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research article

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

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Internationally, many care-recipients and unpaid carers are not receiving the services they need to live full and independent lives, representing substantial social injustice. We 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. We 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.

Key words inequalities in long-term care • unmet need • unpaid carers • social rights

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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 (for example, Rodrigues et al, 2014; García-Gómez et al, 2015; Albertini and Pavolini, 2017; Floridi et al, 2021) and in China (Wang et al, 2020). While 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 while 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

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investigating gaps and inequalities in care. Our 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 for whom they care (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 (Fernandez et al, 2019; O'Rourke et al, 2021). Publicly-funded LTC services are allocated according to both care need and financial eligibility criteria (Her Majesty's Government, 2014). 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. Our 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, 2018a). 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). Our 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; Kroger, 2022). This article draws on insights from these approaches. The article is further conceptually framed by Andersen's behavioural 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 healthcare 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 (for example, Travers et al, 2020; Floridi et al, 2021). Our article 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 our article 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, for example, 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

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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 multiple 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 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 us to explore other definitions and perceptions of unmet need for services, and to bring in carers' perceptions. This meant we 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. As was being able to investigate unmet need for services among a wider range of carers and care-recipients, enabling us to include working-aged disabled people and their carers; a population that is growing in size and policy and practice importance. Thus the functions of the multiple methods research design in this article 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 weakness 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 article 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. We 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. We 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.

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Measures

We 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 care worker/home help/personal assistant; reablement/intermediate care; occupational therapist/physiotherapist/nurse; cleaner; other. We look first 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, we additionally look at service receipt if a person has care needs below the policy-defined eligibility threshold, defined as difficulties with less than three ADLs. We 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 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. IMDs 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 earlier) and unmet need for services. The descriptive analysis used in this article 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 policymakers about

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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, we 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 among 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. Similar 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 us to explore the nature as well as the extent of unmet need. We 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 than others to receive the services they needed. 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; collating codes into potential themes; gathering all data relevant to each potential theme; and reviewing 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

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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; (d) a wider conceptualisation of unmet need for services that included 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 1 shows that approximately half of the care-recipients were male (47%) and half female (53%). Seventeen per cent 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.

The interview sample comprised 26 unpaid carers. Six were male and 20 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, 12 as White, the others did not say. Interviewees were from a wide range of socio-economic backgrounds and geographic areas and types (for example, 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 our 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 1). 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.

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Table 1: 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	
Owner occupied	83.0 (930)
Social housing rented	13.0 (145)
Private housing rented	4.0 (45)
IMD 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)

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 2) 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, while 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). (Results available on request.)

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Table 2: Composition of service recipients and non-recipients

N=1,141	Care-recipient has eligible care need		Care-recipient has non-eligible ADL care need		Care-recipient has IADL need	
	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
Care-recipient is from ethnic minority background (%)	75.4 ns	24.6 ns	**81.8***	**18.2***	92.8 ns	7.2 ns
Care-recipient is from white ethnic background (%)	67.4 ns	32.6 ns	**67.7***	**32.3***	90.1 ns	9.9 ns
Carer is from ethnic minority background (%)	73.4 ns	26.6 ns	77.6 ns	22.4 ns	92.5 ns	7.5 ns
Carer is from white ethnic background (%)	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 total monthly income (mean, £)	1453.64 ns	1286.09 ns	1219.75 ns	1103.02 ns	**1198.42***	**1660.46***
Private rented housing (%)	81.8 ns	18.2 ns	70.0 ns	30.0 ns	90.0 ns	10.0 ns
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
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

Housing tenure was not significantly associated with non-receipt of services (survey data;Table 2).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 among those living in the most deprived local areas.

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

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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 older relative 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 my [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)

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> 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:

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> 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)

The quality of the 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 was 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)

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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 2). 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 this 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)

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> 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

Our 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 our 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 our finding of lower receipt of services for non-eligible care needs than for eligible care needs. However, in our 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 for whom they care, 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 our study, where

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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 our interviews, the expectation came from the care practitioners carrying assessments of care need. 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 our 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 may 'ameliorate but do not remove the increased risk among people in low-income households' (Burchardt et al, 2018: 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. Our 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.

Our 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 et al, 2018b). 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.

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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-aged 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, thus giving a broader view. Interviewees were recruited from a range of regions and hence a range of local authorities – which is 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 our study are issues across the LTC sector as a whole (ADASS, 2019). Our 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 a binary variable 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. While funding for care has recently been increased, this will not be enough to close the gap nor ameliorate inequalities. Furthermore, this extra funding will be derived from a regressive taxation change, so 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-group 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 (ADASS, 2019).

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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.

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Conflict of interest

The author declares there is no conflict of interest.

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