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Health Policy

Covid-19 and UK family carers: policy implications

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Abstract

Summary

Informal (unpaid) carers are an integral part of all societies and our UK health and social care systems are dependent upon them. Despite their valuable contributions and key worker status, their lived experiences, and the impact of the pandemic on their functioning and needs have been neglected. This paper brings together a broad range of clinicians, researchers, and those with lived experience to share their reflections on the impact of Covid-19 on UK carers, many of whom have felt abandoned while services shut down and focused on the pandemic. It focuses on children and young people, adult and older adult mental health, alongside intellectual disability, and neurodevelopmental conditions, and across different care settings over the lifespan. Policy recommendations are offered with the unequivocal aim of improving outcomes for all carers.

Background

11th March 2021 marked the twelve-month anniversary of the World Health Organisation (WHO) declaration of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic [1]. On this date, the global number of recorded Covid-19 deaths was approximately 2.6 million people, which included over 124, 987 deaths in the United Kingdom (UK); a figure that positions the UK with the highest Covid-19 fatalities across Europe, and top five nations of overall fatalities globally, with only the USA, India, Brazil, and Russia reporting more deaths [2].

To reduce and control virus transmission and subsequent burden on the National Health Service (NHS), particularly the need for intensive care provision, the UK government introduced a series of national, regional and locally enforced lockdowns which included the closure of educational institutions, community facilities (e.g. libraries), and all non-essential shops and services. People have been instructed to remain at home, and where possible, to work from home, to home school, and to avoid close physical proximity (to socially distance) with others outside of their immediate household, including first-degree relatives, friends, and the general public [3].

Public health guidelines, including the use of face masks, frequent hand hygiene, and restrictions on individual liberties and freedom of movement, underpinned by an Act of Parliament [4] have co-occurred with a sharp rise in unemployment, households experiencing food and financial insecurity (e.g. accessing food banks), and domestic violence [5-7]. In parallel, access to and the delivery of primary and specialist health and social care services have been significantly impacted by the pandemic and lockdown restrictions, with many undergoing rapid alterations to their standard

operating procedures. The implementation of remote health delivery, including telephone and online consultations for some, delayed, or cancelled assessment and treatments for others, have increased hugely since the pandemic onset [8-9]. This occurred at the time that the UK negotiated the final terms governing its exit from the European Union(EU), which has had implications for the residency and employment rights of EU nationals in the UK, including those in health and social care.

The adverse mental health and wellbeing sequelae of Covid-19 have been widely reported. Data published from nationally representative samples in the UK [10-12] and elsewhere [13-14] suggest the first few weeks and months following the start of the pandemic and implementation of the first lockdown were associated with large deteriorations in mental health, including elevated depression and anxiety symptoms, and markers of poorer wellbeing such as loneliness. Specific populations have had poorer mental health linked to Covid-19 including children and younger people [15-17], university students [18], frontline health workers, teachers, and in racial and ethnic minority groups [19-20]. However, across all the different groupings, there has been considerably less focus on the health impacts and the identified needs of informal family carers.

Informal (unpaid) caregiving

In the UK approximately 26% of the population, around 13.6 million people, have informal caregiving roles. This figure includes a reported 4.5 million new carers since the start of the pandemic [21-22]. Informal (unpaid) carers are engaged in a broad range of duties for relatives and close others who are living with physical, mental, and social disabilities, and care needs linked to advanced age. Carers are heterogeneous and include adults caring for their young or adult children or for their partners, parents,

and siblings, as well as the young, (i.e. <18 years) caring for adults. Although typically a female dominated activity, the informal carer role is intersectional with gender and other attributes such as ethnicity, age, and social and economic status [23]. Informal caregiving is an essential feature of health and social care systems against a backdrop of limited financial resources and competing health and care priorities; a growing aging population and increased prevalence of age-related conditions (e.g. dementia); and a focus on community based care for those living with disabilities. However, caregivers' own wellbeing has largely been neglected [24-25]. This is despite their large numbers, their unique and valued contribution to the health and wellbeing outcomes of care recipients, and the dependence of healthcare providers and society on their contributions. On an almost daily basis, there is news and discussion on the rapidly changing landscape of Covid-19, its new variants, vaccination efficacy, rollout plans and priority groups, and revisions to shielding categories and lockdown restrictions. However, the plight of informal carers has not attracted the same attention of clinical service providers, policy makers and the wider public.

Aims

Our paper seeks to highlight the needs and issues faced by informal carers during the pandemic and to offer recommendations and policy considerations. We convened a diverse group of carers, clinicians, and researchers to share their experiences and reflections on the impact of Covid-19 on carers. Their expertise was focused across the lifespan of children and young people, adult and older adult mental health, alongside intellectual disability and neurodevelopmental conditions and across different care settings, including the family home.

General caregiving challenges

Caregiving and remote access

Over the course of the pandemic there has been a focus on the remote access of health and social care provision, and this has further highlighted the issues of digital poverty and social inequalities [26-28]. Primary care consultations have witnessed a shift to 90% General Practitioner remote consultations [29]. However, the specific needs of informal carers and remote access have been overlooked.

We already know that family carers, across the life course, engage in diverse care activities, including personal and intimate self-care, emotional, social, psychological, financial, and physical health support [30-31]. For care recipients with a broad range of mental health conditions and communication needs (e.g. psychosis), feedback from carers can be invaluable to healthcare providers. This is particularly evident when care recipients might be less motivated, or not in a position to communicate or engage with their care and treatment plans because of their age, their developmental phase or specific nature of their difficulties (e.g. hallucinatory experiences, cognitive decline, suspicion and paranoia).

Prior to Covid-19, some family carers might have been invited into face-to-face health provider review meetings. Instead, some families, particularly those not co-resident with care recipients, have been excluded from this process. If we consider informal caregiving relationships, where the care recipient was residing in separate accommodation (e.g. supported housing) from their carer, issues related to insufficient time, regulations about face-to-face contact, and limited workforce resources have led to staff prioritising access just with care recipients. Consequently, carers have reported

a sense of disconnection from their relative's care and 'abandonment' from the service provider.

In households with co-residing carers and care recipients, implementation of remote access appointments has afforded minimal privacy for carers to explain their experiences and observations pertinent to care recipient assessment and treatment plans. This is important particularly where carer accounts might differ from care recipients and has potential implications for the emotional or physical safety of carers. For some carers, there has been a concern that the care team have not been able to access the most accurate picture of a care-recipient's wellbeing and functioning because carers have not been able to speak freely and provide their perspective. Further, remote access appointments, typically by telephone, do not ordinarily make provision for three-way discussions, and this too can make it harder for carers. For children and young people, parents and carers will often be the ones who need to make remote sessions happen (e.g. by being available themselves, encouraging the young person to attend). The overall impact is that family carers find it more difficult to advocate with health and social care providers at the very time when many care recipients would particularly benefit from their input over pandemic related challenges.

Caregiving and hospital visits

Covid-19 management plans and associated hospital and visiting restrictions have left many carers of people across the lifespan feeling isolated and fearful about the wellbeing of their care recipient in psychiatric units [32]. This fear is often linked to concerns about hospital acquired Covid-19 or how they would fare were they to test positive during an admission, in terms of tolerating treatments and management strategies (e.g., isolation). These concerns were realistic with excess infection and

mortality in hospital settings, at least in the initial phase of the pandemic [33]. Restrictions on onsite face-to-face contact and visits have exacerbated these concerns and represent a source of considerable distress to carers. Direct exposure to, or being informed about, a care recipient's upset and puzzlement about lack of family visits during a hospital admission has been difficult for carers, in addition to dealing with the circumstances and context of psychiatric admission. This is particularly challenging in those instances where care-recipients have lacked an awareness of the pandemic and/or shared view of what the virus has meant for organisations, freedom of movement, and infection control procedures.

Psychiatric inpatient services have sought to employ alternative, remote based methods for informal carers to maintain contact with care-recipients. However, in reality, its successful implementation is dependent upon several factors including the mental state, wellbeing and receptiveness of the care recipient, availability of staff, and the digital resources and capacity of service providers. The confidence of carers, who themselves vary in demography and technology proficiency, to participate in varied communication strategies, is easily overestimated. Yet the negative impact on carers not able to visit is under-estimated.

Specific issues across the lifespan

Children and young adults

In general, parents and carers of children and young people have reported a negative impact on their mental health and wellbeing, with observable deterioration following implementation of national lockdowns and home-schooling. However, there are sub-groups that have shown greater vulnerability to poorer levels of mental health, including those in single adult caregiver households, families on low

incomes, and where children and young people have special education needs or neurodevelopmental disorders [34-35]; many have found themselves forced to take on roles that might otherwise have been offered by school based pastoral support and mental health professionals [36].

As the pandemic unfolded and lockdown measures followed, we have seen a parallel public health focus on promoting wellbeing through managing (restricting) food and alcohol consumption and introducing optimal exercise routines. Though laudable and led by evidence highlighting significant increases in problematic drinking and lifestyle behaviours during lockdown [37], and confirmed links between obesity, increased risk of poorer Covid-19 outcomes [38-39], this focus has proved even more complex for those with emerging or established eating disorders [40].

Carers are often involved in facilitating positive behaviour change of care recipients through employing different strategies, including motivational interviewing and anxiety management. With the transfer of specialist eating disorder services to remote access provision, healthcare providers have been increasingly reliant on the involvement of family carers to support care recipients with accessing their physical health checks (e.g. weigh in, blood tests). These can also impact on the caregiving relationship and support needs of the carer.

When we consider individuals, particularly young children and young people, living with complex neurodevelopmental needs such as autism spectrum disorders (ASD), intellectual disability, and other neurodevelopmental conditions, their interface with the world is often mediated via their carers. Family carers are frequently the chief negotiators and advocates of which services their child can access, including those within the family home. This liaison with statutory, voluntary, and third-sector service

providers can leave carers as de facto case managers; a considerable responsibility, particularly for single parent households.

The pandemic and changes to service delivery have increased uncertainty for nearly everyone. For specific groups, however (e.g. those with ASD), who depend on routines, consistency, predictability, and familiarity to function optimally in their environments, the impact on their behaviours and wellbeing and direct and indirect implications for the wellbeing and needs of informal carers, have not been fully considered [41-42]. For example, we know lockdown restrictions on educational access and specialist learning provision, and the cessation of community-based resources (e.g. swimming, soft play), which are essential elements for families in managing the daily and unique challenges of their caregiving role, have left many families feeling desperate and isolated [43-44]. Sources of support (such as day care, individual help, educational provision) that parents might have used to prior to the pandemic, and which supported their efforts in managing the impact of their child's complex needs on their wellbeing, have largely disappeared [45]. Compounding this effect, sources of support for carers themselves have been less available. In addition, some young adults living in supported residential group settings have returned to their family of origin, initially as a temporary measure, with the intention of minimising the risk of virus transmission. Such developments have presented new challenges and stressors for both carers and recipients) [43-44].

In young children (and adults), complex neurodevelopmental needs will often co-occur with other morbidities, including Axis 1 mental health conditions such as anxiety or eating disorders, and physical health problems, which add to the challenges of the caregiving role [46-47]. Though not exclusive to, or applicable, to all children and adults with complex neurodevelopmental needs, the national lockdowns, with their

service closures, reduced footfall in public places, and an overall quieter and slower daily life pace were believed to have led to reductions in common sources of anxiety and stress. Thus, the easing of lockdown measures and re-entry into our 'usual' lives (e.g. school) can be linked with mixed emotions for carers. For some, the end of lockdown will be a return to old challenges (e.g., supporting a young person with mental health difficulties and social vulnerabilities with school attendance). In contrast, understanding and adhering to lockdown rules have sometimes presented unique challenges for carers, such as care recipients 'over compliance' or literal interpretation of public health guidance. Some families have dealt with situations where care-recipients have chosen not to leave their homes, under *any* permissible circumstances (e.g. shopping) and/or not to see others, including family carers, as part of their literal interpretation of public health guidance. In these situations, family carers have had to engage in different strategies to mitigate the potential for care recipients acquiring further health and social disabilities, as well as source creative ways to deliver usual care.

In addition, there are stressors for carers currently waiting for the commencement or completion of the diagnosis process for their loved one with complex neurodevelopmental needs. In some areas, for example, Covid-19 has added further to diagnosis assessment waiting times that were already two to three years [48]. This, in part, reflects the transition services have had to make to adjust to and integrate the collection of diagnostic data using remote methods which, hitherto, was gathered across settings, including the family home and school. Since the diagnosis is often the required gateway for accessing specialist services and educational support, diagnostic delays exacerbate the stress exposure and strain for carers and the vulnerability of the family unit.

Older adults

The disproportionate number of deaths recorded in UK care homes for older adults was only reported a few months following the onset of the pandemic [49]. It also sat alongside the existing, but widely publicised, data and public health messages that Covid-19 differentially impacted older adults and those with pre-existing health conditions. It is in the context of this background information that carers' concern for older adults with underlying health conditions are best understood. This situation is further complicated for carers of relatives residing in care homes, where policies of no family visits or close contact (e.g. hugs), or severely restricted visits (e.g. through a bedroom window) have dominated over the course of the pandemic and been both frustrating and distressing. Like the rest of the nation, family carers of these older adults have been exposed to daily media updates on coronavirus infections and deaths, but without being able to witness, first hand, how their relative was. For some, their contact has included FaceTime and video conferencing platforms; for others their relative is not cognitively able to use them, even with help, and telephone updates from third parties (i.e. paid care staff) have had to suffice.

The additional emotional challenges (e.g. feelings of loss, grief, frustration) faced by families of care recipients living with organic conditions, typically dementia related disorders that impair memory, recognition of close others, and communication styles, have had limited coverage, despite the progressive nature of the condition. These feelings have been complicated by variability in visiting policies between regions and individual care home providers and by concern and observations that their relatives deteriorate faster when isolated [50].

If we focus on family carers that are co-resident with older adult care recipients with dementia related conditions, their own risk benefit calculations have left some declining offers of home care [51]. This is because of fears that formal (paid) carers (i.e. outsiders), might change frequently and be a source of infection. Without external home support, family carers have had to fill this gap. Additionally, services care recipients might have accessed outside of the family home (e.g., respite care, day centres), have been closed or severely restricted in the pandemic [52-53]. Consequently, family carers have been left supporting relatives, who themselves may have become under-stimulated and distressed by these losses and changes to their routines. Therefore, family carers have had reduced support but increased caregiving load over the pandemic, including exposure to dementia behaviour changes that can be both challenging and anti-social. Despite this, some carers have also been reluctant for care recipients to be admitted into specialist care facilities due to fears about being unable to see them or only see them just before their death.

These informal carers of older adults have also been impacted by digital inequalities and access issues. Some, (e.g spousal partners) have not had Internet access or have not been confident with its use. Outside of home visits, care has therefore relied heavily upon phone-based assessments. This has its own limitations on what family carers can report or feel comfortable sharing, in the presence of the care recipient. This can include concern about protecting the reputation of the care recipient in the eyes of others, particularly if this relates to sharing information about disinhibited, anti-social behaviours, or aggression. Consequently, details about the family experience and needs have risked being missed, unexplored, and/or mis-interpreted, particularly in situations where the family caregiving relationship was breaking down.

Family carers of older adults with dementia related conditions provide the bulk of their community-based care and were already over stretched and stressed before the pandemic. Coronavirus and the lockdowns have left many carers of older adults with dementia conditions stuck in a vicious cycle of social isolation, adverse impact on care recipient illness related symptoms and behaviours, and limited or absent social or physical, as well as mental health, professional support, due to concerns around virus transmission within the home and risk of death [54].

Additional health morbidities

The increased vulnerability to Covid-19 and poorer outcomes, including death, for people with physical health morbidities (e.g. obesity, diabetes, respiratory conditions) is well established, as is the importance of their optimal treatments [55]. Supporting care recipients with multiple morbidities to access the right care has always been a challenge for carers but experienced at much greater levels during the pandemic. This is particularly the case for those from racial and ethnic minority groups, where there has been a sustained spotlight on Covid-19 and its impact. Care for health morbidities is typically met by different health providers (e.g., primary/secondary care), staff groups, and often across different geographical locations. For many carers, the navigation of these health silos during the pandemic has been problematic.

Discussion

Our discussion on the experiences of informal carers over the course of the pandemic remains incomplete without acknowledging that carers are rarely afforded options other than to carry on, and the pandemic has not changed this. Covid-19 and its impact on community facilities, and health, social care, and educational provision, has helped to re-focus attention on the care and support inequities carers were already dealing

with, prior to the pandemic. Health and social care systems remain inextricably linked, influenced by, and heavily reliant upon the simple fact that primary carers are often close family members who continue to provide care, irrespective of support they may or may not receive from external agencies.

Covid-19 has focused a sharp lens on societal inequalities, including the higher rates of co-morbidities associated with poorer Covid-19 outcomes and/or the disproportionate number of Covid-19 deaths in marginalised communities. These communities include people with intellectual and developmental disabilities, severe mental illness, residents in care homes, people with dementia at home, those from racial and ethnic minority backgrounds, and those living in deprived areas [55-56]. Our own experience, and clinical and research observations over the preceding 12 months, speak to a process whereby families have found themselves locked in virtuous or vicious cycles of functioning, such that those who were doing better at the start of pandemic generally continued along the same trajectory. However, for those who were struggling from the outset, these mainly continued and worsened [57]. Social inequalities, including less optimal living arrangements (e.g., living in overcrowded accommodation, limited/no access to green spaces), financial insecurity, and social isolation appeared to play key influencing roles on whether families found themselves in vicious or virtuous cycles.

Carers have been resourceful in responding to the immediate challenges of the pandemic and problem-solving specific presenting issues. We know, however, that their adaptations have not been without cost to their own mental and physical health, wellbeing, and family relationships [58]. Much is already known about the poor psychological health and wellbeing of family carers, predating the pandemic [59]. The importance of ensuring that family carers are not left socially isolated and have

opportunities to connect with peers, safely, must be a priority for future problems of this nature, and we could consider what we might all have learned from these experiences.

Helping families to establish their own closed support bubbles with a small group of other families would have been helpful. These could offer a range of functions including companionship and mutual support, particularly in single carer households, plus information and coaching. They could also provide opportunities for supporting blended learning for school age children when school building access or school provision is disrupted. Data from consultations events with parents and teachers, on this type of lockdown model are ongoing and have been encouraging [60]. Disseminating written and audio-based material on how to deal with different family presentations and sharing resources digitally for those families with access, would also be useful [61].

Informal carers are a precious and invaluable resource. The pandemic has highlighted their 'hidden key worker' status. It is essential, however, that as we make progress with the pandemic and vaccination programme, our health, social care and education, systems avoid taking carers for granted and inadvertently exploiting their involvement, goodwill, and kinship. Addressing the health and wellbeing needs of carers has never been a central objective of health and social care providers.

Policy recommendations

- 1). The ongoing programme of vaccination for Covid-19 should recognise informal carers as 'hidden key workers' whose contributions is often just as essential as paid frontline health, education and social care staff. However, to ensure that carers no longer remain hidden from services and overlooked for important health interventions

[62], we recommend an ongoing incentive scheme and national standard for general practitioners to identify informal carers and record updated contact details, to implement subsequent effective and targeted support packages.

2). Prior to the pandemic, carers reported unmet needs for emotional, social practical, and financial support. These needs have increased. We suggest that public health programmes at community and national levels publicly and proactively recognise carers as a *vulnerable group*, whose unmet mental and physical health needs have substantial negative implications not only for carers themselves, but also for care recipients, health and social care systems. The inclusion of carer focused public health messaging and accessible resources to support carers with their wellbeing, using different communication mediums, would be of benefit.

3). Ensuring carers can access freely available information and resources to target and facilitate their wellbeing is recommended. Developing scalable programmes that help carers deal with the immediate impact on their mental health must be a priority; for some this might include wider and larger provision of special funded leave from employers and financial support for those in Gig industries. It is important that employers actively seek to understand the impact of caregiving roles amongst employees. Facilitated access to peer networks and prioritised access to mental health support are also indicated.

4) The provision of respite care for co-residing carers, who have not had the opportunity to have breaks, should be prioritised. Respite care can yield benefits for carers and care recipients, and this will be particularly indicated given an increase in caregiving load over the pandemic that has left many carers reporting fatigue and burnout.

5). The detrimental impact on carers who have not been able to visit loved ones in residential care and inpatient psychiatric admissions must not be overlooked and underestimated. It is not uncommon for people living with life-long care needs that impact their everyday behaviour and functioning, to reside in a specialist care home facility. Ensuring that health and social care providers have sufficient digital resources to adequately facilitate contact between informal carers and care recipients should be prioritized. These need to include identified staff members who can support carers and care recipients, who might require additional help with using remote access.

6). Supporting families without Internet access and/or devices to have access to large screen mobile and portable devices (e.g. Tablets), without incurring additional financial responsibilities will enable many carers to have contact with non-resident care recipients and remain involved in their care. The appreciable benefits for care recipients are also recognised.

7). To minimise the need of carers feeling forced to choose between maintaining safety in their homes and being supported, the provision of adequate personal protective equipment and the same care staff, plus enhanced and rapid Covid-19 testing procedures should be a standard.

8). Creating opportunities for co-production with informal carers to identify optimal approaches and pathways to supporting care recipients with multiple morbidities to access their health and social care is recommended.

9). The heterogeneity of carer backgrounds, including ethnicity, socio-economic status and family situations must be acknowledged. The importance, therefore, of health, education, and social care providers avoiding the use of a homogenous lens for carer narratives and needs is emphasized. A condition specific approach to examining the

needs of carers during Covid-19 might be a helpful starting platform. This would allow for greater flexibility in understanding how disability specific issues might have impacted, and the different lessons to be learnt, as well as future needs led and targeted support and care options.

10). Closer partnership working between health, education, and social care providers will minimise the risk of carers (and care recipients) amassing high levels of unmet need that no single provider views as their job to address. We must re-double our efforts in supporting families, and place carers at the centre of care provision, as we all stand to lose without this approach.

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