

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

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, our study aimed to explore the impact 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.

Keywords

Unpaid carers; England; long-term/formal care; constrained choices and opportunities

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, 2014); 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, 2014). 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 our 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 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). 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. 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 ASCOT-Carer (Rand et al, 2019), studies on outcomes for carers of unmet, or met, need for services, have tended to focus on single outcomes, usually carer's employment (Heger, 2014; Geyer and Korfhage, 2015; Pickard et al, 2015). Our 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, 2014)

Our 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). We 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, our 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, we 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, we 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, we 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). Services and support received included that provided through day centres, personal assistants, paid home care workers, short breaks in care homes, and mental health services. Some people received more than one service. 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 care for had care needs, and then reported not having received any or adequate services to meet those needs. Subjective unmet need enabled us to explore experiences, preferences and choices as well as access. If the carer perceived unmet need for services, we 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. We 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 (HM Government, 2020). These measures included closure of many long-term care services provided by the private, public and/or voluntary sector 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 care workers, 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 us 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 new 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 used NVivo 12 software (QSR International Pty Ltd., 2018) 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, we use pseudonyms and have further anonymised the results by removing potentially identifying information.

Results

Consequences of unmet need for services

We look first at 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, we 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 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 care worker 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 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, restrictions placed on movement and social interaction. Therefore analysis on the relationship between unmet need for services was restricted to interviews carried out pre-COVID-19. The following comments illustrate 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.)

Carol. 'I would like to be able to get out evenings with more simplicity. They cut back the hours I could have in the last round of cuts, which meant that although I could have help during the day I couldn't ever get out in the evening..... I haven't been out at night for three months, I don't think.....Sometimes I have been very stuck at home, unable to get out, with insufficient help. You know, I can't leave him.' (Provided care for partner who had paid care visits and attended day centre; perceived as needing more services.)

Lack of community participation potentially had impacts on the community itself as well as the carer. A number of carers interviewed ran community group and/or supported others in the community. They reported being less able to do this because of the time spent providing 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 our 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 has 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 cheated 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 our study. This may be because employment effects usually occur over longer timeframes (Arksey & Glendinning, 2008) and when the interviews took place COVID-related cessation of services had only been in place for a few months. However, the ability to balance work and care was also related to an increase in flexible working from work during COVID-19 experienced by some carers in our 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; a UK government 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 on the multiple areas of carer's 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 our 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. We saw both multiple impacts and trade-offs in our 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:

'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 our 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 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 our 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 can 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 care workers.

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 person they cared for.

Discussion

Our 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 US 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). Our 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 our 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 carer's 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, 2020). 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 our 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 our study, as in others, perceived choice and the meaning a person attached to their objective caring situation, were important explanatory factors for carer's mental health, wellbeing and personal and social relationships. There are two key implications of our 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 our 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 our 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 we were able to explore newly unmet need during the pandemic, but a possible limitation, as our 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 our relatively small sample size and sampling strategy mean we cannot generalize our 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 are 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 costs (Rodrigues et al, 2013), economically, 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 toward 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 (Yeandle et al, 2007; Brimblecombe et al, 2018b). 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.

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