Impact of Covid-19 pandemic on Hospices (ICoH)
Carer Cohort Report

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Main findings

- Carers often felt isolated, abandoned (especially during lockdowns), and left to provide essential personal and clinical care with little support. Palliative services and support often seemed poorly coordinated. Although not exempt from these experiences, hospices were found to be able to intervene in primary palliative care.

- The loss of volunteers was noted by some carers, but they understood that volunteers were also affected by the pandemic protections.

- Not being able to visit a dying person in a hospice inpatient unit meant some carers sought to keep the person they were caring for at home, despite the often significantly increased difficulties they faced in doing so. Carers who did visit people in the hospice inpatients found the protections limited communication with staff and the person they were visiting, but understood the why the rules were in place.

- Carers appreciated the national pandemic protections that had been put in place, despite some of the difficulties they may have caused, but felt more vulnerable after they have been removed.

- Carers saw how the people with life-limiting conditions struggled when day and out-patient services were withdrawn; but that the hospice's doorstep visits, telephone calls and video support groups helped sustain wellbeing in the interim. However, despite some advantages these forms of support brought, in-person support was preferred, even with protections such as PPE and testing still in place.

- Video calls and support groups were seen by carers of people with life-limiting conditions as mostly beneficial – although not always appropriate – stopgap when in-person support was not available.

- As with video calls and support groups, telephone calls were useful during periods when hospice staff could not visit. But carers of people with life-limiting conditions found that there were limitations of what could be learnt about a person's condition over the telephone.

- Although some participants received (pre) bereavement support, those that have been previously offered, but not been able to take it up, may now be in ready and in need of support.

Implications for practice and recommendations for policy

1. Hospices should explore ways they can bring people with life-limiting conditions, and those that informally and formally care for them, together to explore their shared needs and concerns as a group and be ready to facilitate, engage and listen to them not just as patients and (in)formal carers, but as citizens, who need to continue to have an active voice in society.

2. Hospices need to be sufficiently resourced so that they can ensure every carer is supported so that they and the person with a life-limiting condition they are caring for is able to connect to the full range of health and social services they require, including out-of-hours care and support.

3. Hospices need to provide online and, whenever possible, restore in-person volunteer-led services that help support and provide periods of respite for carers.

4. Service providers and commissioners need to ensure carers and the people they are caring for, have a meaningful voice in national and local conversations about the ongoing Covid-19 response, as the easing of restrictions on socialising and visitors to in-patient settings will have significant implications for the quantity and quality of their lives.

5. Many of those with life limiting conditions are entitled to equitable treatment under the Equality Act (2010). Policy makers should ensure that those with life limiting conditions are not marginalised or discriminated against, and that the quantity and quality of their lives are valued equitably in any (new) policy.

6. Carers of people with life-limiting conditions need all the hospice services that were disrupted during the pandemic emergency response to be restored as soon as it is safe to do so. This includes:
    a. Hospice should be provided with the resources to be able to experiment with online and in-person day services, so patients have options for accessing support that suit their needs.
    b. Hospices need to be properly resourced so that they can provide safe and effective hospice-at-home services 24 hours a day.

7. Supporting carers by ensuring they and the person they care for have a range of digital options to access care and support, alongside in-person and telephone options across all settings.

8. Provide hospices with the resources to offer all carers pre and post bereavement counselling and support services, including specialist support for complicated grief, by offering a range of ways to access support through one-to-one or group support, whether that is in-person, telephone or online video.

Introduction

In the UK hospices provide holistic healthcare (physical, emotional, social and spiritual), with a focus on quality of life for those who have life-limiting conditions (Clark, 2014; Taylor, 2019). Hospices can provide multi-disciplinary support via a range of services, from (specialist) palliative care in-patient beds, day services (e.g. social and support groups), and out-patients (e.g. specialist palliative care, physiotherapy, breathlessness clinics); to those services offered off-site, such as community nursing services, and/or hospice at home (Hasson et al., 2021; Hospice UK, 2017). Pre-pandemic, most hospice support was premised on being provided in-person, whether that was on an inpatient unit, in a day service, or at the patient's place of residence. However, the pandemic brought rapid and significant changes to how hospice care and support was delivered (Dunleavy et al., 2021). This was not only due to national restrictions, but also because many of those with life-limiting conditions are especially vulnerable to Covid-19, as it could both shorten the amount of life they had, as well as significantly affect their quality of life.

Little is known about what happened to people with life-limiting conditions who were discharged home or who experienced changes to hospice community services during the first lockdown or throughout the Covid-19 pandemic (MacArtney et al., 2021). While each specialist palliative care service and hospice's response to Covid-19 has reflected local conditions, common to all in England has been the theme of adapting large portions of care and support to a now dispersed community of service users (Dunleavy et al., 2021). These changes will have affected how people lived with life-limiting conditions during the pandemic and how they were cared for. Moreover, their experiences could provide insights into the uneven and inequitable affects of the pandemic (Pickersgill, 2020), which may need addressing through changes to policy and practice.

Background to this report

This report describes the diversity of experiences informal carers for people with life-limiting illnesses who were supported by hospices in the West Midlands during the pandemic. It is one of four cohort reports – the others focus on patients, frontline hospice staff, and senior managers respectively – that form the evidence base for a Policy Report into the impact of Covid-19 on hospices. In these reports we address the nine key themes that were identified as potentially important in our previous collaborative knowledge synthesis (MacArtney et al., 2021) and seek to address some of the policy gaps we identified in our review of recommendations for hospice practice and policy (van Langen-Datta et al., 2022). Together these outputs are the result of an Economic and Social Research Council funded study (grant number: ES/W001837/1). This is one of the first studies to contribute an in-depth exploration of hospice-based experiences of the pandemic to the growing body of knowledge about the effectiveness and effects of changes to hospice services, at regional and national levels in response to Covid-19.

The aim of this report is therefore to explore experiences of those informal carers of people with life-limiting conditions and the effects of the Covid-19 pandemic on the care and support they experienced, to identify recommendations for clinical practice and healthcare policy. Drawing on these findings, this report offers **recommendations for hospices and clinicians** who continue to provide care and support for people with life limiting conditions and those that care them during the ongoing pandemic. These recommendations will also be of interest to **local commissioners** who will need to work with hospices in their region to ensure informal carers receive the support they need, and **national policymakers** who will need to ensure the necessary resources and guidance are available.

Methods

Design

We used an interpretive qualitative approach (Silverman, 2011), as this best allows us to explore and describe the range of patient experiences of hospice care and support during the pandemic.

Setting

The West Midlands is a vibrant and diverse community – including the largest ethnically diverse population outside of London – that is distributed across a range of geographical locations, from inner city to rural areas (Evans et al., 2012; Medland, 2011).

Sample and recruitment

We contacted all 13 non-NHS hospices caring for the adult population in the West Midlands and asked them to recruit participants for the study. Nine hospices agreed and seven successfully recruited participants. Hospice staff were asked to share the participant information leaflet with patients who had used any of their services during the pandemic, i.e. in-patient or community since March 2019. If the patient agreed the hospice would then pass the patient's details to the research team, who would then contact the patient to answer any outstanding questions, ensure they were happy to take part, and arrange a time for the interview.

Data collection

In-depth interviews were conducted by AE, JF, CG and JM via telephone or MS Teams, whichever the participant preferred. The researcher recorded verbal consent before starting the interview. The interview then started with the open question, "Could you tell me a bit about your background and what kind of contact you have with the hospice during the pandemic?" Follow-up questions would be in response to the participant's story, but would include prompts on accessing services, experiences of different locations of care, concerns about Covid-19, or the impact of the pandemic on care and family.

Analysis

The recordings were automatically transcribed via MS Stream, checked by researchers

CG and AE and coded in NVivo 1.5 by AE, JF, CG and HW using the anticipatory themes (Braun and Clarke, 2019), developed during the collaborative knowledge synthesis (MacArtney et al., 2021). A sample of collated extracts (approx. 30,000 words) from the coded anticipatory themes were shared with co-authors and collaboratively analysed using the One Sheet Of Paper (OSOP) method (Ziebland and McPherson, 2006) at a knowledge translation workshop to identify any new (sub) themes, as well as any recommendations for practice and policy. JM then summarised the NVivo nodal outputs for each theme and identified any further recommendations. Using the themes identified in our previous study (MacArtney et al., 2021), JM drafted a working paper and shared this with the co-authors for further interpretation and comments.

Results

15 informal carers were recruited from seven hospices and interviewed either on MS Teams or on the telephone. 14 identified as female and one male; all identified as heterosexual; and eleven identified as white-British ethnicity, two as Asian or Asian British Indian or Bangladeshi, one as Black, African, Caribbean or Black British, and one Mixed or Multiple ethnic groups, White and Black Caribbean. Age ranges by decade were requested, with the greatest number of participants (n=6) being between 40-49, ranging from one participant in their 30s and three in their 70s (see Table 1, participant characteristics). Interviews lasted between 30 minutes to 1.5 hours. Interviews provided rich and in-depth descriptions of participants' experiences of hospice care during the pandemic. The following analysis sought to explore those experiences to identify opportunities to better deliver hospice services and support to those with life-limiting conditions and those that care for them.

	n	%
Participants	15	
Female	14	93%
18-29	0	0%
30-39	1	7%
40-49	6	40%
50-59	3	20%
60-69	2	13%
70-79	3	20%
80+	0	0%
White, British	11	73%
Mixed or Multiple ethnic groups, White and Black Caribbean	1	7%
Black, African, Caribbean or Black British, Caribbean	1	7%
Asian or Asian British, Bangladeshi	2	14%

Table 1: Participant characteristics

Impact of changes to hospice services during the pandemic

In the first months of the UK and England's Government's response to the Covid-19 pandemic significant attention was focused on readying hospitals and intensive care units. At the same time – receiving far less national attention – were the efforts of regional community health and social care services who were preparing for a rapid and significant shift in how they would care and support people (Bowers et al, 2021; Mitchell et al., 2021; Oluyase et al., 2020). This included the non-NHS hospices (Sleeman et al., 2021), which are the focus of this study. Based on the findings from our collaborative knowledge synthesis we anticipated that there would be three main areas of concern relating to how changes to hospice services might affect experiences of those with life-limiting conditions: the impact upon resources and funding; loss of volunteers; and changes to visiting arrangements (MacArtney et al., 2021).

Impact on resources and funding

A potentially important issue that we previously identified was how specialist palliative care in the community can make better connections and alliances with primary and secondary (palliative) care providers (MacArtney et al., 2021). The participants we spoke with described a range of issues relating to support that was provided by their General Practitioners (GPs) or by district nurses (sometimes referred to as primary palliative care by participants), as well as the communication between these two services and with the hospices.

Participants were aware that GP practices were struggling pre-pandemic, “I think it's a general issue anyway, an ongoing issue. I don't think the pandemic helped because they were so stretched” (ICOH14). Another participant reflected how she had found her GPs to be:

> “*Overwhelmed and it's not it's not their fault . . . they really do care about people and they're willing to give more time to them, but they are under a lot of pressure and they are measured on the time that they spend with the patient*” (ICOH13).

One participant described the impact of GPs being unable to help with providing a blood test for her sister, as the GPs were unable to visit due to a lockdown. Whereas, ““it would have been very simple for the GP to come out” (ICOH40), it took 13 hours to get her sister to and from hospital, including waiting for paramedics, time at the hospital, and waiting for an ambulance to return them home. She said, “that's basically the effect that covid had . . . It was just the GP surgery: it was difficult to get hold of them” (ICOH40).

Some participants described the **difficulties with the primary palliative care support they got at home**. A participant explained how the district nurse would come out when called, as well as having set visiting times “just check the medication and whatever, but they would not provide care” (ICOH77), going on to describe the personal care she had to provide on her own, after her mother had been incontinent.

One participant explained how her father was returned home from hospital with only her and “the district nurses, [but] they just didn't want to know . . . they'll come back give him a top up and then that was it and they'd go” (ICOH16). The participant went on to describe the effects of feeling on her own to provide care for the person who was dying:

> "*So I'd say complete abandonment and very lonely and very scar[ed] . . . that I am missing something that I should be escalating . . . Nobody was there to come out to say this is right, this is normal*" (ICOH16).

Another participant said:

> "*It was very stark when I say we were frightened. We didn't go crazy. We just we were just scared because we realised that we've got to do it ourselves and there's nobody is going to be coming in to check things*" (ICOH13).

A participant contrasted her two experiences of primary palliative care provided by district nurses during the pandemic. With her father, district nurses visited regularly and were "fantastic". But for her husband, "We've seen them twice has not really helped" (ICOH20). Instead, it has been the hospice that have provided the mainstay of support at home and as an in-patient.

Communication between GPs, district nurses and hospices was also identified as an issue for several participants. A participant explained how at the start of the pandemic she was told by her GP that they would "see you on the other side" and she and her family were left unsure as to what that meant and having to care for her elderly father (ICOH14). She described her practical and emotional difficulties in providing personal care to him and that "we did feel very lost, alone and left" (ICOH14).

Several months later the participant was able to speak to the GP practice manager, who was able to put the participant in touch with social care and the local hospice, who organised night support that she felt:

> "*kept dad alive for weeks and weeks longer than then he would have. And certainly if he'd had to go into the hospice facility he would have gone downhill very, very rapidly because it's not what he wanted*" (ICOH14).

Another participant reflected on the impact the pandemic had on the ability of GPs and hospices to communicate effectively:

> "*The GPs that my parents had, and I think this is in common with the rest of GPs, are not experts in end-of-life care and the [hospice] people are were. And they could have been talking more to particularly the new GPs who had taken over my dad's care when he moved into the care home. There was no nowhere for them to meet or whatever, and it was just left, and I think that was that was a shame really*" (ICOH15).

Other **participants also reported experiencing a lack of hospice support during the first lockdown**. One participant found that the reluctance of any healthcare professional to visit left her feeling, "quite abandoned really". Despite being with the hospice for about a year before the first lockdown, once it was in place “that was it then. It was just an occasional phone call are you okay?” She went on to say:

> “*They just kept referring to other people . . . people were afraid. I think health professionals were afraid weren't they, but we all still had a duty of care to provide [care]*” (ICOH16).

However, both during the first lockdown and throughout the pandemic there were accounts from participants of hospices that would, “contact the GP for you, if you if you felt you weren’t getting anywhere” (ICOH13). But this did not always go smoothly; one participant provided an example of a hospice doctor requesting a blood test, but the district nurses said they knew nothing about the request, and waited to be instructed by the GP, “so I had a few days of chasing a doctor, to instruct the district nurses, to try and get the blood taken” (ICOH72).

There were participants who felt strongly that **the role of the hospices in the community was crucial to ensuring the treatment and support the person they were caring for was timely and appropriate**, particularly during the pandemic. One participant said he wanted to stress:

> “*the importance of hospices now in the community, because your hospitals they can’t provide that sort of cover. The [GPs] haven’t got that time . . . So, I think they do play a really important part within the community.”*

He went on to link the difficulties of providing integrated palliative care in the community to hospices’ funding:

> “*I think instead of being pretty much dependent on charity, I think it should be funded by the government or they should put a lot more money into, even if it’s not wholly supported. But there's definitely a place for it*” (ICOH05).

Similarly, another participant described the difference hospices could make to those with life-limiting conditions in the community, when they were available, another participant said:

> “*I'm just saying that if anybody could, if they could do more for hospices, they need more help, so that they could have more people in there . . . they rely on donations don't they? They get some help but not a lot. You know, and if they could, you know there's so many people who would benefit by going. 'cause I think the staff in the hospice are trained differently. And I think you need to be the right type person to be there . . . They're absolutely lovely*.” (ICOH28).

Loss of volunteers

Hospices traditionally rely on volunteers to help provide many of their services, so we were interested to know about the effect on participants of the loss of the voluntary workforce. However, it was only raised as an issue by a small number of participants. When the loss of volunteers was discussed in the interviews, it echoed the following participant’s reflections:

> “*And I think, as well, because there's such a lot of volunteers like that collected dad, I think their volunteer had caught covid or if I remember correctly, he might have been a certain age where his family didn't want him to volunteer because of being in touch with other people. So just as us, I think they found that the volunteers and that were dropping off, which was having an effect on what [the hospice] could offer as well*” (ICOH20).

Changes to visiting arrangements
From the first lockdown and throughout the period of the pandemic we investigated (up to February 2022), hospices had some form of protections in place for inpatients and their visitors and for hospice staff. We found that this affected participants in several ways. This included how they and/or the person they were caring for evaluated the benefits of inpatient care, as well as how it affected the quality of their experiences of inpatient care.

The **decision to support the dying person at home was affected by knowledge of hospices having Covid-19 protections in place, including limits to the number of visitors**. As one participant said, “one of the reasons why I wanted to keep [my mother] at home and not into the hospice because at the hospice there were [visiting] restrictions” (ICOH77). Another participant explained how the limits on visitors affected the family’s decision to take on caring for her mother, who had dementia:

> “*Obviously she, had it not been a pandemic I think she would have been admitted to the hospice, but we didn’t want that with the restrictions around visiting her . . . it was an easy decision, because not being with our mum every spare second that we could, was just not an option for us.*” (ICOH72).

Similarly, another participant who described many difficulties of caring for her father at home on her own explained why she did not want him to be admitted to a hospice:

> “*Well, you know, you can't time when someone is going to die. So, I can't, I can't even imagine, it's awful as it was what we went through, caring for him at home, at least we were with him*” (ICOH16).

Some participants were concerned they would not be allowed in to visit at all – a limit in place at some hospices during part of the first lockdown. Finding this was not in place was a relief, “We were allowed to visit, which was amazing because, you know we had he was allowed two visitors a day, so it was absolutely brilliant” (ICOH15).

Participants acknowledged the difficulties the protections brought, including the number of people who could visit each day or week. A participant described the visiting arrangements for her hospice later in the pandemic:

> “*They started to allow like two people in to see him per day, but they both people have to go in together. Once you go out, you weren't allowed back in, which is fair enough, and it was just the same two people. Like today would be two people, tomorrow it would be different [two]*” (ICOH24).

Those participants who visited people in hospices described a number of difficulties that affected the quality of their experiences of the hospice care and environment. One participant noted that the various protections in place at the hospice included the visitor having to stay in the room, made it difficult to speak to staff:

> "*You know if they came into the into the room, it's not so bad 'cause you could then ask them the question, but to actually go and look for somebody to ask. Oh, something you couldn't do that . . . You had to reach out to ring a bell. Yeah, and then they come when they could. It felt a bit sort of a bit prison, like almost, on that bit*" (ICOH20).

Wearing PPE also brought issues for some carers as, "We were instructed to keep the masks on all the time". For this participant this was a particular issue when her mother slipped into a coma. Although she would open her eyes occasionally but, "she was so confused because everybody around her had masks then she wouldn't be able to tell us apart from other people". She went on to say how:

> "*That was quite distressing . . . I'm I think she wanted to say something and then she died, but . . . we had the masks [on] and I hope, I hope that she realised it was us*" (ICOH77).

Another participant explained that her father did not want to be admitted to the inpatient unit at the hospice, despite knowing how the hospice "went above and beyond" caring for a friend there a few years before, saying, "it wasn't necessary [then] for everybody to wear masks all the time. So that's a difference" (ICOH14).

Despite the issues faced, **participants acknowledged the need for the protections to be in place**, "I understand the risk as well and I'm not… it needs to be balanced" (ICOH77). Another participant gave some insight into what this balance might be, describing how the protections in place during the third lockdown (early 2021) on the in-patient unit were, "upsetting, but it wasn't that upsetting knowing that everything is being done" (ICOH78). As another participant said, "The last thing we want to do is, you know, take covid in there so you know understood it, didn't make it that much easier, but it's what had to be done" (ICOH20).

Although hospitals were not the focus of this study, there were participants who described how they worked to ensure the person they were caring for was not admitted to hospital, as it was seen as somewhere the person might contract Covid-19. In contrast, a participant explained how she was happy for her husband to be in the hospice, "I don't know, he just felt that he was he was safe there . . . He's better there than he was in the hospital" (ICOH20). The idea that the hospice was a safe space related to the Personal Protective Equipment (PPE) they saw at the hospice, as one participant recalled, they "had all the PPE, you wouldn't have to worry . . . everything was there so you felt safe going inside the hospice" (ICOH24). Many hospices were also able to provide patients with individual rooms, something that was seen to have a particular association with quality of care but also to ensuring that the dying person had a safe space during the pandemic:

> “*He had his own room and he had his own space, which I think at that time of your life it's really important to have some normality considering that we've got Covid-19*” (ICOH78).

Quality of care

The second major theme that our previous work identified as needed further examination was how the pandemic would affect the quality of how care was provided by hospices and experienced by people with life-limiting conditions and those that cared for them. To understand this further we looked at the demographies and geographies of care; places of care including the day and outpatient services, and as part of hospice at home services. We also looked to see what changes to care were enacted because of the pandemic and how these were experienced. Finally, we asked participants about the (pre) bereavement support they had been offered, sought or received.

Demographies and geographies of care

The Covid-19 pandemic affected everyone, but it affected some groups more than others. In this theme we look at how the pandemic was understood to have affected participants because of who they are or because of the places in which care and support were (or were not) available to them. In particular, **people with life-limiting conditions were especially at risk of Covid-19 severely affecting the quality of the life they had left, as well as Covid-19 shortening that time**. We therefore looked to see if there were any disproportionate or inequitable effects in the way the pandemic affected people caring for those with life limiting illnesses and what additional support they might need to compensate for that.

Caring for someone at home has socio-economic implications, which one participant was explained he was “fortunate” to be able to accommodate, by converting his “spacious” and “airy” conservatory, so his father had somewhere safe to be during the pandemic (ICOH78). However, another participant explained how the pandemic meant, when she had to leave her job to become her mother’s carer, “I found it quite difficult to, you know, [do] this without an income and just well, yeah, it was extremely difficult” (ICOH77). Another participant explained:

> “*For me, yeah there's always the worry and still is the worry that you know, I get it from someone and bring home, because I still gotta go to work to bring the money in*” (ICOH05).

A participant described how the pandemic appeared to exacerbate the “postcode lottery” of access to care in her area. She explained how her parents lived a mile and a half from her GP surgery, but that it was in a different county, which affected the signing off of authorisations for the district nurses, which delayed administration of care and treatments for her father:

> "*And I think maybe that could have been a bit covid driven because, you know, people just weren't in the office properly and they were, you know, it was very hard to get hold of people at the right time*" (ICOH14).

Participants also described how **PPE affected the communication** some participants witnessed between those they were caring for whom English was a second language, and the hospice staff. This occurred in hospice inpatient units:

> "*I think there was also the added problem that my mum's English was very poor, and so in her case it was compounded by the lack of English language skills if you'd like. Those cases she would have relied a lot on this nonverbal cues to communicate and understand what was going on*" (ICOH77).

Another participant explained that the carers the hospice sent to her home three times a day during 2021 were very rushed,

> "*And the language, my mum didn't speak, my mums English was quite poor and they didn't speak her language and they would say, you alright? How are you? And my mum would just nod her head and for them that was their assessment of her, but you'd speak to my mum and ask her, are you a cat? And she would nod her head. So there was kind of that disconnect in communication as well*" (ICOH72).

The participant went on to explain that the carers "didn't really listen" to the family, when they interpreted or explained how her mother was doing, "saying 'the patients communicating' when she wasn't" (ICOH72).

An issue **participants felt strongly about was how Covid-19 virus disproportionately affected the quality and quantity of life of those they were caring for, as well as their own lives**. This was because most people who are dying with what is sometimes referred to as having a "pre-existing condition" and were classed as Clinically Extremely Vulnerable (CEV), as Covid-19 could severely affect their quality of their life left and hasten death.

In this context one participant emphasised how important the hospice care approach was because, as well as its holistic focus, hospice care prioritises quality of life left, as they explained:

> "*And we as a family thought [the hospice] really supported us. I think it made dad happy. Little bit easier in that, you know, the philosophy that death is you know, just another part of your life. While you are alive, you know it is about the quality of life that you have. I think that's what really helped us*" (ICOH14).

Participants described the extra precautions they took to protect those they were caring for from Covid-19. A participant described his "worry" for his partner as, "she can't afford to get covid at all, it would definitely see her off. Even though she's been double jabbed" (ICOH05). He went on to explain that, because of her breathing condition, she was unable to wear a mask and so social distancing was therefore really important to them when out in public. Another participant explained how during the first lockdown she ensured she had a mask and gloves on to see her father at his home because:

> "*We were all that scared . . . that we were going to give him covid and you were trying to balance that even though we knew he had very little time left. You know, I didn't want that little time taken away by covid or it being covid and he's in the hospital where we can't be with him because that's definitely what he didn't want*" (ICOH16).

One participant explained how, during the first lockdown, "we're very careful 'cause we weighed it up and we thought . . . right okay, and [husband name's] very poorly" (ICOH13). She bought not the "basic" but the "expensive" masks and gloves and would wipe everything down. Even with these precautions, "I was very scared and [husband] was scared for me" (ICOH13).

There were sometimes **different understandings of risk between the participant and the person with a life limiting condition**. The following participant explained how the pandemic affected caring for her husband during the first pandemic:

> "*I felt very vulnerable, yeah. And I've got two grown up children that both moved home and they really, you know, like my daughter, for example, was even scared to go for a walk in, case she brought something home to her dad. So we felt quite vulnerable, but he was a bit more blase about it [laughter], you know. 'if you're gonna get it, you're gonna get it', you know. But we were a bit more anxious, about protecting him really*" (ICOH41).

The issue of whether to have visitors – or not – at home was also complicated by the awareness of the pandemic that the person with the life-limiting condition had, as one participant caring for both parents with life-limiting conditions described:

> "*My dad avidly watched the news and so completely understood what was going on. As my mum's condition deteriorated, she was less conscience of why, why people couldn't be [there] and that was hard*" (ICOH15).

The familial sharing of vulnerability to Covid-19 was also described by a participant whose husband had dementia and whose sons did not visit during the first lockdown:

> "*They didn't want to come in to pass anything to us," she went on to explain, "we was so scared in case we got covid. Because of you know the effect it would have on [husband]. You know, who would look after him?"* (ICOH28).

Another participant described how her young grandchildren lived with her and her husband, who was clinically vulnerable to Covid-19. The grandchildren were old enough to understand why they needed to be extra careful, but that the teenage grandchild found it "very hard" when she "she sees her friends doing things that she feels they shouldn't during the pandemic" (ICOH11). One participant described the need for lateral flow tests before her husband visited the hospice for day service support:

> "*We mustn't forget that the staff there also look after very poorly patients, who are, you know, in the hospice permanently, really. So there can't be any worry about passing infection around. That would be totally wrong*" (ICOH13).

These relational experiences of risk extended beyond immediate family to how the health service was seen to share – or not – the heightened vulnerability that those with life-limiting conditions had. A participant described how her husband was invited for his Covid-19 vaccination, but, "he was too vulnerable to go out. And he was getting the letters saying he's vulnerable and is not to go out. Yet, I was told to take him and then I find that a little bit distressing" (ICOH22). It took several phone calls, but the participant was able to organise someone was able to visit the house and vaccinate her husband there.

The pandemic and the protections brought in had implications beyond protecting the person with a life-limiting condition being cared for from Covid-19. Participants reported how **the pandemic made those with life-limiting conditions more vulnerable to emotional, social and economic impacts of changes to protective measures**. Participants explained how the people they were caring for were especially vulnerable to closures, as one noted, the loss of hospice in-person services had a big impact "especially [on] his wellbeing" and mental health (ICOH11). When asked about the care and support she received during the pandemic a participant, who had been an informal carer most of her working life, tearfully reflected, "Sometimes you feel as if you're left alone. And us carers, I always think I was forgotten" (ICOH22).

In terms of feeling forgotten, another participant also described how she was reassured that her husband could go to the hospice, because of the precautions being taken there, from wiping surfaces to lateral flow tests. However, she said, "the fear is that people will stop doing that" outside of the hospice, referring to mask wearing and social distancing (ICOH13). She was concerned that divisions were being created between groups of people and that too high a cost was being associated with the protections, saying, "Wearing a mask, washing your hands and keeping your distance, being sensible doesn't cost any. It doesn't cost anything if you're still alive" (ICOH13). What is needed, she felt, is, "reassurance that everybody else is doing the same thing" (ICOH13).

Lockdowns were also experienced differently by those caring for people with life-limiting conditions. One participant explained how the first lockdown allowed her to gain a better understanding of her sister's condition:

> "*Lockdown helped because I was working from home since last March and I was able to understand what was happening to her . . . [it] actually helped me because she couldn't hide [her deterioration]*" (ICOH40).

Another participant compared her experiences during the three lockdowns, reflecting, "I quite enjoyed [the first] . . . you was in the same situation and the weather was quite good. So, we were in the garden all the time" (ICOH28). But "the worst one was the winter one right. Yeah, 'cause you couldn't even go out in the garden”. It was made worse by the ‘rule of six’ at Christmas, preventing her large family from meeting as they usually would:

> “*And that that that was a horrible lockdown. And then after Christmas it was 'cause it’s horrible anyway after Christmas depressing time. So that was awful as well. Yeah, that was that was the worst time for me*” (ICOH28).

Participants were **aware that a balance needed to be struck with national protections to ensure lockdowns did not become a way of life**. One participant reflected on the easing of restrictions saying, “I don't know whether I'm glad in one way and not in another” (ICOH28), as while she was happy to be able to go shopping and out for meals again, her concerns about contracting Covid-19 and the effects on who would care for her husband remained. She said, “I still don't feel safe if I'm anywhere where there's a lot of people and they're not wearing masks, you know, I prefer not to be in a place where there's people not wearing masks” (ICOH28). Similarly, another participant noted how vaccinations had eased some anxieties about going out:

> “*I felt a bit stressed about to begin with, but over time and having the vaccinations you do feel a little bit more relaxed about it. But I still have my mask on. Always wear my mask and I take my hand gel as well. But I did find it a little bit stressful to begin with*” (ICOH22).

A participant reflected on the easing of protections on ‘Freedom Day’ (July 2021) and its impact on her and her husband’s socialising outside of the house:

> “*It's still quite unnerving really, I think, the pandemic. We still tend to wear our masks and things like that if we do go out. Because I know now is coming to an end, so they say, but you just don't know it's still about . . . But now, because we've been given the freedom and it's personal choice. It's a little bit more frightening, a little bit more, you feel more vulnerable . . . The last thing I want is for, you know, the pandemic, covid, to take him. So yeah, so probably in our situation we feel a bit more vulnerable now*” (ICOH20).

The pandemic also brought significant changes to the plans many people had, sometimes in their favour – such as early retirement – but for others it meant ‘bucket-list’ holidays might never be fulfilled. A participant explained how the first lockdown effectively allowed her to retire early, which meant she was better able to care for her husband:

> “*Actually it did kind of come at quite a good time for me 'cause I was really trying to spin too many plates, And so actually I was quite relieved just to sit in the garden for a few months*” (ICOH41).

Another participant said, they had booked a cruise which was cancelled, with the offer to rebook, “but we didn't know if [husband with motor neurone disease] would be well enough to travel this year, so that was. Uhm, quite devastating really for us that was” (ICOH41).

Places of care: hospice day and out-patient services

We asked the participants about their experiences of caring for people who used hospices day and outpatient services. Some of the participants we spoke to had been caring for people who had been able to access day hospice and outpatient services prior to the pandemic. One participant explained that her husband was taken to and brought back from the hospice once a week for social activities like quizzes, support groups, to get a hot meal, and to check-in with the medical and nursing staff. Some participants were able to use hospice services themselves, joining yoga, Reiki and meditation groups "to help me slow down and cope" (ICOH13). Another participant described how his partner being taken to and from day services helped her "psychologically" and her "morale", saying it "just eases some of the pressure" (ICOH05). Similarly, a participant explained how important these social activities were:

> "*The hospice is very much in that vein all the time in it builds up the confidence, you know, and keeps people cheerful as well as the serious stuff. This is a sort of you, wouldn't think it was serious to look at it, but actually it is really important and they do that*" (ICOH13).

However, these in-person services stopped during the lockdowns. A participant described how her husband had started an in-person group at the hospice three weeks before lockdown and that it stopping, "hit him very hard actually . . . he withdrew into himself more again" (ICOH11). A participant's father had to stop attending the day services at the hospice said, "he quite enjoyed [going] and doing things he had never done before. So, yeah, I think I think he was disappointed, but [he] understood [why]" (ICOH20). Another participant told us how her husband would visit the hospice once-a-week before the pandemic, but that stopped during the first lockdown. The participant reflected that "when that stopped and I think everybody with dementia who couldn't have contact with other people, that made things worse" (ICOH28).

Some **hospices sought to put measures in place as stand-ins for day-services** to support people with life-limiting conditions and those caring for them. This included telephone check-ins and video support groups (both discussed in more detail below). One hospice would visit people every five or six weeks, staying outside and bring "a little care package with lovely little things in" at Christmas and Easter (ICOH28). Another participant described how hospice staff would visit, standing outside, but "bring little gifts [and] the newsletter, they'd come to have a little chat", explaining the difference this made, "I think it's made [husband] feel very happy. I think it's that part of, I mean all through our lives, wherever we go, we rely on our networks don't we" (ICOH13)

When protections eased a participant explained how they would visit the hospice to attend a group of four patients with their carers, for six-weeks, to socialise, hear talks and get physiotherapy, "at least we went and we were with other people and it was lovely" and "he loves it" (ICOH28). Another participant described how her mother was also able to visit the hospice early in 2021 as a day patient, to see palliative doctors and have dialysis.

Places of care: Hospice at home

The pandemic meant that it was likely that more palliative and end of life care would be provided at home, rather than in the hospice. We asked participants about their experiences of this and how it affected them, their family, and the person they were caring for.

A participant explained how the hospice had been “brilliant,” with two or three staff visiting her and her husband each time. During the first lockdown they would stay outside, but later would go in to attend to her husband, which “it's such a help to give him that support because I can still go out . . . locally to the to buy provisions” (ICOH13). However, another participant recalled:

> “*But because of the pandemic everything kind of stopped and then you're, kind of, really left to your own devices really. So I mean, we're kind of people that kind of plod along, kind of right now. [But] to begin with, it was quite difficult really dealing with things*” (ICOH22).

Similarly, a participant described how the hospice at home:

> “*. . . stopped coming in. We had no support as soon as that day when they, you know, they put us into national lockdown, we had nothing at all . . . It was just an occasional phone call are you okay? Well, and that was it*” (ICOH16).

The participant went on to describe the effects this had on her:

> *“Obviously it’s very hard to deal with because I was almost, I couldn't be the daughter sitting outside being sad because I had to step up to think of dad. Everything really that I would have liked from a hospice carer but that wasn't available, or the district nurses”* (ICOH16).

She also questioned the hospice’s rationale for stopping the visits, noting her father was largely bed bound:

> “*He was a poorly man. You know this is not someone who was out on day trips and things and. This is a poorly man, so there was no reason for those visits to stop. That was an essential visit*” (ICOH16).

Another participant explained how **the pandemic brought staff shortages**, meaning the three visits a day hospice at home support would be reduced to one. This left her frustrated, “it was the unpredictability of the service which was really difficult” and having to cope on her own with her mother, “I was really scared that she was gonna fall and I won't be able to catch her or in time” (ICOH77). The participant tried to get private carer support, but again none was available due to staff shortages. The lack of care support meant taking on extra personal care for her mother, which brought a significant change in the participant’s identity and relationship with her mother:

> “*Switch from the position of providing that, you know, moral support of going through that period of somebody dying and journey with them and then switching*

> *to the role of carer. I think that was that was quite difficult for both of us. Yeah, so I think that yeah, definitely, it did impact on – I don't know – the quality the experience going through this journey that is difficult anyway at the best of times*" (ICOH77).

A carer explained that pre-pandemic the hospice's clinical nurse specialist, "went down to the GP, had meetings with the team down there and they worked together to look after my mum" (ICOH15). However, around March 2020 her mother rapidly deteriorated at home, but she was unable to get anyone from the hospice to visit outside of the scheduled time later in the week. She called an ambulance, "We didn't want her to go into hospital because she would have been with people who were masked and gowned up". Her GP was able to organise two night sitters and her mother died with her and her father by her side. She reflected:

> "*But it wasn't as slick as I thought it was going to be. I think that's the thing. I thought that would be a quick response [from the hospice]. You know, I can blame the pandemic, I'm sure maybe that you know they were stretched or whatever, but that's got to me, the sadness*" (ICOH15).

Some **participants who had experienced hospice at home support later in the pandemic or outside of national lockdowns reported different experiences** of the support they received. One participant described what it was like to have the hospice doctor visit after restrictions had been eased:

> "*That was lovely. Lovely to see somebody. You know you get quite excited, really thinking [laughter] somebody coming out and you somebody on the phone and then you then can actually see them*" (ICOH22).

Another participant explained how the nurses would visit in the first half of 2021 and stay, "as long as she needed" and "she always came in with her mask and stuff, her gel, her apron" and so "I honestly didn't have a problem at all, even with her going in the bedroom, no problem none at all" (ICOH24). A participant who was supported later in 2020 during the pandemic said:

> "*The [hospice] were pretty extraordinary, actually, you know, at all times it is about dignity and respect for the patient, and the care package that we have, we have a carer coming in three times a day*" (ICOH14).

A participant described how, later in the pandemic (January to June 2021), they were able to access all the support they needed from the hospice, which was particularly helpful when it came to discussing advanced decisions, when the hospice "sent one of the nurses to the house to sit down with him, one-to-one and explain everything" (ICOH78). This willingness to enter the home later in the pandemic also helped another participant who explained that the hospice was now able to organise night sitters, "so I could get a night's sleep" (ICOH40). Another participant reflected that despite the difficulties the hospice had in providing staff to support her family at home, "We're just really grateful that [hospice name] were able to adhere to [my father's] wishes of dying at home" (ICOH14).

Digital palliative healthcare support

Although digital forms of hospice support – such as video calls or support groups – were possible before the pandemic, none of the participants recalled hospices offering them. However, most digital support that hospices put into place were aimed at the people with life limiting conditions. A participant said:

> "*And I just was aware that everyone was working really hard to try and keep those forms of communication open. I was really aware of the of the effort that they were making to make sure that we were all speaking to someone regularly*" (ICOH41).

This included a hospice supplying a special tablet computer that had software for visually impaired people that one participant reported "has opened up a lot to him" (ICOH11). **Being able to continue meeting people via video calls was seen to help those they were caring for**, as the following participant described, "you can just hear it in her voice" how "the psychological support through phone calls and the zoom they did the job," helping the person they were caring for avoid becoming depressed (ICOH05).

However, **video calls were not found to be suitable for all participants**, as this participant reflects on the offers of video support show:

> "*. . . like people would say, Oh well, you know you can FaceTime and there was Houseparty and all that, and I'm like. When you've got somebody who's dying who is very ill, they don't want to FaceTime. They don't want to Houseparty. You know, it's just you know, and it's hard for people you know to understand because you know when somebody is in that position. They can barely even lift their head. They've got no energy to, so they don't want to talk on phones and all of that, do they?*" (ICOH16).

In contrast, another participant explained some of the benefits she found with the move to digital support groups saying:

> "*[It] saves an awful lot of traveling and the stress out of the traveling . . . So now being able to do this in the comfort of your own home is actually, I think it's a positive. It's not for everybody, but I do think there is some positives to be taken from this . . . it's not the same as face-to-face in some respects, but I don't find it impersonal*" (ICOH40).

Although video calls and support groups were welcome during the pandemic and lockdowns it was felt "physical meetups are better" (ICOH05), both because of the technical difficulties of video calls "the delay and someone's over talking" (ICOH05) and because in-person has a preferable quality to it.

Changes to services that worked, changes that did not work

The pandemic and protections put in place, including national lockdowns, meant that hospices had to implement new services, or adapt or cancel existing services. This was noticed by one participant, who reflected on how thankful she had been that her husband had been referred to the hospice during the pandemic, “particularly because of covid because they never stop looking for ways to make improvements” (ICOH13).

However, as we have explored above, **the cancelling of some services left some participants in very difficult situations**. This participant described the effects of how her local hospice stopped providing home visits for her house-bound father, and how she was left to care for him until he died:

> “*I think, you know, some of the hospices they need to take responsibility, they did make some wrong decisions, actually [professional] carers still should have been going into the home and supporting families and we still should have been carrying out visits. So they, you know, they will have to, we will all have to justify, won't we, the decisions that that we made or it doesn't help all the families, you know, that it's affected during that time*” (ICOH16).

One service that was put in place at the start of the first lockdown in many hospices was a regular (weekly to monthly) **telephone check-in** call. They were mostly with the person with a life-limiting condition, but one participant described how she had started receiving weekly counselling over the phone from a hospice during the first lockdown (ICOH41).

Participants explained how the telephone check-ins were beneficial for those they were caring for, as the following participant explained that they allowed “continuous contact with people [at the hospice],” which was especially important as their other forms of social contact and support were also closed at the time (ICOH11). Combined with video calls, “the two together really helped” (ICOH11). Another participant who described getting monthly calls said, “Oh yes, yeah, I could phone. And yeah there was not any problem with, you know, talking to them over the phone” (ICOH22). A participant said, “I think they were very useful, because again if you have any doubts or worries or concerns, she could talk to the [hospice] carers” (ICOH05).

However, the **telephone calls were seen to be provide limited support or be of restricted practical use**. One participant reflected that she received:

> “ . . . *just a phone call saying we're here if you need us, but you know there wasn't much he needed them for because things were put into place, but there was no wellbeing for the patient as such*” (ICOH20).

Another participant said she had been told to call if she needed anything, “there was some back up there if you and they said if you're stuck for your medication we'll bring it, we'll deliver it. But I was fine with that” (ICOH28). The following participant pointed to a significant limitation of the telephone calls for her, caring for her dying father on her own at home, saying they were:

> "*Of no use whatsoever! Because, they'd speak to my dad and he goes, 'Yeah I'm okay today'. Well no, you're not okay, you haven't eaten, you can't lift your head . . . and so they needed to see him. Anybody can say anything on the phone*" (ICOH16).

Some participants did not receive regular calls at all and others said that this service was stopped after the first lockdown. In its place participants were told to call the hospice if they needed. However, a participant explained her preference to be called regularly by the hospice, rather than just knowing they could call if they needed:

> "*I think you put off calling, don't you? In those circumstances you think, well, you know, maybe I will last a little bit longer. That sort of thing. I think them calling regularly was really good*" (ICOH11).

Similarly, a participant described how having the number for the hospice's 24 hour emergency helpline, "we wouldn't be doing that unless it was really critical really. I mean, we're not going to just ring up for a chat" (ICOH13).

The telephone calls were seen to be a useful and necessary service during lockdowns and periods when participants and those they were caring for could not easily access hospice services. However, it was noted that in-person visits were preferred, "I know you got that contact with him on the telephone, but you've got that visit . . . so you are expecting someone to come to see how he's going would be nice" (ICOH22). Another noted how her father, "He prefers the face-to-face. But he does look forward to the phone calls when they you know when they had to be that way" (ICOH11).

Impact on bereavement support

We asked the participants to tell us about their experience of (pre) bereavement support from hospices. A participant described the bereavement support the hospice provided:

> "*I knew every time I spoke to [counsellor name] she always would say, 'I'll speak to you next week at this time, but if you need anybody in between, you can always ring this number or send an email to this, somebody will always be here for you.' And so that was really reassuring to know that if I was facing any kind of crisis that that there would always be somewhere for me to turn*" (ICOH41).

Another participant explained how the hospice provided, "pre-bereavement counselling, [which] prepares you for everything going forward and it makes the whole bereavement process a lot easier" (ICOH40). This was provided on the phone and via video support groups, "it was very beneficial for me" (ICOH40).

There were other participants who described counselling being offered after the death, but they did not take it up. However other **participants explained they had also been offered bereavement support or told that someone would call, but have had no contact from the hospices since**. One participant described how her young daughter had witnessed her difficulties of caring for her mother at home. She explained that, because of the pandemic, her daughter was only offered telephone or video consultation with a child psychologist, but she felt her daughter was, “just too young to do stuff online or understand on the phone what's going on” (ICOH77). There was a suggestion that in-person support would be offered once the hospice was open again, but she never heard anything further. Another participant explained how it was the hospital, where her father had died, that organised bereavement support, rather than the hospice where he had been cared for a few weeks previously, but had been discharged. She noted, “in my case [the hospice] didn't keep in touch, until I contacted them” (ICOH15).

The pandemic and protections in place meant that **some participants experienced exceptional circumstances not only around the care and support offered at the end of life, but around their grieving** and making funeral arrangements:

> “*You're not being able to see him in the chapel of rest. That he didn't have a funeral service, you know. People did come to like the graveside and then the cemetery manager was sending people away saying they were gonna hold the barrier, you know, it was just it was just horrible*” (ICOH16).

The participant questioned the effects of this and the poor support she and her dying father had received during the first lockdown had on her:

> “*I think it affected us how we've all grieved and because I can't, I think, I can't get past those ten days really, even though we're probably about 16 months, I can't get past how awful those ten days were*” (ICOH16).

When asked if the hospice had offered and bereavement counselling she said:

> “*It is something I feel like I do need to. I haven't been offered, you know the I mean [hospice], nobody's offered anything. We might have had one wellbeing call and then that was it. So no. But it is something that I think probably that we that we will explore*” (ICOH16).

A participant described how she had been offered bereavement counselling, but “they said they would call me back and they never did” (ICOH72). She went on to consider how helpful some follow-up support from the hospice would have been:

> “*And I think if I had had more support, you know, just some support that the outcome, the ultimate outcome was the only outcome, there was nothing I could have done. Then maybe that would have helped me and my family with their grieving process, there’s a lot of unanswered questions . . . You know almost when, I don’t know if you’ve ever had a child but you know when you have a birth debrief, I think almost like a death debrief*” (ICOH72).

Summary of findings

In our interviews we found that carers of those with life-limiting conditions often felt isolated, abandoned (especially during lockdowns), and felt they were left to provide essential personal and clinical care with little support. For some carers palliative services and support often seemed to be poorly coordinated and the withdrawal or minimising of some hospice at home services during the lockdowns had profound effects on some carers. Carers also described how the people with life-limiting conditions they were caring for struggled when day and out-patient services were withdrawn.

We heard about a range of initiatives and forms of support that were put into place to support carers and those they were caring for during lockdowns and the pandemic. This included doorstep visits, telephone calls and video support groups; all of which helped sustain wellbeing during lockdowns. However, despite some advantages these forms of support brought, in-person support was preferred, even with protections such as PPE and testing still in place. Indeed, some carers explained how they feel the person they care for is more vulnerable now that such protections have been removed in some contexts.

Carers appreciated the need for the national pandemic protections that had been put in place. However, not all compromises were easily negotiated, including early limits on not being able to visit a dying person in a hospice inpatient unit. This limit meant some carers sought to keep the person they were caring for at home, despite the often significantly increased difficulties they faced in doing so. For those carers who did visit people in the hospice inpatient units, they found that the protections limited communication with staff and the person they were visiting. Although some carers received (pre) bereavement support, those that have been previously offered, but not been able to take it up, may now be in ready and in need of support.

Summary of the implications for practice and recommendations for policy
We found that during the pandemic people caring for those with life-limiting conditions needed their hospice to be adequately resourced and available out-of-hours, to help avoid them being left inadequately supported. For those at home this may include providing safe and effective hospice-at-home services 24 hours a day. For others it will necessitate providing online and telephone support, as well as, finding ways to safely restore in-person day and outpatient services, which can help to meet the holistic needs of individual patients. More resources for bereavement services will be needed to support carers grieving for those who have died in the exceptional circumstances of the pandemic. Providers and commissioners need to ensure carers have a meaningful voice in national and local conversations about the ongoing Covid-19 response, as any changes could have significant implications not only for their own wellbeing, but also for the quantity and quality of their lives of those they are caring for. This includes the easing of protections related to socialising and visitors to in-patient settings, as well as the role of volunteers in providing safe and ongoing support at home and in the hospice.

Most importantly, policy makers should ensure that those with life limiting conditions, and those that care for them, are not marginalised or discriminated against, and that the quantity and quality of the lives of those with life-limiting conditions are valued equitably in any (new) policy. Hospices should recognise the importance of their position in the community and the ways that they can bring people with life-limiting conditions, and those that informally and formally care for them, together. Hospices should be ready to facilitate, engage and listen to those they care for, not just as patients and (in)formal carers, but as citizens, who need to continue to have an active voice in society.

Conclusion

This is one of the first studies to report on the experiences of people caring for those with life-limiting conditions, as well as those who were bereaved carers, who used hospice services during the Covid-19 pandemic. We found that carers experienced exceptional difficulties, especially during the first lockdown, when services were reduced or even withdrawn. However, carers were appreciative of the efforts hospices made to provide support to them and those with life-limiting conditions that they were caring for, whether that was on the telephone, online, or in-person visits with PPE. The strict protections and limits to visiting people at the hospice inpatient units caused upset and distress to some carers, especially at the start of the pandemic. Nonetheless, the removal of protections has caused some concern, as it may expose those with life-limiting conditions to increased risks of infection, affecting the quality and quantity of their lives left. Given the risks to this population, both carers and those they are caring for will continue to need Covid-19 tailored consideration and support from hospices, healthcare commissioners, and policy makers.

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