CARING and COVID-19
Loneliness and use of services
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Professor Sue Yeandle is Professor of Sociology in the Department of Sociological Studies at the University of Sheffield, Director of the Centre for International Research on Care, Labour & Equalities (CIRCLE) and the Sustainable Care programme’s Principal Investigator.
Unpaid carers support people who need help to manage everyday activities, usually because of illness, disability or advanced age. In the early months of 2020, as the COVID-19 pandemic spread across the UK, Government introduced ‘lockdown’ measures that restricted people’s movements and their freedom to spend time together. These measures, and the priority given within the NHS to treating people with COVID-19, also affected access to health and social services.

This second report in the Sustainable Care programme’s Care Matters Series looks at carers’ experience of feeling lonely and at their use of health, social and community services in April and May 2020. It explores the responses of a large, representative, sample of the UK’s population collected in the Understanding Society panel study. Where possible, we have compared data on these topics with information on the pre-pandemic situation. As noted in our first Care Matters report, an estimated 799,583 carers reported COVID-19 symptoms in April 2020, at which point 60,180 carers had been tested for the virus.

Caring can be a lonely experience, as shown in other research, including the Getting Carers Connected and The World Shrinks reports produced by our programme partner Carers UK in 2019. This new report shows that 1 in 3 female carers reported feeling lonely in May 2020, and that carers were more likely to have felt lonely than other people.

The report also shows that during the lockdown, 9 in 10 carers awaiting an NHS treatment had it postponed or cancelled. Carers also found it more difficult than other people to get in-patient services, to access their GP or to use the vital NHS111 service. Beyond the NHS, half of carers who needed formal care could not get this support. The Government’s policy of ‘protecting the NHS’ did not, it seems, extend across all the services it provides, or to crucial services needed in the community.

We shared our findings with Carers UK. Their comments on the study findings and recommendations for Government and policymakers on how the difficulties it highlights can be avoided in future are included at the end of the report.

COVID-19 has focused new attention on the importance of care. As this new report shows, some of the restrictions Government introduced in spring 2020 had troubling effects on carers. We hope the report will raise awareness of this situation so that, in any similar future scenario, carers can be protected from feeling lonely and from being unable to access crucial health and care services.

Helen Walker, Chief Executive, Carers UK

As a member of the NHS Assembly and working closely with all parts of the NHS, these results from the Universities of Birmingham and Sheffield come at a particularly useful time from as the NHS plans for winter and preventing and preparing for a potential second wave. Carers UK is pleased to work with Sustainable Care to ensure this work has the impact it needs to improve support provided to carers and their families.
KEY FINDINGS

This report focuses on experiences of feeling lonely and of accessing support among a key group of carers in April and May 2020, during the official COVID-19 'lockdown' period. It contrasts their experiences with those of other people.

An estimated 6,048,286 adults in the UK provided care to someone living outside their own household in 2020. They are a 'subset' of the 10,991,440 estimated adult carers.

LONELINESS

Our analysis shows high levels of loneliness in May 2020 among carers who were female, employed or younger:

- 1 in 3 female carers (1 in 4 male carers) had felt lonely in the previous 4 weeks
- 1 in 3 carers who had a paid job (1 in 4 carers without paid work) had felt lonely
- Carers were more likely to have felt lonely than other people
- Loneliness varied greatly by age: over half of carers aged 17-45 had felt lonely compared with fewer than 1 in 4 carers aged 65 or older.

CHANGES IN FEELING LONELY

Changes in feeling lonely (between 2019 and April / May 2020) varied by sex.

- Figures for the 1 in 3 female carers feeling lonely in April 2020 were higher than in 2019
- Working carers were more likely to feel lonely than carers without a paid job.

ACCESS TO HEALTH SERVICES

During the lockdown, many people were unable to access NHS services:

- 1 in 4 carers (1 in 5 other people) were undergoing or waiting for an NHS treatment in April
- 9 in 10 carers (8 in 10 other people) had their treatments cancelled or postponed

Among people with health conditions, 1 in 3 people requiring NHS services reported unmet need in April:

- 4 in 5 carers (3 in 4 other people) did not get a hospital in-patient service they needed
- Over half of carers who needed the NHS111 service (NHS24 in Scotland) were unable to use it or decided, during the pandemic, not to access it
- Half of carers (1 in 2 other people) could not get an outpatient service they needed
- 1 in 4 carers in April, and 1 in 5 in May, needed to, but could not, access their GP.

ACCESS TO SOCIAL AND COMMUNITY SERVICES

In April 2020, half of carers with health conditions (2 in 5 other people) needed community services. Overall, 1 in 4 carers needing help did not get a service they needed. Figures improved in May, but carers remained worse off.

- In April, 50% of carers (2 in 5 other people) needing formal care did not get it
- 2 in 5 carers and others who required a psychotherapy service did not get it
- 1 in 6 carers (1 in 4 other people) were unable to access required pharmacy services.

About the study

‘Carers’ were identified by combining data in the COVID-19 April 2020 wave¹ with data in wave 9 (2017-19)² of Understanding Society. Wave 9 asked people if they provided care to anyone outside the household who was elderly or had a long-term illness or disability. The COVID-19 April 2020 wave asked respondents about care for persons outside the household (data on their age, long-term illness or disability status were not collected). People who answered ‘Yes’ to both questions are the (unpaid) carers providing care outside the household referred to in this report.
CARING and COVID-19
Loneliness and use of services

New analysis of the COVID-19 April and May 2020 survey and 2017-2019 survey of Understanding Society [the UKHLS] shows that:

LONELINESS AND CARE

1 in 3 female carers had felt lonely in the previous 4 weeks
1 in 3 carers who had a paid job had felt lonely
Carers were more likely to have felt lonely than other people
Over half of carers aged 17-45 had felt lonely

CHANGES IN FEELING LONELY

Figures for the 1 in 3 female carers feeling lonely in April 2020 were higher than in 2019
Working carers were more likely to feel lonely than carers without a paid job

ACCESS TO HEALTH SERVICES

9 in 10 carers had treatments cancelled or postponed
4 in 5 carers did not get a hospital in-patient service they needed
Over half of carers who needed NHS111 could not access it
1 in 4 carers needed to, but could not, access their GP in April

ACCESS TO SOCIAL AND COMMUNITY SERVICES

In April 2020, 1 in 4 carers needing help did not get a service they needed
In April, 50% of carers needing formal care did not get it
2 in 5 carers requiring a psychotherapy service did not get it
1 in 6 carers were unable to access required pharmacy services

In this document, all references to ‘carers’ are to people in the UK who are unpaid carers for people who live outside their home.
Loneliness and care during the COVID-19 pandemic

Carers who are female, employed and younger are more likely to feel lonely

In May 2020, 1 in 3 carers (32.6%) said they had felt lonely in the previous four weeks. This varied by sex: more than 1 in 3 female carers (36.3%) had felt lonely, compared with fewer than 1 in 4 male carers (23.5%) – a striking ‘loneliness gap’ of 12.8% (Figure 1).

Figure 1: Loneliness and caring by sex

Figure 2: Loneliness and caring by employment

‘Working carers’ (carers who also have a paid job) were more likely to have felt lonely (in May 2020) than carers who were not in employment. More than 1:3 (37.4%), compared with 1:4 (26.8%) had felt lonely – a ‘loneliness gap’ of 10.5% between these groups of carers (Figure 2).

Among all people in paid work, those who were carers reported loneliness (37.4%) more often than other workers (33.0%) - a loneliness gap of 4.4% between carers and other workers (Figure 2).

In all age groups, carers reported feeling lonely more often than other people of the same age (Figure 3).

Carers in younger age groups were particularly likely to have felt lonely. In May 2020, more than half of younger carers (58.1% of those aged 17-30 and 51.3% of those aged 31-45) had felt lonely, compared with fewer than 1 in 3 carers aged 46-65 (30.7%) and less than a quarter of carers aged 65 or older (23.5%) (Figure 3).
Changes in feeling lonely

Feeling lonely varied by both sex and age in the early months of the pandemic

The proportion of female carers who felt lonely was higher in April and May 2020 than before the pandemic, although this was not the case for male carers (Figure 4).

Loneliness among female carers rose by 5 percentage points between 2019 and April/May 2020 [from 32.2% in 2019 to 37.4% (April) and 36.3% (May) 2020].

Thus in the early months of the pandemic, a large loneliness gap developed between female and male carers [rising from 3.3% in 2019 to 12.4% in April and 12.8% in May 2020] (Figure 4).

Figure 4: Changes in loneliness by sex

Loneliness among female carers rose by 5 percentage points between 2019 and April/May 2020 [from 32.2% in 2019 to 37.4% (April) and 36.3% (May) 2020].

Thus in the early months of the pandemic, a large loneliness gap developed between female and male carers [rising from 3.3% in 2019 to 12.4% in April and 12.8% in May 2020] (Figure 4).

Figure 5: Changes in loneliness by employment

Both before and during the pandemic, working carers were more likely to feel lonely than carers who did not have a paid job (Figure 5).

Here too, a larger ‘loneliness gap’ emerged. In 2019, 1 in 3 (33.54%) working carers reported feeling lonely, about 5% more than other carers (28.43%).

For working carers the figures in 2020 were 36.9% (April) and 37.4% (May) (Figure 5).

Overall, the loneliness gap between employed and other carers increased from 5.1% in 2019 to 6.9% (April) and 10.5% (May) in 2020 (Figure 5).
Experience of health services during the pandemic

Many people were unable to access NHS services during the pandemic

In April 2020, almost 1 in 4 carers (23.5%) were undergoing or waiting for an NHS treatment, compared with 1 in 5 other people (20.2%).

In April 2020, the vast majority – 9 in 10 – of the carers who were undergoing or waiting for NHS treatments (89.3%) said that their treatments had been cancelled or postponed. This figure remained high in May, dropping slightly to 8 in 10 (81.2%). The figures were higher in both months for carers than for other people, around three-quarters of whom [77.0% in April and 72.9% in May] were similarly affected (Figure 6).

Figure 6: Cancellation of NHS treatment

The proportion of carers requesting an NHS treatment decreased from 23.5% in April to 18.0% in May; this is a little higher than, but similar to, the decrease (from 20.2% to 16.0%) reported by people without caring responsibilities (Figure 7).

Figure 7: NHS treatment and care

In the early months of the pandemic, high proportions of people had a health condition and needed at least one of the NHS services (a GP consultation, to access a medical prescription, a hospital outpatient or inpatient service, or to use the NHS111 service). Among carers, the figures were 82.6% (April) and 81.4% (May), compared with 85.51% (April) and 82.7% (May) for other people who needed such support (Figure 8).

Figure 8: Demand for NHS service and caring
Difficulty in accessing support

Unmet need for (any type of) NHS service among people with health conditions was high

One in three carers with a health condition (34.3%) reported unmet need for NHS services in April, compared with just over 1 in 4 (28.2%) in May. For people who were not carers, the comparable figures were 30.3% (April) and 23.4% (May) (Figure 9).

There was notable unmet need for NHS 111 services too. In April, well over half (58.1%) of carers, compared with 1 in 3 non-carers (33.3%), required the 111 service but were unable to access it. In May, the figures were just under 1 in 2 for carers (48.4%) and about 1 in 5 for other people (20.6%) (Figure 11).

Difficulty in accessing these services varied according to the service required:

Inpatient services were especially difficult to access. In April, more than 4 in 5 carers (82.9%, compared with 75.6% of other people) had an unmet need for an inpatient service. This figure remained high in May, 74.3% for carers (68.9% for others) (Figure 10).

Figure 9: Unmet need for NHS service and caring

Figure 10: Unmet need for NHS inpatient services and caring

Figure 11: Unmet need for NHS 111 services and caring
Difficulty in accessing support

Many people were unable to access NHS services during the pandemic

Accessing outpatient services was also very difficult. In April, almost half of all carers (48.9%) were unable to access an outpatient service, compared with 4 in 10 non-carers (44.5%); in May these figures were 49.6% for carers and 40.3% for other people (Figure 12).

Accessing GP services was also problematic. In April 1 in 4 (24.3%), and in May 1 in 5 (19.9%), carers were unable to access their GP, similar to the figures for other people (25.6% and 20.7%) in these months (Figure 13).

Access to medical prescriptions was, by contrast, far less affected. Fewer than 1 in 50 carers (1.9% in April; 1.72% in May) were unable to get a prescription that they needed, compared with 1.2% and 1.1% in the same months for other people (Figure 14).
Many carers could not access social and community care services during the pandemic

In April 2020, half of carers with health conditions (50.5%) needed one or more of the following social and community care services: pharmacy services; ‘over the counter’ (non-prescription) medicine; services provided by a care worker; psychotherapy services. This figure was 46.0% in May. The figures for carers were considerably higher than for other people [1 in 4 (44.7%) in April and 1 in 3 (37.0%) in May] (Figure 15).

Carers with health conditions were more likely than other people to need social and community care services. Overall, the percentage of carers who needed social and community care services was 5.5% higher than for other people in April, and 9.0% higher in May (Figure 15).

Among carers who needed one (or more) of these services in April, over a quarter (27.4%) could not access it; this dropped to fewer than 1 in 5 (19.8%) in May. The figures were similar (within 1 percentage point) to those for other people (Figure 16).
Social and community services

Access to specific social and community care services varied greatly

Half (50.0%) of carers who needed a service provided by a care worker (formal carer) could not obtain this in April (40.0% in May), compared with 2 in 5 for other people who needed such support (44.4% in April and 37.0% in May) (Figure 17).

Two in every five carers (41.9%) who needed a psychotherapy service could not access this in April, a situation that was similar in May (45.2%). Other people needing such support also had difficulty getting this type of service in April and May (40.9% and 35.5%) (Figure 18).
Social and community services

Access to specific social and community care services varied greatly

In April 2020, 16.7% of carers (compared with 25.4% of non-carers) could not access a pharmacy; in May, the figures were 15.4% for carers and 23.9% for other people (Figure 19).

Figure 19: Unmet need for over-the-counter medicine

About 1 in 13 carers (7.9%) were unable to access the over-the-counter (non-prescription) medicines they needed in April; this was 2.6% in May. By contrast, the figures for other people were 5.9% in April and 4.0% in May (Figure 20).

Figure 20: Unmet need for over-the-counter medicine

Access to specific social and community care services varied greatly
Carers UK comments...

The pandemic has been extremely tough for carers. Even prior to ‘lockdown’, many started to worry about infection and risk to the person they cared for and to themselves, and these fears are yet to abate. Carers UK welcomes these findings which increase our understanding of the pandemic’s impact, and what needs to change going forward.

The report shows that while some improvements were made to services once the pandemic struck and some carers received support, the disparity between carers and non-carers is still very high. We know that carers forgo medical treatment and are less able to look after their health due to caring; the higher level of cancelled treatments is particularly concerning, as carers’ health tends to be worse than that of the public.

It is also concerning that the 111 service wasn’t there when carers needed it. Our previous research shows that this usually leads to increased trips to A&E, but during this time, carers struggling with increasingly difficult caring situations were often too worried to travel or visit A&E, leading to even worse health outcomes. It is likely that people living alone with disabilities or illnesses were at greater risk (this research only concerns caring outside the household).

Carers UK and others have documented the increased demand for mental health support as carers faced extremely stressful situations with very little support during the pandemic. It is extremely worrying to see the disparity between non-carers and those caring at a distance – who are far less likely to receive services at a time when they most need them. Given that access to other health services improved during the pandemic, it’s worrying that access to mental health support became worse.

Carers UK was proud to be an active member of the Jo Cox Commission on Loneliness and our previous work has highlighted the scale and impact of loneliness on carers. Throughout this pandemic, local carers’ organisations and Carers UK have worked hard to ensure that carers are still connected to family, friends, and support. Our work pre-COVID-19 showed that carers were seven times more likely to be lonely than the public. Carers reported they were often lonely at work, but equally that work could be an important touchpoint that reduced loneliness – something that employers need to address as staff return to work over the coming months and that should form part of their health and wellbeing programmes for carers.

Carers UK

Across the UK today 6.5 million people are carers – supporting a loved one who is older, disabled or seriously ill. Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person’s health, finances and relationships. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

Carers UK is here to make sure that no matter how complicated your query or your experience, you don’t have to care alone. We provide information and guidance to unpaid carers on a range of subjects. You can contact our helpline on 0808 808 7777 or by email advice@carersuk.org, or visit our website at www.carersuk.org
Carers UK recommendations

In the short term, Carers UK recommends that Governments across the UK:

Urgently review carers’ access to 111 and contingency planning for emergencies
NHS England and the Government needs to review carers’ access to 111 and contingency planning for carers, working closely with local authorities to ensure that those most at risk have the right resources in place to manage for any second wave.

NHS England needs to issue new guidance to CCGs and NHS Trusts to ensure that carers are made a priority for planned treatment, working in partnership
New guidance is needed to highlight the health inequalities for carers and risks to further health and wellbeing if cancelled treatment does not go ahead, and set expectations for CCGs, working with local authorities to ensure that care is in place to enable carers to take up NHS treatment.

Employers need to incorporate loneliness into health and wellbeing support for carers
Good practice employers have already increased measures to support working carers – but far wider adoption is needed to make this standard practice.

Put in place measures to ensure services are reinstated to their former levels, support carers and the people they care for and provide sufficient funding for care
The impact of reduced services is also affecting carers’ ability to juggle work and care, as well as their health and wellbeing. Where possible, local services should be reinstated / reopened / augmented, to ensure carers can take a break from their caring role, and look after their own health and wellbeing. Government also needs to ensure that there is sufficient short-term funding to meet need.

In the longer term, as we move through and beyond the current crisis, Governments across the UK must:

• Ensure the needs of carers and those they support are fully considered in recovery
• Implement Carers UK’s Recovery Plan for Carers in full
• Place a new duty on the NHS to identify carers and promote their health and wellbeing
• Make social care a priority for funding, ensuring it delivers vital support to people who need it
• Improve carers’ rights to take time off to juggle work and care.
Appendix

- Unpaid carers were identified by combining data in the COVID-19 April 2020 wave with data in wave 9 (2017-19) of Understanding Society. Wave 9 asked people if they provided care to anyone outside the household who was elderly or had a long-term illness or disability. The COVID-19 April 2020 wave asked respondents about care for persons outside the household (data on their age, long-term illness or disability status were not collected). People who answered ‘Yes’ to both questions are the (unpaid) carers providing care outside the household referred to in this report. Care provided to someone within the respondent’s own household was not reported, so total care provided will be greater than shown here.
- Unless otherwise stated, all data are for the UK.
- The 95% confidence interval is displayed in the figures.
- All differences and changes reported between groups or over time are statistically significant (5% level).

Table 1 Loneliness and caring

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## Appendix

### Table 2 Service use

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Appendix

Endnotes


3 The exception to this is May 2020 when loneliness was experienced by 58.06% of carers aged 17-30 and 59.76% of non carers of this age (this difference is not statistically significant).

4 Before the COVID-19 pandemic, data on this topic were not collected in the UKHLS.

5 NHS 111 (NHS24 in Scotland) is the telephone/online service through which people can access the national 24/7 integrated urgent care service.

6 Here, ‘unmet need’ is defined as requiring a service and either being unable to access it, or not seeking help due to the pandemic.
About the research

Sustainable Care

The Sustainable Care: connecting people and systems programme is a multi-disciplinary Economic and Social Research Council-funded research programme (2017-2021) exploring how care arrangements, currently ‘in crisis’ in parts of the UK, can be made sustainable and deliver wellbeing outcomes.

It aims to support policy and practice actors and scholars to conceptualise sustainability in care as an issue of rights, values, ethics and justice, as well as of resource distribution.

Sustainable Care is a collaborative research programme, bringing together academics from eight universities and Carers UK, and works with an extended network of national and international policy, practice and academic partners.

About the report

The report authors are Dr Matthew Bennett, Dr Yanan Zhang and Professor Sue Yeandle.

All data analysis was performed by Dr Yanan Zhang and Dr Matthew Bennett.

The report was designed by Dr Kelly Davidge.

The authors gratefully acknowledge the support of the Economic and Social Research Council (award reference ES/P009255/1, 2017-21, Principal Investigator Sue Yeandle, University of Sheffield).

To cite: Bennett M.R., Zhang Y. and Yeandle S. (2020) CARING and COVID-19 Loneliness and use of services. Sustainable Care: Care Matters 2020/01, CIRCLE, University of Sheffield.

ISBN 978-1-9993572-3-8 © CIRCLE, August 2020