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

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Main findings

- Patients described how hospices often ‘stepped-in’ to help bridge primary and secondary service gaps that they experienced during the pandemic, especially during lockdown(s).

- For some patients the loss of volunteers felt very keenly, especially the loss of friendships established at the hospice.

- Some patients were reluctant to be admitted to a hospice’s inpatient unit because of the protections on visitors and also the perceived increased risk of contracting Covid-19, for them and their visitor(s).

- Many people with life-limiting conditions remain vulnerable to Covid-19 reducing the amount, as well as the quality, of life and were worried about the lack of consideration of their circumstances in the removal of national Covid-19 protections.

- There was a real sense of loss by those patients who were unable to access hospice day and out-patient services and a sense of high, but scarce, value associated with those services that were available when people were able to return to the hospice in-person.

- The home was often viewed as a safe place to be, especially when hospice at home was providing good quality support; but being at home left some participants feeling isolated during the pandemic, especially during the lockdowns.

- Online video support groups provided a useful stopgap for many participants, but others struggled with IT equipment and access or did not like the format of online interactions.

- Participants found that hospices regular telephone check-ins (proactive approach) were a good way of maintaining physical and mental wellbeing during the pandemic. Having a ‘hotline’ patients can call (reactive) was found to be reassuring, but it lacked the engagement that some participants needed, and others worried about being a burden if they called. Regular telephone check-ins were felt to be superfluous once in-person support was available again.

- Participants appreciated their family and friends being included in hospices (pre-bereavement) support activities.

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. Patients need hospices and primary (palliative) care services in community settings to be adequately resourced and available out-of-hours in all areas, to help avoid patients being left inadequately supported.

3. Hospices need to provide online and, whenever possible, restore in-person volunteer-led services that help to meet the holistic needs of individual patients, especially through the prevention of loneliness and isolation at the end of life.

4. Service providers and commissioners need to ensure patients and their carers have a meaningful voice in national and local conversations about the ongoing Covid-19 response, as the easing of limitations 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. Hospice patients need all the palliative 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. Support patients by maintaining a range of digital options for how care and support is delivered – across all settings – alongside in-person and telephone options.

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 protections, 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 effects 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 of 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 carers, 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) that 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 with life-limiting conditions the effects of the Covid-19 pandemic on the care and support 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 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 people with life-limiting conditions 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 patient’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 *et al.*, 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

18 patients were interviewed either on MS Teams or the telephone. 12 identified as female and six as male, all identified as heterosexual; 15 identified as white-British ethnicity, two as Asian or Asian British Indian, and one as Black, African, Caribbean or Black British. Age ranges by decade were requested, with the greatest number of participants (n=8) being between 60-69, ranging from one participant in their 30s and four in their 80s (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 the pandemic during their hospice care. 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	18	
Male	6	33%
Female	12	67%
18-29	0	0%
30-39	1	6%
40-49	1	6%
50-59	1	6%
60-69	8	44%
70-79	3	17%
80+	4	22%
White, British	15	83%
Asian or Asian British, Indian	2	11%
Black, African, Caribbean or Black British	1	6%

Table 1: Participant characteristics

<u>Impact of changes to hospice services during the pandemic</u>

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 that are the focus of this study (Sleeman *et al.*, 2021). 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
We found that participants were aware of the increased demands the pandemic brought upon both hospice resources and the NHS more widely. Participants described a number of palliative services – such as, patient transport and COPD nurse home visits – that, “Bang! Stopped” (ICOH12) at the start of the pandemic. One hospice in-patient participant described how the loss of staff from hospices meant that the quality of the food deteriorated, “which is important thing in a way, because when you're in hospital or in a hospice, food is the marker of the day” (ICOH23). The pandemic protections not only affected the services provided by the hospice to in-patients, but limited those services that could visit, such as hairdressers and chiropodists.

Several participants reflected on how the changes were, initially, understandable as hospice resources and staff were redeployed to manage the pandemic. Nonetheless some **participants who were supported in the community reported how the removal of services had left them feeling uncertain and vulnerable**, as the previously regular sources of advice and support were no longer available. Furthermore, once the first lockdown had ended in June 2019, some participants did not see a return of all of the community support previously offered. However, as the following participants described, their experiences had given them a strong perspective on the role and importance of hospices both during the pandemic and in general. As the following participant said:

> *But I really believe the government should give the [hospices] more money for the job they do, they are not recognised enough. They're really not!* (ICOH01).

For many participants – especially during the first lockdown – **their hospice became a pivotal healthcare resource**, either via hospice staff directly providing the care and support needed (whether that was for general healthcare support, or primary or specialist palliative care), or by acting as intermediaries and arranging the necessary appointments with a primary care healthcare professional. For example, one participant explained how she struggled to see her hospital specialists at in-person appointments, but the hospice was able to run and report on the tests she needed. Other participants described how there were times when the usual routes to care and support in the community via primary care were not accessible, with their GPs oversubscribed with appointment requests and with limited time to speak when they did get an appointment. As one participant said, “I do feel like, you know, perhaps the hospice staff nurses very much stepped up in covid time and GPs have stepped back” (ICOH21). Another participant whose life-limiting condition meant that she could not always be awake in time to call the GP first thing to book a same-day appointment. In contrast, she could speak to the hospice at any time of the day to access the support she needed, saying, “I knew, right, I'll get more support – more than [from] my GP – I'll get it from there [the hospice]” (ICOH06).

Hospices were therefore an important resource to people with life-limiting conditions in the community, as the following participant said:

> *I mean hospices, it's important that they stay, yeah, people like for people who are vulnerable and need them. But they're definitely needed in the community*. (ICOH27)

As we go on to discuss in ‘quality of care’, although many participants experienced significant change to the services provided by their hospice, participants described ways in which their hospice was able to continue to find ways to address their feelings and sense of vulnerability that they felt during the pandemic.

Loss of volunteers

During the first lockdown and throughout the first year of the pandemic many hospices were unable to draw upon the volunteer workforce. Volunteer roles range from being someone patients or carers can have a conversation with, to supporting people with day-to-day activities such as shopping or transport. Although the role of volunteers was a topic in our interview guide to prompt participants to speak more about should they raise the issue, it was only raised by a small number of participants. **For those that had relied on volunteers the loss of this support, as one participant described, therefore had a “big impact” (ICOH12) on them**. This sense of loss was particularly strong for a participant who had developed friendships with volunteers, but was no longer able to keep in touch with them.

Changes to visiting arrangements

The first lockdown brought limitations on visitors to inpatients at the hospice, and some forms of visitor protections were kept in place throughout the pandemic period of this study. One participant described how knowledge of the protections meant she was reluctant to be admitted to a hospice because her daughter might not be able to visit her and if she was allowed, her daughter might be reluctant to visit because of the threat of contracting Covid-19. However, another participant reflected that he did not worry about being admitted to the hospice, even once the lockdown protections eased as, “it was the safest place to be because they was cleaning all the time and following all the guidelines and they got all the right PPE” (ICOH25).

Participants described the difficult balances of risk and compromises to care that managing visiting arrangements brought. One participant who had been admitted during a lockdown described how the care she had received was “fantastic,” but that she wanted to return home “mostly due to the problem of not being able to see many relatives due to the Covid” (ICOH21). She said that for most of the time she was an in-patient she had to name six visitors she would like and only they would be allowed to visit. The participant explained:

> "*I did understand that because there are people that are at end of life in the hospice and they have to be cautious. And but that was a yeah that was a difficult frustrating time*" (ICOH21).

This frustration was because she had some friends and family members who lived quite a distance away, and were only expecting to visit once, who could not come, as she had to choose those who lived locally who would visit more frequently. Even so, the participant said, "because of the list of six, I didn't have a visitor every day. So there was many days when I would be, you know, sat on my own in that room" (ICOH21). For those who did visit, another participant explained how the strict rules around infection control and personal protective equipment (PPE) left her and her visitors feeling "very much that we were being watched" (ICOH17).

Quality of care

During the collaborative knowledge synthesis we found that the pandemic was posing significant challenges to the expectations of high-quality of care and support that were usually associated with hospice care. To explore this further we identified six related issues through which to explore issues of quality of care (MacArtney et al., 2021): demographies and geographies of care; places of care: hospice care day and out-patient services; places of care: hospice at home; digital and remote palliative healthcare; changes that worked (or did not); and bereavement support.

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 with life limiting illnesses and what additional support they might need to compensate for that.

Some of the changes to healthcare services that were brought into place because of the pandemic helped provide those with life-limiting conditions with palliative care and support they were previously unable to access e.g. via digital and remote care (see below). This supportive ethos extended to members of local community, with some participants describing how in the first lockdown neighbours would collect and deliver medications and food. However, the lockdowns also enforced a disconnection not only from other people, but away from a group identity and acceptance. When one participant reflected on what was lost by not being able to visit the hospice, he noted that the hospice had created a non-judgmental, comfortable space, "I find in public or even around friends and family they, I feel that they pity us or pity me. As opposed to just talking to me like I'm normal” (ICOH35).

Life beyond the lockdowns remained difficult for some participants whose life-limiting condition or treatment left them more vulnerable to community transmission of Covid-19. These **participants were concerned that Covid-19 could both shorten the amount of time they had, as well as significantly affect the quality of that time**. One participant explained that she had not left her house, other than for healthcare appointments, for 18 months. Another participant said that what worried him was, “the amount of people [who] think it's all over and done with” (ICOH20). As a consequence, he had only left home twice since the end of the first lockdown (i.e. in the following 12 months). This sense of marginalisation was exemplified in one participant’s account of the agency carers repeated failures to consider her condition by failing to bring adequate PPE to her home, especially after “freedom day” (14 June 2021), “which was a bit of a frustration because carers were still supposed to wear masks, weren't they?” (ICOH21).

Places of care: hospice care day and out-patient services

Several participants had experiences of hospice care pre-pandemic and so the first lockdown involved the ending of direct care provided by the day services and outpatient clinics they had come to depend upon. Participants also described the loss of serendipitous or potential future care that they had experienced, whether this was the organised ‘extras’ hospices provided (e.g. talks by dieticians or symptom management discussion groups) or the chance opportunities or referrals that came from informal conversations with staff and service users. Several participants described the psychological and emotional effects they felt from the loss of friendships and camaraderie they had experienced with clinicians and other service users:

> “*Yeah, purposeless, I felt. Just useless I had no – empty – nothing to fill my life. Yeah, very empty and sad, very sad, thinking, ‘Will it open ever open again or will it be years or will it be…?*” (ICOH33).

Another **participant described how she had enjoyed the day services and support she had received, but the pandemic “ruined it”** (ICOH02). She explained how, during the first lockdown, she had struggled to get the care and support she needed from the hospice and that there was rarely anyone to speak to when she called. This had affected her experiences of the hospice overall, “I used to like to go there, as I said and everything, but how things have got now since it all closed down and opened up. I don’t seem to have any faith in them for it, so I just leave it” (ICOH02).

Between lockdowns some hospices were able to provide limited day and out-patient services. But for one participant, the loss of several day-patient services significantly affected the hospice environment. Returning to the hospice in the context of apparent and actual scarce resources left one participant feeling “really guilty” and a “burden” about taking up hospice staff time (ICOH01). Nonetheless, other participants explained how being able to access physiotherapy and complementary therapies at the hospice after the first lockdown helped them “feel good . . . you were not forgotten then” (ICOH25). Similarly, another participant said that she really appreciated the opportunity to talk to staff, even though her adult children were very supportive, she was careful about expressing her feelings to them as, “you don't want to lay it on anybody else” (ICOH08).

Places of care: Hospice at home

The changes to how palliative care was provided during the pandemic also meant changes to where it was – or could be – provided. **The home was viewed by some participants as the safest place to be**. As one participant explained:

> “*The GP was saying take her to the hospital and ambulance crew was saying like to take me to the hospital, but I refused it because [of] the covid - so many high deaths and in my family lost so many people. They was healthy. They went to the hospital they did not come out*” (ICOH06).

The quality of hospice support at home was also a consideration for some participants, especially in comparison to the other services they had experienced. Hospice staff were seen to “take the time” (ICOH12), be more sympathetic, less dismissive to worsening symptoms – as one participant recalled a GP saying, “your condition will get worse, not better” (ICOH06) – and be better able to pick-up on nuances of a person’s changing condition. For example, a participant described how a healthcare professional from the hospice visited him at home and was able to see that he needed changes to his pain medication to make him more comfortable. Another participant explained that she had no contact with her GP other than repeat prescriptions, and it was during a Community Nurse Specialist’s face-to-face visit (12-18 months into the pandemic) that the nurse was able to see that she needed to be admitted to the hospice.

Palliative care provided by **‘Hospice at home’ meant that some participants felt isolated during the pandemic, particularly during the lockdowns**. A participant explained how the first lockdown did not affect her capacity to go outside and socialise, as she was already somewhat housebound. However, it did affect what support was available and – most importantly for them – who could visit. A participant explained that the only people to enter her house during the first lockdown were paramedics, who she did not mind being there “as long as everybody is observing the rules. I was quite ok with it” (ICOH17). Another participant described how it was “very hard” (ICOH20) to be shielding for a year with his wife, with no visitors despite his daughter and granddaughter living close by. Despite this, he sought to avoid being admitted to the hospice and to manage his pain at home. He reflected, “It was a very awkward time”, but the regular telephone calls “really worked well . . . rather than being stuck in the in the dark” (ICOH20). Unfortunately, his pain developed and he was admitted to the hospital, rather than the hospice due to the protections in place at the time. However, the hospice team were able to see him in the hospital and supported him there also.

Digital and remote palliative healthcare

Most participant interviews contained detailed discussion of how either digital or remote methods of staying in touch were a significant part of their hospice experience during the pandemic. We discuss the use of telephone calls below as a case study in '*what worked…*', here we explore participants descriptions of how online, and later hybrid, approaches to various support groups allowed more people to engage what were previously in-person hospice day or community support services during the pandemic.

Video calls were used to maintain support groups or therapies, such as relaxation, breathing, and even "spa days" (ICOH04) at several hospices. These video calls would include other patients from the hospice and would include opportunities for "a little chat" (ICOH04) and were a way to "get ideas from each other" (ICOH06) to manage during lockdown. One participant explained how it was sometimes a struggle to get dressed every day during lockdown but, "that was another good thing. [The video meetings] gave you a buck up, so you get dressed and then sort yourself out" (ICOH04). The other described how the online meetings she had with hospice staff and patients once a week were "really nice" and that the staff made her feel like they were "looking after family members" (ICOH06). She reflected on how the video meetings helped prevent her feeling lonely, "cause you're looking forward for every week or you go to see each other and talk over problems" (ICOH06).

Online video platforms were found to be supplemental to in-person support – especially given the circumstances of the pandemic – even for those participants that felt strongly about the benefits of using them. Although one participant said that staff at the meetings were "open [to] any questions we can ask them" (ICOH06), another participant described how there was no easy way to have side-conversations with staff (even if they could get the breakout room to work), as they could when meeting at the hospice. One participant explained that the group video calls were not the place to discuss her condition or how she was (or was not) managing. Therefore, **as welcome as the video support groups were, some participants reflected that they would not be needed once the pandemic was over**. A participant, who had found the online and telephone support very helpful, described the difference returning to the hospice made to her, after the first lockdown, "the welcome was so nice. I really cried" (ICOH06). But another participant noted that the on-going pandemic limitations on the numbers for in-person attendance meant she did not get to see everyone at the hospice, as she could on the video meetings. However, the hybrid meetings – with some patients at the hospice and some on a video call – were not always judged to be very successful, as some participants said they struggled to hear what was happening in the hospice group.

There were also access issues that limited who was able to take part in the online groups. A participant said he was aware that support and therapies were available via Zoom, but he did not have a computer with a microphone and there was no one available to show him how to use Zoom on his phone, which he could not get to work as he was "not very technical" (ICOH25). Similarly, another participant explained how she was aware that some people she had previously met at the hospice were not able to join the video support groups as, “some people didn't have the right equipment to do it or didn't feel it was for them” (ICOH04). The right equipment meant more than having a device with camera, microphone, and that could access the internet, but also devices that accommodated particular disabilities, such as hearing loss or visual impairments. Some hospices were aware of such access issues and one participant described how hospice staff, “came [into my house] and sorted it for us” (ICOH04). However, another participant explained that although the hospice offered to help with setting up video calls on his computer, he declined as “I wasn't particularly interested in doing . . . that kind of thing on [the] computer” (ICOH12).

Changes to services that worked, changes that did not work

In the collaborative knowledge synthesis we recognised that many hospices would implement changes or new services that would be specific to their local circumstances or that we were unable to anticipate. In this section we continue with the concern of how hospices sought to keep in touch with patients, by first documenting some of the initiatives hospices undertook before looking more closely at the use of ‘telephone check-ins’ that several hospices in the region implemented.

Hospices undertook several initiatives to keep in touch with patients. One participant described how he received a monthly eight-page newsletter with information about what was happening at the hospice and that also included pieces from other service users at the hospice. Several participants from one hospice described how the hospice staff would visit, but would stay outside. These participants explained that during festivals periods – Christmas, Easter, valentines – staff would deliver gifts such as hampers or pot-plants. The participant reflected how, “They made us feel secure and wanted all the time” (ICOH04). Another participant told us that hospice staff would visit at other times,

> “*The surprise visits were just lovely. You know when you can't get out. All of a sudden there's a tap on the window, and there's you friend tapping outside being silly, you know?*” (ICOH08).

Most participants who experienced hospice support during the first lockdown (March to July 2020) reported that they received **telephone check-ins** from the hospice. Some participants reported receiving two or three calls a week, with several saying it was a weekly occurrence. The calls would include getting an update on the participant’s condition, if they needed any changes to medication, and general discussion about their physical and mental wellbeing. As one participant said, “it doesn't have to be all medical” (ICOH08). One participant said she took part in one-to-one meditation over the phone.

For some participants **the telephone check-ins that some hospices initiated were very welcome**, “I really do not know what I would have done without their weekly phone [calls]” (ICOH01). Another participant said, “Right through lockdown I was housebound. The conversation was very, very helpful and useful. And they did it regularly and they were lovely" (ICOH10). One participant said the calls made her feel "we are really valued people for them" (ICOH06), another said the calls "was never rushed" (ICOH12). A participant who said they had good family support during lockdown explained how the calls prevented her from feeling isolated. The hospice calls were particularly important as the participant did not "want to lay this – this feeling – onto my family" (ICOH08). Another participant noted that having hospice staff who "understand and talk with you, [meant] you didn't feel like a burden or anything" (ICOH27). A sentiment echoed by a participant who reflected that it was important that the call came from the hospice as they "know what they're talking about" (ICOH12).

The telephone check-ins did not always work for everyone. One limitation to the phone calls a participant experienced was that her condition made her forgetful and so she would rely on her daughter to support her at meetings with clinicians. The one-to-one nature of the phone call made this difficult, so she would hand the call to her daughter, meaning she did not always get to speak to clinicians directly. Another participant explained that she struggled to know what she "wanted to say and how I articulate it" (ICOH33). Whereas, when visiting in-person, she found it was easier to find an opportunity to talk to staff about problems she was having.

Some hospices stopped the regular check-in telephone calls after the first lockdown. Although one participant explained that she was never told why, others said that they could call the hospice if they needed to, as the hospice "made you feel as though they was still on the end of the phone for you. So, if I had any worries or anything I could pick up and phone" (ICOH08). Another said, "And we knew, if we've got a problem, all we had to do is pick up a phone and they was there at the end of the phone, even though we was in lockdown" (ICOH04). However, **another participant explained that although they appreciated knowing there was a number to call, she was reluctant to call as she did not want to "bother" the staff** (ICOH33). One participant described the loss of reassurance that this "keeping an eye on me" (ICOH12) brought to her and her carers. However, another explained how this loss of telephone contact would be less of a concern once she was able to visit the hospice again. This was echoed by other participants who also suggested that the regular calls would be less needed – if at all – once they were able to return to regular visits to the hospice.

Impact on bereavement support

Two participants mentioned the pre-bereavement services their family members were getting from the hospice and the impact of the pandemic upon that support. One participant described how the ending of support groups for in-patient family members affected her daughter's willingness to visit, as she did not feel supported or comfortable attending the hospice. Another participant, who was supported by the hospice at home, described how "important" (ICOH12) to him it was when hospice staff spent time with his wife when they called, either on the telephone or in-person visits to his home.

Summary of findings

Our interviews show how the Covid-19 pandemic affected the clinical care people received, but also the impact on the emotional and social wellbeing of individuals with life-limiting conditions. Participants reported they were reluctant to be admitted to a hospice because of the limitations on visitors and the perceived increased risk of contracting Covid-19, for them and their visitor(s). In contrast, their home was often viewed as a safe place to be, especially when hospice at home was providing good quality support; but being at home left some participants feeling isolated during the pandemic, especially during the lockdown periods and with the loss of the volunteer workforce.

Participants reported how hospice staff and services adapted to support them in a number of important ways. We found many occasions where hospices stepped-in to help bridge primary and secondary service gaps that participants' experienced during the pandemic, especially during lockdowns. Participants described how the closure of hospice day and outpatient services left a real sense of opportunities lost for care, support and friendships. However, for some participants the hospice video support groups provided a useful stopgap; others struggled with IT equipment and access or did not like the format of online interactions. There was a strong feeling by those participants who received regular telephone check-ins that they were a beneficial way of maintaining clinical care, as well as supporting mental wellbeing during the pandemic. Some participants also found having access to a 'hotline' was reassuring; others perceived it lacked the engagement that they needed or were concerned about being a burden if they called.

Summary of the implications for practice and recommendations for policy

We found that during the pandemic people with life-limiting conditions needed their hospice to be adequately resourced and available out-of-hours, to help avoid them being left inadequately cared for and poorly 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. For those admitted for inpatient stays service providers and commissioners need to ensure patients and their carers have a meaningful voice in national and local conversations about the ongoing Covid-19 response, as any changes could have significant implications for the quantity and quality of their lives. 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 are not marginalised or discriminated against, and that the quantity and quality of their lives 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 with life-limiting conditions who used hospice services during the Covid-19 pandemic. We found that while many patients felt safer at home, especially during lockdown periods, others felt isolated or emotionally low. Hospice staff were able to help participants get support from other healthcare services (e.g. appointments with primary care) or stepped in to provide that service themselves (changes to medications). Participants that experienced regular contact with hospices, either via video support groups or on the telephone, found these groups helpful, but they did not see such contact as a replacement for in-person support outside of Covid-19 pandemic context. We have recommended that hospices should be supported and properly resources so that they can implement the lessons learnt from the pandemic and play their fullest part in ensuring patients have the best possible end of life experience, both now and in the future.

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