IADL care needs of care recipient	**-0.36*** (-0.52, -0.20)	0.09 ns (-0.19, 0.38)	0.04
Care recipient mental health score (lower = worse mental health)	**-0.15*** (-0.21, -0.10)	-0.06 ns (-0.16, 0.02)	-0.09
Care hours per week (increasing)	**-0.74*** (-1.20, -0.28)	**-0.71*** (-1.27, -0.21)	-0.16

MATERIAL CIRCUMSTANCES			
Equivalised household income quintile group			
1 (lowest quintile)	**-1.88*** (-3.79, 0.04)	-1.84 ns (-5.12, 1.44)	-0.08
2	-1.05 ns (-2.97, 0.87)	-0.48 ns (-3.77, 2.80)	-0.02
3	-0.81ns (-2.72, 1.10)	0.40 ns (-2.84, 3.65)	0.02
4	-0.18ns (-2.10, 1.73)	0.67 ns (-2.58, 3.93)	0.03
5 (highest quintile)	Ref	Ref	Ref
Wealth quintile group			
1 (lowest quintile)	-1.34 ns (-3.59, 0.91)	-	-
2	-1.35 ns (-3.57, 0.86)	-	-
3	0.14 ns (-2.10, 2.39)	-	-
4	-0.22 ns (-2.50, 2.05)	-	-
5 (highest quintile)	Ref		
LIVING CONDITIONS			
Housing tenure			
Owner-occupied	Ref	Ref	Ref
Social-rented	**-3.44*** (-5.33, -1.54)	-0.99 ns (-4.18, 2.21)	-0.04
Private-rented	-1.91 ns (-5.05, 1.23)	-4.09 ns (-9.01, 0.82)	-0.08
Area deprivation (IMD quintile group)			
1 (most deprived)	-1.37 ns (-3.34, 0.60)	-	-
2	-0.56 ns (-2.53, 1.41)	-	-
3	-0.49 ns (-2.39, 1.41)	-	-
4	0.74 ns (-1.10, 2.58)	-	-
5 (least deprived)	Ref		
Neighbourhood cohesion (highest = most cohesive)	**2.32*** (1.43, 3.21)	**3.49*** (1.89, 5.09)	0.24
LONG-TERM CARE SUPPORT RECEIVED			
Care services received[1]	-0.43 ns (-1.85, 0.99)	-	-
Other unpaid carers[2]	0.79 ns (-1.83, 3.41)	-	-
PSYCHOSOCIAL FACTORS: SOCIAL SUPPORT			
Number of close friends (increasing number)	**0.26*** (0.16, 0.36)	**0.20*** (0.02. 0.37)	0.12

* $p< 0.05$; ~ $p<0.10$. Notes: (1) Controlling for total care needs, care recipient mental health need (MCS score); all are significantly associated with receipt of services. (2) Controlling for total care need, care recipient mental health need (MCS score), and care hours; all are significantly associated with receipt of other unpaid care. Multivariate regression model fit: Adjusted R2= 0.1105

Table 9. Factors associated with carers' wellbeing: bivariate and multivariate regression analysis models

	Wellbeing score (WEMWBS)		
	Bivariate linear regression	**Multivariate linear regression**	
	Coefficient (95% Confidence Interval)	**Coefficient** (95% Confidence Interval)	**Standardised coefficient (beta)**
INDIVIDUAL DETERMINANTS (CARER)			
Female	-0.09 ns (-0.67, 0.48)	-	-
Ethnic minority	-0.52 ns (-1.33, 0.30)	-	-
Highest qualification: degree or higher	0.04 ns (-0.63, 0.71)	-	-
In partnership	**1.45*** (0.57, 2.33)	**0.94~** (-0.05, 1.94)	0.06
CARE PROVIDED			
Total ADL + IADL care needs of care recipient	**-0.11*** (0.18, -0.03)	-0.52 ns (-1.22, 0.19)	-0.05
Care recipient mental health score (lower = worse mental health)	**0.05*** (-0.07, -0.03)	**-0.03*** (-0.06, -0.002)	-0.08
Care hours per week (increasing)	-0.13 ns (-0.34, 0.09**)**	-	-
MATERIAL CIRCUMSTANCES			
Equivalised household income quintile group			
1 (lowest quintile)	-0.61 ns (-1.54, 0.31)	-0.25 ns (-1.21, 0.69)	-0.02
2	**-0.98*** (-1.91, -0.05)	-0.56 ns (-1.52, 0.40)	-0.05
3	-0.50 ns (-1.43, 0.43)	0.06 ns (-0.89, 1.01)	0.01
4	-0.16 ns (-1.09, 0.76)	-0.04 ns (-0.98, 0.90)	-0.004
5 (highest quintile)	Ref	Ref	Ref
Wealth quintile group			
1 (lowest quintile)	-0.43 ns (-1.53, 0.66)	-	-
2	-0.51 ns (-1.59, 0.57)	-	-
3	-0.27 ns (-1.36, 0.83)	-	-
4	-0.28 ns (-1.40, 0.83)	-	-
5 (highest quintile)	Ref		
LIVING CONDITIONS			
Housing tenure			
Owner-occupied	Ref		
Social-rented	**-1.69*** (-2.60, -0.78)	**-0.99*** (-1.95, -0.01)	-0.07
Private-rented	-0.52 ns (-2.08, 1.03)	-0.44 ns (-2.03, 1.16)	-0.02
Area deprivation (IMD quintile group)			
1 (most deprived)	0.01ns (-0.95, 0.96)	-	-
2	-0.54 ns (-1.49. 0.41)	-	-
3	-0.34ns (-1.26, 0.57)	-	-
4	-0.04 ns (-0.92, 0.85)	-	-
5 (least deprived)	Ref		

Neighbourhood cohesion (highest = most cohesive)	**1.51*** (1.09, 1.94)	**1.18*** (0.73, 1.63)	0.18
LONG-TERM CARE SUPPORT RECEIVED			
Care **s**ervices received[1]	**-0.60~** (-1.30, 0.10)	-0.51 ns (-1.22, 0.19)	-0.05
Other unpaid carers[2]	0.22 ns (-1.00, 1.44)	-	
PSYCHOSOCIAL FACTORS: SOCIAL SUPPORT			
Number of close friends (increasing)	**0.13*** (0.08, 0.18)	**0.12*** (0.07, 0.18)	0.15

* $p< 0.05$; ~ $p<0.10$. Notes: (1) Controlling for total care needs, care recipient mental health need (MCS score); all are significantly associated with receipt of services. (2) Controlling for total care need, care recipient mental health need (MCS score), and care hours; all are significantly associated with receipt of other unpaid care. Multivariate regression model fit: Adjusted R2= 0.0889

Carers' outcomes are associated with their material circumstances

In the quantitative analysis, financial resources were significantly associated with mental health in bivariate analysis (Table 8). Carers in the lowest income quintile group had significantly worse mental health than those in the highest income quintile group. Savings were not significantly associated with either mental health or wellbeing. In interviews, material circumstances were also key. In addition to income, the qualitative analysis identified that competing financial priorities was also a factor. Charlotte's experience below shows that lack of financial resources, and competing priorities and needs for the money, were associated with her not getting the mental health support she needed:

> *'I was having counselling through my GP, but that was only six sessions and the lady would have seen me privately, but it was £40 a week, but I couldn't justify that.'*

However, an increase in resources, in this case through a one-off payment following a carer's assessment, was going to enable her to do activities of her choice that she knew would improve her wellbeing:

> *'I've just had a carers' assessment and the really positive outcome of that is that they're going to give me [amount] as some kind of payment thing, so that when all this is over, I can have a day out at the seaside or get my nails done or something, which is fantastic' (Charlotte, carer for partner).*

Carers' outcomes are associated with their living conditions

In the quantitative analysis, carers' mental health and wellbeing were associated with their living conditions (Table 8 and Table 9). Living in socially-rented housing was associated with poorer mental health and wellbeing. Area deprivation was not associated with carers' mental health or their wellbeing (Table 8 and Table 9). Higher neighbourhood cohesion was associated with better mental health and wellbeing for carers in the survey analysis (Table 8 and Table 9). Qualitative analysis added to this picture by showing that community resources – leisure facilities, social clubs, shops – were an additional aspect of living conditions that were supportive to care recipients and directly or indirectly to carers. The role of community resources was brought into sharp relief when some stopped during Covid-19 lockdown measures in England in 2020 and 2021:

> *'For example, he'll just go for the bingo and then they'll have tea…they just kind of like chat and stuff like that and just be cool and you know, and it just gives me the time to just rally the baby and run around….But it's like all that's just kind of gone for them….It's very isolating' (Sonia, carer for grandparent).*

> *'Before it was a little bit challenging, but since the lockdown, it's become mentally challenging now because we can't really take her where she wants to go, and we can't take her to who she wants to go and see' (Penelope, carer for older relative).*

Carers' outcomes are associated with their social support networks

Quantitative analysis showed that having close friends was associated with better mental health and wellbeing for carers (Table 8 and Table 9). Investigating this in more depth, the interview analysis showed that support from others (e.g. friends, family, or other carers) provided important emotional and/or practical support for carers. The following quotes illustrate how this support network supported carers emotionally:

> *'I've got very, very good friends. They're very supportive. And also one of the things with going through this for quite a long time, I've made friends with people who have been through the same thing, and that is supportive, people who have experienced what you're going through or are still experiencing it' (Frances, carer for partner).*

> *'The only time I get any support is through our friends, who obviously realise that, you know, the carer needs as much help as the person they're caring for' (Larry, carer for partner).*

Support from others could also include information-sharing, a useful form of practical support as Sonia describes:

> *'Luckily, I've got good friends…they help support me cos they know it's not easy, looking after an individual, especially like every need, it's not something that we ever really thought we'd have to do….[And] in regards to the professional side, my friend showed me how to…assist to change him and stuff like that and what needs to be done' (Sonia, carer for grandparent).*

Carers' outcomes are associated with other support received by the care recipient

Indirect support for the carer can be provided via other support for the care recipient, either formal or unpaid. In the survey analysis (Table 8 and Table 9), other unpaid care being received by the care recipient was not associated with better mental health for the main carer. In interviews, however, other unpaid care for the care recipient was reported to be helpful to the main carer in reducing the stress of caring. This reduction in stress occurred either by giving the main carer a break and/or through sharing the emotional and practical responsibility. It also facilitated the main carer's ability for social connections with family and friends, an important part of wellbeing:

> *'Yeah, we've already got trips lined up where we're expecting [other unpaid carer] to come and step in because we've got a wedding coming up, which…my dad won't be well enough to go to' (Lucy, carer for parent).*

> *'I do get a break because I have [siblings] who I've allocated certain work to so I'm able to go and stay at my partner's some days' (Julia, carer for parent).*

In the quantitative analysis, receipt of formal care services for the care recipient was also not associated with better outcomes for the carer, even when controlling for care need. Receipt of services is measured categorically in the data. This category is likely to contain a variation in terms of quantity and quality of services received. Interviews helped explore other, qualitative aspects of LTC receipt and thus helped add to and interpret this quantitative finding. The two main sub-themes of services for the care recipient that were found to be helpful to carers were 'a fuller life' and 'dignity and respect' for the care recipient, both interlinked. A fuller life for the care recipient was achieved when LTC services fulfilled needs above and beyond basic care needs such as nutrition or bathing. Services that enabled the care recipient to live a fuller life also increased carers' wellbeing: '*if he comes home* *happy then I'm happy'*. An example of a service that met the care recipient's social and emotional as well as personal care needs and reduced care provision by the carer is given by Bridget, a carer for her adult daughter:

> *'They go to restaurants quite a lot. There is a club they go to. So they go there sometimes and cinema, bowling, gym – she goes to the gym….She does like going out with her friends – that's what I call it when she goes out with the [service] – she does like it. She's quite sociable' (Bridget, carer for adult daughter).*

Alex gave another example:

> *'After being diagnosed with [condition], she went along to the [support group name], she goes once a week….they do various activities. I think it's the beneficial side of being sociable, it doesn't improve her memory, but it's the getting together with like-minded people – not that I think she's probably aware that they're like-minded – but they all chat and say the same thing…they have a really good time. There's a lot of laughter so that's good' (Alex, carer for parent).*

Dignity and respect were closely related to the quality of the care and the careworker's approach, attitude, and ability to spend time with, and get to know, the disabled person:

> *'She knew me very well. She knew my children very well. She knew my wife very well. So she understood…what needs to be done, how, and when.' (Robert, carer for partner).*

> *'[The careworker] knows him, she knows how he likes to be washed, how he likes to be changed. I feel safe….I can rely on her to know what to do with him' (Emma, carer for adult son).*

Good quality care – services, environments, and people that promoted wellbeing, dignity, and inclusion for the care recipient and were appropriate to their needs and circumstances – gave carers a proper short or long-term physical, mental, and emotional break, enabling them to pursue chosen and necessary activities, live a fuller life, and experience less stress. This break or reduction in caring did not necessarily mean away from the person with care and support needs. Spending time with them but not as their carer was an important aspect and an important part of a dyadic approach and understanding:

> *'We can sit and have breakfast quite happily together usually, with the carer who looks after him, and generally get the pills down a bit better, so that can be quite pleasant to start the day, we have it together' (Catherine, carer for partner).*

Discussion

In my study, unpaid carers' mental health and wellbeing were associated with the care they provided and the individual, community, financial, and living context in which they provided it. In terms of individual determinants, female carers had poorer mental health than male carers. Previous research on gender differences shows similar results (Bauer & Sousa-Poza, 2015; Bom et al., 2019). Lower household income, sense of financial insecurity, and concerns about current and future financial situation were associated with worse mental health and wellbeing for carers in my study. Of the few other studies that look at material resources, there is some evidence that wealth may be a factor in carers' wellbeing (Brandt et al., 2021)

Living conditions are a key component of social determinants frameworks but have not been much studied previously in the context of outcomes of unpaid care provision, although a small-scale study of carers of people with dementia found that carers living in areas of high deprivation had the greatest decline in quality of life during COVID-19 (Hicks et al., 2022). In my study, living conditions – neighbourhood deprivation and/or cohesion and housing tenure (living in social-rented accommodation) – were associated with poorer mental health and wellbeing. Social networks were also important: greater number of friends was associated with better mental health and wellbeing, and supportive friends, family, and neighbours were perceived to be an important source of practical and emotional support for carers.

Support for the care recipient from sources other than the main carer were found in interviews, although not in the quantitative analysis, to be associated with better carer wellbeing. Evidence from previous studies on help from other unpaid carers, sometimes termed the 'informal care network', shows that it can have a positive effect on carers' wellbeing (Tolkacheva et al., 2011). Previous research on LTC services for the care recipient has shown mixed results. Some quantitative studies show positive effects on carers' wellbeing (Heger, 2014; Rand & Malley, 2014). However, other studies have found no effect in some quality of life domains (Tough et al., 2019; Rand et al., 2020a), as was also the case in my quantitative analysis, although again my qualitative analysis found differently. The reasons for the differences seen for both formal and unpaid help between the methods in my study may be similar. Previous research suggests that it may not be receipt of additional support for the care recipient *per se* that is beneficial but certain aspects of it. Tolkacheva et al. (2011) found that informal care networks were more beneficial to the main carer when more types of tasks were shared, care was shared for a longer period, and there were no disagreements with the other members of the network. Studies on formal LTC services have found that amount, adequacy, appropriateness, and quality are key (Trukeschitz et al., 2021; Brimblecombe, 2022b). Services that do not adequately meet care recipient or carer needs, what Winslow describes as a 'sub-therapeutic amount of service' (Winslow, 2003, p. 342), may therefore not be associated with better carer outcomes. In these cases, any effects of service receipt will not show in analyses that simply measure service receipt versus non-receipt.

That LTC services are not the major contributor to outcomes is also consistent with the frameworks guiding this paper which emphasise the importance of factors outside of health or care services. There are two implications of this finding. The first is that although services make only a small contribution to carers' outcomes, could they make a greater contribution if they were improved and/or available more widely? There are encouraging signs. First, good quality LTC services can and do make a difference to carers (Rand & Malley, 2014; Winslow, 1997; Zarit et al., 1999). Second, a study by Buck and Maguire showed that services, in this case health services, had the potential to make a greater impact than they currently did (Buck & Maguire, 2015). Third, my study illuminates some of the ways in which services were found to be helpful by carers and contributed to better quality of life, and therefore some of the ways in which LTC services could be extended and improved to better support carers and care recipients. These aspects align with key principles of the UN Convention of the Rights of Persons with Disabilities (United Nations, 2006) of full and effective participation and inclusion in society for disabled people, dignity and respect, individual autonomy, and the freedom to make one's own choices.

A strength of my study is that a breadth of individual and contextual determinants could be considered in both the quantitative and qualitative analysis, alongside caring-specific factors such as care need, care hours, and care support. The mixed-methods approach enabled me to look at a wider range of factors overall and to explore some of these in depth, showing some key additions and differences between findings from each method. This further illuminated the picture of what contributes to better outcomes for carers. However, a limitation is that there may be other contributory factors, such as psychological or physiological factors, that are not included in the secondary dataset nor could be explored in the interviews. Although there was a large sample size overall, the sample size was too small to categorise carers' ethnicity into more than two groups; this is a limitation.

There may also be issues with measurement. As alluded to earlier, the quantitative measure of service receipt (services versus no services) does not capture where services are received but do not adequately meet needs. However, the qualitative analysis enabled me to broaden this picture by looking at aspects of services that *did* work for carers. Some of the interviews took place during the COVID-19 lockdown measures in England which resulted in cessation or reduction in usual care service provision for many people (Carers UK, 2020; Giebel et al., 2020). The quality or quantity of services received may thus have differed from pre-COVID-19. However, drawing on both their current and previous experiences, participants were able to say what worked well about services both before and during this period..

My study has a number of implications for policy and practice. Multiple individual and contextual factors contribute to carers' outcomes in addition to their care responsibilities. This means that actions for improving carers' outcomes do not just lie within long-term care policy and provision. An example is the need to improve the financial situation of carers and disabled people. Welfare benefits to compensate carers for some of the economic impacts of caregiving can often be too low to effectively relieve financial hardship, as seen in the UK context, and can be very restrictive in practice (Bouget et al., 2016). A review of this benefit is needed. Neighbourhood cohesion and community and social support were found to be beneficial for carers in my study. The mention of community connectedness in current health and care policy in England is welcome in this context. However, community resources need to both exist and be accessible to carers. Substantial cuts to voluntary and community sector funding in England over the last ten years, seen disproportionately in more deprived areas (Marmot et al., 2020), have led to reduced community assets. This needs to be reversed. Carers also need the time, and in some cases money, to be able to access community assets and connect with social networks.

Reduction in care hours and breaks from caring would give carers more time to access valuable support and would help address the negative impacts on carers seen at higher care hours (e.g. Brimblecombe, Fernandez, et al., 2018a). Reduced caring and carer breaks are already set out in LTC policy in England; however, fuller and fairer implementation is required (House of Lords Adult Social Care Committee, 2022). Reduction in caring could also come about through prevention of the care recipients' mental and physical care needs occurring or worsening. This has implications for LTC and health policy, and because of the role of social determinants of health, for tackling those social determinants (see e.g. Marmot and Bell, 2012; Marmot et al., 2020). Lastly for policy, services for the care recipient have the potential to be improved and so make a greater contribution to carers' quality of life. Quality and amount of services, and better alignment with care needs, are important to improving services and to the main sub-themes identified in my study: dignity and respect for the care recipient and a full life for the care recipient and carer both individually and together.

Chapter 7

Conclusions

7.1 Synthesis of findings

Each of the four papers of my thesis contributes different insights to address the overarching research aim to investigate the extent and nature of inequalities in unmet need for services for unpaid carers, the consequences, and what other factors contribute to these consequences. Using quantitative longitudinal analysis of secondary data and social determinants of health and stress process conceptual frameworks (Pearlin et al., 1990; Solar and Irwin, 2010), Paper 1 showed how the effects of care provision vary among co-resident or higher intensity unpaid carers in the UK (research question 1). Asian carers had lower earnings from paid employment than White carers. Female carers had worse mental and physical health than male carers and lower earnings. Carers with lower educational qualifications (a measure of social class) had worse mental and physical health than carers with higher qualifications, were less likely to be in paid employment, and had lower earnings when they were in employment.

There are a number of reasons why carers from some population sub-groups are less likely to be in employment or have worse health and wellbeing than others, some of which are returned to below. One pathway, however, by which social and economic factors may determine health and other outcomes is via people's ability to access social care and other services (WHO, 2002; Solar and Irwin, 2010). Paper 2 investigated exactly this by looking at the extent and inequalities in unmet need for social care services for disabled adults or older people and their co-resident unpaid carers, as well as the nature of and possible reasons for this variation (research question 2). In order to provide a detailed and rich understanding of the patterns and nuances of unmet need for services, Paper 2 used a mixed-methods research design and was informed by Andersen's multi-level BMHSU (BMHSU; Andersen and Newman, 2005; Andersen et al., 2013).

Methods for Paper 2 comprised in-depth interviews with carers and secondary analysis of paired care recipient-carer data from the UK Household Longitudinal Study collected 2017/19. I found extensive unmet need for services across all carer groups. Within that, male care recipients were less likely to receive services than female care recipients. Ethnic minority care recipients were less likely to receive any services or to receive services that were perceived to be appropriate to their care needs. Care recipient-carer pairs living in lower income households or in more deprived areas were also most likely to experience unmet need for services. In terms of reasons for unmet need for services, some factors found in my study to result in unmet need for services, such as ineligibility and lack of availability, arguably apply to all carers. However, having greater resources helped circumvent this in some circumstances. Affordability of privately funded services also differentially affected some sub-groups.

As can be seen, there is some overlap between the sub-groups of carers and care recipients who do not receive adequate or appropriate services (Paper 2) and the sub-groups of carers that experience worse outcomes (Paper 1). This may be because those carers who experience worse outcomes are also less likely to be able to access services, and/or it may be that not receiving services leads to worse outcomes. Paper 3 looks at these possible links between lack of services and poorer outcomes by exploring the consequences for unpaid carers of unmet need for social care services and how these consequences occur (research question 3). Paper 3 took a qualitative approach to understanding the associations between unmet need for services and carers' outcomes in order to take into account aspects of unmet need such as adequacy, appropriateness, or quality of services received. These aspects are established as important in Paper 2 and other literature (e.g. Winslow, 2003; Yeandle and Buckner, 2007; Trukeschitz et al., 2021), but are not measured in the quantitative data. Paper 3 used conceptual frameworks that take a multidimensional approach to outcomes (Sen, 1985a; Hrast et al., 2013), and those that foreground the role of choice and the individual and structural constraints on choice (Sen, 1992; Abel and Frohlich, 2012; Robeyns, 2016; Al-Janabi et al., 2018).

In Paper 3, I showed that unmet need for services – services not being received at all or not adequately meeting care needs – was associated with negative outcomes for carers in a number of life domains: paid and voluntary employment, health, relationships, social and community participation, and leisure activities. As unmet need for services is more likely to be experienced by some sub-groups than others, as found in the analysis for Paper 2, this has equity implications. Paper 3 also found that lack of choice over whether or not services were received was associated with carers having poorer mental health, relationships with the people they cared for, and social connectedness. Again, some sub-groups of carers may have more choice and fewer constraints on choice than others. For example, in Paper 2, material resources were a constraint on receiving any or adequate and appropriate services. Similarly, as other research has also found (e.g. Moriarty, 2008; Greenwood et al., 2014), there is a lack of culturally appropriate support for people with care needs from ethnic minorities, meaning less choice.

As is clear from Paper 3 and other literature (e.g. Zarit et al., 1999; Rand and Malley, 2014), lack of social care services can have negative consequences and social care services are an important and beneficial part of the support needed by both care recipient and carer (see also e.g. Zarit et al., 1999; Rand and Malley, 2014). However, as suggested by the individual-structural determinants frameworks that inform and shape my thesis, social care services will be only part of the complex determinants of negative or positive outcomes among carers seen in Paper 1. Paper 4 explored these wider determinants to better understand what factors contribute to unpaid carers having better or worse outcomes (research question 4). Paper 4 took a mixed-methods approach to answering this question, using longitudinal analysis of data from Waves 9 (2017/19) and 10 (2018/20) of the UK Household Longitudinal Study and qualitative interviews with unpaid carers.

Building on other papers in this thesis, Paper 4 found key associations between a range of individual, structural, and care-related determinants and co-resident carers' mental health, and wellbeing. Carers' mental health and wellbeing were associated with their material circumstances (household income, competing priorities and needs for the available financial resources, and sense of financial (in)security). Carers' mental health and wellbeing were also associated with their living conditions (housing tenure, neighbourhood, and community resources); their social support networks; and the receipt of other unpaid care by the care recipient. As with Paper 3, and core to my thesis, Paper 4 showed the importance of good and life-enhancing services to carers and care recipients. Paper 4 also showed how services could play a greater role in supporting the dyad to have more fulfilling lives, both individually and together. However, the findings of Paper 4, in conjunction with Papers 1 and 3, show that support for carers must also consider the context of carers' and care recipients' broader circumstances, needs, and the choices they wish to and can make.

In summary, and in answer to my main research questions, higher intensity or within-household female, Asian, or lower socio-economic status carers experience worse health, lower likelihood of being in employment, and/or lower income than male, White, or higher socio-economic status carers respectively (research question 1). These same sub-groups of carers, with the addition of carers in lower income households or living in more deprived local areas, were also less likely to receive any or adequate or appropriate services (research question 2). Unmet need for care services for the person they support, either in the form of no services or ‘sub-therapeutic’ (Winslow, 2003) levels of service provision, was associated with negative consequences for carers’ employment, health, relationships, social participation, and leisure activities (research question 3). This unmet need may then partially explain the more negative experiences of some sub-groups of carers seen in Paper 1. However, lack of services is not the whole picture in explaining better or worse outcomes for carers. Other factors include household income, other financial demands and sense of financial security; housing tenure; neighbourhood; community resources; social support; and other informal care (research question 4).

7.2 Limitations

There are several limitations to the data, methods and thus the thesis overall. The limitations of the data are outlined in Chapter 2 and include, for the quantitative data, that the use of secondary data meant that I was not able to study some outcomes and population sub-groups. The latter included working age disabled people and their unpaid carers. This group would valuably be a subject of future data collection in longitudinal large-scale surveys such as UKHLS, as well as future research. These gaps in the survey data were partially offset by the interviews which collected information both on carers of working age care recipients and on a wider range of outcomes. However, quantitative large-scale longitudinal data would valuably add to this picture. A further limitation to the quantitative data and one that has turned out to be fundamental to the study of unmet need and inequalities in care is the way the questions about receipt of services are asked in the UKHLS survey: currently binary information is collected on whether services were received or not. More nuanced and detailed questions would give a more complete picture; however, it may be that mixed methods are always needed to really understand the nature, extent, and variation in unmet need as perceived by carers and care recipients and to help future researchers and decision-makers.

The potential limitations of the qualitative data, also described in Chapter 2 include that some carers do not identify as such and even with careful language choices for the research materials, this barrier to participation might remain to some extent. Other barriers to participation in the interviews may include those of time, confidence, or trust. Some of the interviews took place during the unusual times of the COVID-19 pandemic and lockdown measures in England which deeply affected social care. This was both a strength and a limitation. On the one hand, it was a time of potentially greater unmet need for care and reduced support for carers as there was a widespread cessation of services (Carers UK, 2020;

Giebel et al., 2020), although data for 2020/21 actually show an *increase* in number of people receiving publicly-funded social care services (Bottery and Babalola, 2020). In addition, my intention in the qualitative data analysis was not to look at prevalence of unmet need for services, which makes the unusual circumstances less of an issue. A strength is that, although newly unmet need for services did occur pre-COVID-19, the high level of newly unmet need for services and other informal support during COVID-19 represented an opportunity to study existing, as well as newly unmet, need for services.

Differential non-response and attrition in the longitudinal survey data and differential barriers to participation in the interviews will mean that some voices and experiences of unmet need for services are missing, despite the measures taken by myself and by UKHLS to minimise this. Future research could focus specifically on the experiences of unmet need for services amongst particularly marginalised sub-groups of carers; peer research might aid this process and reduce some of the barriers to participation. Sample size, even in a large-scale survey like the UKHLS but also in the interviews, meant that in many aspects my study does not have the intersectional approach or analysis that might shed further light on inequalities in care. Pooling data across waves might be a partial solution for future research but a qualitative study focusing on the intersectional effects could also be very illuminating.

My choice of conceptual frameworks for the thesis, comprising individual and structural elements, resulted from a deep reading and critical evaluation of the conceptual literature. However, it is also influenced by, and influences, my political and ontological viewpoint. The choice of framework to guide the study is therefore not value-free. As this framework is used to inform the interview questions and analysis, it will have shaped the findings. A different conceptual framework, or a different researcher, might also have considered different implications for policy and practice, ones that, for example, just included actions for individuals or families rather than the state as well. The potential effects of researcher bias are not limited to qualitative data collection and analysis. Although the use of secondary data in my thesis will have reduced the effects of my researcher bias on sampling and questions asked, as the example of conceptual framework shows, the analysis, interpretation, and implications may have been partially influenced by this.

7.3 Contributions of the thesis

My thesis makes empirical, conceptual, and methodological contributions, which are described in this section. It also generates policy insights which are considered in Section 7.4.

The empirical, conceptual, and methodological contributions are deeply interlinked and each enabled the other.

My thesis makes several core conceptual contributions to the ongoing, although fairly recently reinvigorated, discussions and conceptualisations of unmet need. First, I contribute to the growing conceptualisation and understanding of unmet need for care as both individual and structurally determined and delineated (Vlachantoni et al., 2011; Kröger et al., 2019). However, unlike almost all other literature on unmet need, including that which takes a contextual perspective, I additionally take a dual perspective to conceptualising unmet need that includes the unpaid carer, where one exists. This brings together two streams of thought: individual-structural theories of unmet need and research and theory that centres the dyadic nature of the caring relationships and the inter-relation of needs (e.g. Twigg, 1996; Fine and Glendinning, 2005). By illustrating why a theoretical framework on the care need-care provision gap should include how care need is being met and any effects on carers, my thesis thus extends current conceptualisations in important ways and helps give a fuller picture of unmet need and its inequalities, underlying mechanisms, and effects.

The social determinants of health are well-researched and well-established. My thesis brings a similar perspective to the study of carers’ outcomes, also incorporating the care provided and the support received. In doing so, it brings together two individual-structural frameworks of how health and other outcomes might be determined: the CSDH (Solar and Irwin, 2010) and the stress process model (Pearlin et al., 1990). The resultant contribution to theory-building is a conceptualisation of unmet need that incorporates a wide and social care-relevant range of individual and structural components and is carer aware and carer inclusive.

The empirical contributions are as follows. First, I add to the evidence base on how provision of unpaid care at higher hours or within the household is associated with poorer outcomes by showing the inequalities within this. This aspect was previously under-researched in studies of outcomes of providing care (Spiers, Liddle, Kunonga, et al., 2021). I also add to the evidence on social isolation among carers caring at higher hours or within the household and how this is differentially experienced. Second, I provide new evidence on the extent to which people with care needs receive care services in the current legislative, policy, and rights context in England. I provide this evidence both for people who are eligible for services and other support, and people who are outside of the eligibility criteria but still have care needs. I also show the perceived reasons for this unmet need. This was previously an under-researched topic with very little research on reasons for unmet need for services that post-date the sweeping changes to rights to services for carers and care recipients since 2014 in England. Not knowing the different reasons for unmet need for services, can hamper policy makers and practitioners taking action to address unmet need; different reasons for unmet need may require different actions. An understanding of the reasons for unmet need can also contribute to unmet need theory, for example by showing how both individual and structural factors contribute to unmet need.

Third, there has been very little research on the consequences of unmet need for either care recipients or carers. My thesis contributes new knowledge on the association between unmet need for services and worse outcomes for carers in a range of life domains and some of the pathways by which consequences are perceived to occur. This includes how choice, and the extent to which it is constrained or unconstrained, is associated with whether and how negative outcomes occur. Fourth, I bring together care-related factors (level and nature of care needs; hours and locus of care provision; informal and formal support for the care recipient) with wider individual and structural determinants to consider the factors which affect carers' outcomes in the round, thus contributing to theory-building. By bringing these factors together conceptually and methodologically, I contribute evidence of the multifaceted ways in which carers could be supported. As a whole, my thesis contributes and adds to the broader body of literature on unpaid carers; support for unpaid carers; and on unmet need and inequalities in care provision, care outcomes, and care service receipt in the English context.

Methodologically, I makes extensive use of the rich data source that is UKHLS and the module on social care collected since 2017; the dataset is still under-used for social care research. I use the data in an innovative way to pair within-household care recipients and their carers. The dataset is not originally paired in this way and it is not that straightforward to do. Other methodological contributions come from the mixed quantitative and qualitative research design. One contribution is that the mixed methods helped shed a great deal of light on the nature of unmet need and the advantages of, and limits to, quantitative measurement of unmet needs for services. A more expansive measurement and conceptualising of unmet need for services, as illuminated by the qualitative results, can give a more accurate estimation and picture of unmet need and of key inequalities in whether care needs are met or not. The binary approach used in most surveys has arguably not been sufficient for investigation of unmet need from a research and policy perspective, as Calderón-Jaramillo et al. (2023) also note in their investigation of unmet need for care across Europe.

Some quantitative surveys do add some nuance. For example, in England, datasets such as the English Longitudinal Study of Ageing, a cohort sample, ask about help with each ADL and IADL difficulty, enabling researchers to know how many needs are unmet in a range from all to none. Although this is again a binary met need for each difficulty, ELSA also asks, ‘Thinking about all the help you/he/she receive(s), would you say that the help meets needs all the time, usually, sometimes, or hardly ever?’ Measures of unmet need in surveys could also benefit from taking into account other aspects of unmet need for services such as adequacy, appropriateness, and quality. My thesis contributes information on what aspects might be included and to wider debates on how to measure unmet need for services in policy, practice, and research. This is a philosophical as well as a measurement issue. Measuring need as met if *any* services are received, even if that is, say, 15 minutes a day for a person with high care needs, is measuring the absolute minimum, that is that needs are not completely unmet. A more comprehensive and nuanced measure would more closely approach ‘met’ care needs in ways that could better enable a full and independent life for disabled or older people and carers.

Bringing together several streams of theory into a combined individual-structural, carer-inclusive conceptual framework shaped the way the analysis explored carers’ experiences of unmet need for services from individual-structural and dyadic perspectives. It thus contributed to the empirical contributions outlined above. In order to understand the structural as well as the individual context and determinants of unmet need and carers’ outcomes, a mixed-methods approach was required (Becker et al., 2012). This mixed-methods approach and what it revealed about the nature as well as the extent and consequences of unmet need for services is a methodological contribution which enabled several empirical contributions. In turn, the methodological and empirical contributions enabled further theory-building and theory-challenging, which in turn informed methods, analysis, interpretation, and theory in an iterative way.

7.4 Implications for policy and practice

The social care policy and practice implications follow on from the empirical, methodological, and conceptual contributions. A substantial implication, and contribution to the policy debate, is that my thesis shows clearly why any consideration of unmet need for care or inequalities in care should include the care dyad, that is it should include the needs, experiences, and outcomes for the carer(s) as well as the disabled person. This would mean, among other things, a policy and practice approach that did not consider care needs ‘met’ if they were being met at a detriment to the carer, and a clear distinction in how care needs are met. There is precedent. The whole family approach is well-established in social care legislation and guidance (Her Majesty’s Government, 2014a, 2014b; Directors of Children’s and Adult Social Services, 2016), if not always well or evenly implemented in practice (House of Lords Select Committee, 2022). However, it is generally seen to mean the children of the adult with care needs; some will be (young) carers, others will not. Whilst outside of the scope of my thesis, it is important to note at this point, that needs being ‘met’ by underpaid and overstretched careworkers is also an important consideration as it can impact disabled people and careworkers alike (Mathew Puthenparambil, 2023; Nishida, 2023).

In addition to incorporating unpaid carers in the understanding of unmet need for services, is the imperative, further identified in my thesis, for more expansive definitions and understandings of unmet need for services in policy as well as research. Conceptualisations and definitions delineate what help should be provided by the state, to whom, and how. Precise definitions may not suit policy makers: demand may not be as great if people are unclear about their entitlements. Less precise definitions may also enable flexibility and professional judgements by social workers, although lack of clarity may cause problems for professional staff as well. Definitions, concepts, and measurement of unmet need also affect what policy makers understand to be the extent and patterns of unmet need and therefore the actions that should be taken, whether they take them or not. As I have argued several times elsewhere in this thesis, excluding carers, or just looking at access to services rather than also experiences of services, gives an erroneous and incomplete picture of the extent and variation in unmet need which is of course an empirical problem, but also crucially, a policy and practice issue as both policy and practice may be predicated on this erroneously-understood picture of unmet need.

Who experiences and who is most affected by unmet need for services is not equitably distributed and this has further implications for policy and practice. By providing evidence on these differences, my study shows which carers are most in need of support. The analysis that informed this particular finding was commissioned by the Department of Health and Social Care in England to address an identified research and policy need. These findings thus directly *informed* social care policy; whether and how policy changed as a result is difficult to ascertain. Social care research, and social policy research in general, can affect policy and practice directly and obviously. However, more often, research affects policy collectively through multiple sources resulting in ‘broader, incremental and often largely conceptual changes' (Boswell and Smith, 2017) in policy, what Radaelli terms 'knowledge creep' (Radaelli, 1995). The implication of this is that research findings may influence policy over long periods through gradual changes in decision-makers' perceptions and ways of thinking. Ultimately, this may result in significant shifts in policy approaches (Boswell and Smith, 2017). However, the pathway, and especially the pathway from a single piece of research, may be difficult to identify.

Showing how some sub-groups of carer-care recipient dyads are more likely to have unmet need for care services, even when they are eligible for support, also has implications for addressing barriers to access such as cost, physical inaccessibility, communication, and cultural appropriateness. Addressing barriers applies to sub-populations of carers and care recipients but also to geographical areas, as my finding on area deprivation and unmet need illustrates. My study did not indicate why people living in more deprived areas experience greater unmet need for services, but as the current funding allocation formula to local areas has disproportionately disadvantaged poorer areas (Foster, 2022), a different way of funding social care at local level seems like a good starting point. Given the widespread unmet need for services I observed in my study, increases in funding and improved ways of allocating resources and commissioning services across the board is another of the implications for policy and practice. Including carers in the unmet need for care picture has the potential to further enhance how this is done and the importance of doing it. My study also indicates policy- and practice-relevant ways in which services can be improved to lead to fuller lives for carers and care recipients.

Showing how carers are also affected by unmet need for services is politically and practically important for the reasons I have just outlined. However, as Papers 1 and 4 show, a number of other factors affect carers' outcomes. This has implications for the policy actions needed, which will be wider than, but still include, policy on social care. For example, actions to address the social determinants of carers' outcomes might include policy on living conditions (housing, neighbourhood, and community) or policy and practice to improve finances in carer-care recipient households. This multi-level approach to addressing inequalities in outcomes is also used in, for example, Solar and Irwin's report on the social determinants of health (Solar and Irwin, 2010), and reports such as the two Marmot Reviews on health equity (Marmot and Bell, 2012; Marmot et al., 2020).

7.5 Implications for research

Future research on unmet need could valuably take into account the conceptual developments of my thesis and take a dyadic approach to unmet need by including unpaid carers in conceptualisations, and measurement, of unmet need for care and not consider care needs ‘met’ if they are being met at a detriment to the carer. Future theory development could expand this conceptualisation further to include all parties, including careworkers.

Future research on unmet need for services, and unmet need for care, should also take into account the measurement issues illustrated by my research findings and discussed in my thesis. This would help give a fuller and more accurate picture of unmet need. Existing surveys and primary survey data could incorporate aspects such as quality, appropriateness, and adequacy and reasons for unmet need, supported by a qualitative element. A starting point for this could be a review of the suitability or otherwise of existing measures, supplementing the work done by, for example, Hill (2022), Vlachantoni (2019) and Kröger (2022), and informed by the qualitative evidence on unmet need.

There are three specific areas where future research could helpfully build on the findings of my thesis. The first is to include the missing voices. My study centres the intersection of being an unpaid carer and people’s gender, ethnicity, socio-economic position, and living conditions. Exploratory analysis for several of the papers examined the intersection between gender and ethnicity and between those characteristics and income/area deprivation. However, sample sizes were too small to pursue this further. This means important intersectional analysis and perspectives are missing. Understanding more about how the intersection of, for example, gender, class, and ethnicity affect carers’ outcomes, likelihood of receiving services, and experiences of the consequences of unmet needs would add considerably to the evidence base. In addition, there are some more marginalised sub-groups of carers that may be missing from the quantitative and qualitative data collection because of initial non-response to the survey or interviews or attrition from the survey. This might include carers from Roma and Traveller or refugee and migrant communities. This research could be peer-led and/or involve participatory methods.

Second, my research found that some sub-groups of carers were less likely to receive services than others, both quantitatively and qualitatively, and sheds light on some of the reasons for this for some of those sub-groups, for example those with limited household resources. However, because of limits to the achievable scope of my thesis and methodological limitations, there are still knowledge gaps concerning reasons why unmet need for services is experienced disproportionately by other sub-groups of carers in my study. Some questions of empirical interest and policy salience to answer if we are to address inequalities in unmet need are why are care recipients living in more deprived local areas less likely to receive services than those living in less deprived areas, even controlling for care need? Area deprivation reflects both individual and structural disadvantage and investigating the role of each would be of policy value. More research could also be done on why ethnic minority care recipients are less likely to receive services.

Third, in writing this thesis, the importance of the type or nature of unmet need for services has become increasingly apparent. This includes aspects of the nature of unmet need described above. It also includes whether lack of services is freely chosen, enforced, or somewhere in between. Work on the dynamics of unmet need would shed further light on the nature of unmet need. Smith and Connolly (2020), looking at the dynamics of unmet need for health care, identified three types of unmet need for health care: (i) non-use of health care services at any time; (ii) delayed and/or diverted use; (iii) sub-optimal use. Building on this, and applied specifically to social care needs, Vlachantoni et al. (2022) identified five possible longitudinal trajectories of unmet need: (i) no longer having a care need; (ii) continued met needs; (iii) delayed met needs; (iv) newly arisen unmet needs; and (v) repeated unmet need. Repeated unmet need might be continuous unmet need but because the data were collected at two year intervals, it is not possible to tell what happens between waves. Research using this typology of unmet need, in conjunction with findings from my and other research on the nature of unmet needs, would add valuably to our understanding of the topic. This research would include expanding on Vlachantoni et al.'s (2022) findings to understand who is experiencing which type of unmet or met need. It would also include an exploration of what any outcomes are and how they occur. Importantly, it would consider how these types of need were met when they were met, take a conceptually and methodologically dyadic approach to unmet need type and dynamics, and include a qualitative component. This would be of academic interest and empirical, conceptual, and policy value.

7.6 Conclusions

Social care and the provision of unpaid care are fundamental to societies worldwide. State, private, and informal provision of care and support for disabled and older people and for carers has the potential to exacerbate or reduce deep inequalities in society related to disability, gender, ethnicity, and income. The empirical, conceptual and methodological contributions of my thesis show how and for whom some of these inequalities manifest and point to some future directions for research and possible policy solutions. My thesis also shows how an inequalities lens can benefit social care research and practice. This important topic does not always get the attention it deserves amongst the maelstrom of the many pressing issues facing social care. And yet, many of these pressing issues – carer strain and underemployment, poorer lives of disabled people, and worsening workforce issues – are fundamentally related to unmet need and inequalities in care. On the other side of the coin, my thesis shows the deep relevance of social care to the gender, ethnic, and socio-economic inequalities debates. Despite this, the study of inequalities in general has focused much less than it perhaps should on social care, particularly in contrast to the attention paid to health, income, and poverty. Of fundamental importance is the acute imperative for action. Unequal effects of providing high levels of care and unequal access to support in the form of services are negatively affecting people’s lives now, with potential for long-term effects into the future. The time for action is therefore also now.

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