Impact of Covid-19 pandemic on Hospices (ICoH)
Senior Management Cohort and Grey Evidence Report

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Main findings

- The impact of the pandemic on resources (such as Personal Protective Equipment) and funding differed at each hospice, but was a key issue all senior managers had to address. Some hospices were able to access emergency funding from the government to provide additional services to support the NHS including making additional bed capacity available at the peak of the pandemic.

- Senior managers described the personal loss and the impact on the workload of hospice clinical staff that losing volunteers had and continues to have, as many volunteers remain reluctant to attend in-person, as they remain at risk from Covid-19.

- Senior managers describe how some of their hardest decisions related to implementing visiting protections, describing the emotional impact to themselves and their staff, as they sought to balance protecting patients, their visitors, and the hospice staff with the need for those with life limiting conditions to be with those that care for them at the end of life.

- To support the NHS at the start of the pandemic some senior managers put processes in place to accepted patients with life-limiting conditions, but who did not have the complex needs hospices traditionally support; during 2021 hospice managers have seen an increase in patients with more complex needs as a result of late-diagnosis.

- Senior managers had to quickly adapt how they provided support to their day service users and outpatients, as well as reallocate staff to other services; they are now trying to find ways to reintroduce the previously suspended services safely, in the context of no national pandemic protections.

- Senior managers had to increase provision of already existing hospice at home services, while those hospices without have seen the increase in demand as providing a strong need to introduce the service.

- There has been a rapid development of a digital infrastructure at many hospices and senior managers have used the pandemic explore how digital services can be further integrated in services.

- It was sometimes difficult to communicate decisions, especially in the rapidly changing context at the start of the pandemic, but senior managers used a range of communication tools and emphasised the need to focus on authoritative sources of information.

- Senior managers sought to support and motivate staff throughout the pandemic, often putting their own wellbeing second; but they are concerned about the lasting impact on staff wellbeing and the resultant loss of experienced staff from the caring profession.

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. Hospice leaders need a long-term, sustainable and resilient funding settlement, with additional statutory funding that recognises hospices as a core part of the health and care system, so that they can better plan for the future.

3. Hospice leaders need to engage a more diverse demographic as part of restoring their volunteer-led services, as well as employing volunteer coordinators with the skills and experience to ensure volunteers are integrated into the hospice workforce.

4. Ensure hospice leaders collaborate in designing guidance for visitor limits and protections for in-patient settings, to ensure they minimise compromises to end-of-life care experiences of individual patients and their families.

5. Provide senior hospice managers with resources so that they can ensure that they can take a pro-active approach to staff health and wellbeing, including fast-track access mental health and bereavement support if required.

6. Local healthcare commissioners need to work with hospice leaders as part of the ongoing Covid-19 pandemic response to develop healthcare environments that are safe for all those involved and to ensure hospices are placed on an equal footing with NHS and other health service providers.

7. Hospice managers will need support from local healthcare commissioners and providers as they seek to adapt to demands for hospice services at home and to ensure hospices are supported to deliver high-quality services in all community settings, available at all times including out-of-hours.

8. Hospices will need to be provided with the resources so they can build on the rapid digital transformation that took place during the pandemic, so that hospice services can integrate digital support alongside in-person and telephone options – in all settings and across all services.

9. Ensure that hospice leaders have a meaningful voice in national and local conversations about the ongoing Covid-19 response, and that any changes to government policy are communicated in a sensitive and professional manner.

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 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 patients, carers, and frontline hospice staff 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 (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.

As the key decision makers during the Covid-19 pandemic, this part of the ICoH study aimed to explore senior managers' experiences and to understand how they responded to the challenges imposed on them whilst still delivering a high-quality palliative care service. Coupled with hospice grey evidence in the form of, for example, senior management emails to staff, policy and guideline documents, we can start to understand the pressures and context in which decisions were made, including what worked well and what did not. The aim of this report is therefore to explore experiences of senior managers during the Covid-19 pandemic to identify recommendations for clinical practice and healthcare policy. Drawing on these findings, this report offers **recommendations for hospices managers 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

Data were collected as part of the wider Impact of Covid-19 pandemic on Hospices (ICoH) study. This paper describes data from hospice senior management qualitative interviews and collection of hospice grey evidence. We used a rapid appraisal qualitative approach (Beebe, 1995). Rapid appraisal is an approach for developing a preliminary, qualitative understanding of a situation, particularly relevant when time constraints preclude use of intensive qualitative methods, and when different perspectives of the research team members are essential for understanding the situation. This approach allowed for iterative data collection and analysis, as well as the triangulation of different sources of data to understand the situation.

Setting

The study began in March 2021, almost a year after the first Covid-19 lockdown, and shortly after the lifting of lockdown 3 (Institute for Government Analysis, 2022). The study took place in the West Midlands, UK. This area includes 13 non-NHS hospices caring for the adult population. It is a vibrant and diverse community, including the largest ethnic minority 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). The West Midlands has also experienced a range of Covid-19 rates, from some of the country’s highest to areas with relatively low incidence (ONS infection survey, 2022).

Sample and recruitment: Interviews

We contacted all 13 non-NHS hospices caring for the adult population in the West Midlands and asked them to provide at least one member of senior management to take part in this study. Hospice staff (who were not senior management themselves) were asked to share the participant information leaflet with members of senior management who might be interested in taking part in an interview and who had been in post since at least March 2019. The member of senior management would either contact the research team directly to take part, or their details would be passed on by another member of hospice staff, for the research team to make contact. At this point, a member of the research team would contact the participant to answer any outstanding questions, ensure they were happy to take part, and arrange a time for the interview.

Sample and recruitment: Grey Evidence

All thirteen non-NHS hospices in the West Midlands were contacted via email between April and November 2021 and asked to provide where possible, grey evidence in relation to hospices' attempts to assess and manage the impact of the Covid-19 pandemic upon service users and staff. Grey evidence in this study refers to *"quantitative and qualitative materials, that were intentionally collected and processed by hospices to address specific service questions or local problems"*. This differs from what is usually thought of as 'research' outputs i.e., not peer-reviewed literature. This was to include:

- Materials such as rough drafts or working documents shared internally within a team or with senior management; or more developed outputs that have already been shared outside of the organisation e.g., at local forums, events, or conferences. We sought to include any mix of approaches and methods used, e.g., internal audits, evaluations, or other Quality Assurance (QA) reviews relating to service changes in response to Covid-19. The materials could take the form of (short) reports, presentations, posters, guidance, working documents, outreach activities, or even applications for funding.
- Email communications between Senior Management and hospice staff during the pandemic.
- Information about the impact of the government's emergency grant funding for hospices.

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, "Can you tell me about your role within the hospice and how long you have been working in that role?" Follow-up questions would be in response to the participant but would include prompts on how their role might have changed, examples of changes that worked well, the impact on patients, carers and themselves, the atmosphere within the hospice workplace, sustained changes in relation to the pandemic response, and interactions with other health professionals.

With regards to the grey evidence, hospices were asked to: 1) identify any potential materials to share; 2) if necessary, seek specific permission from the document owner and/or person with appropriate authority to ensure they can share the document; 3) check that the document does not identify service users i.e. is either anonymised or pseudonymised (e.g. for interview or open text survey data) at the level of individuals; 4) if necessary, redact any information they do not wish to share with a note why something was removed e.g. 'deleted to preserve patient identity' or 'business sensitive content'; complete any necessary sections of the 'cover sheet' and 5) send the material(s) and cover sheet(s) to the research team.

Data Analysis

The interview 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).

All grey evidence was collected by JF and a narrative review was undertaken using documentary analysis (Petticrew and Roberts, 2006). The documentary analysis was informed by the relevant academic literature and knowledge exchange associated with the impact of Covid-19 on hospices (MacArtney et al. 2021). A sample of collated extracts from the grey evidence (approx. 30,000 words) were subsequently 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. JF then summarised NVivo nodal outputs from the senior management interviews in conjunction with the grey evidence for each theme and identified any further recommendations.

This analysis has focused on providing insights and answers to questions about what should change in hospice policy and practice both during this Covid-19 pandemic, which maybe relevant for future pandemic contexts, and as hospice care moves onto (or between) the epidemic-endemic phases. To provide this analysis quickly we prioritised the anticipatory themes developed through the collaborative knowledge synthesis (MacArtney et al., 2021).

Results

12 senior managers from nine hospices were interviewed, either via MS Teams or on the telephone (Table 1). All participants identified as white British and nine identified as female. We asked participants to identify their age decade and age ranges, from 30s to 60s, with most being in their 40s or 50s. Interviews lasted between 30 mins to 1.5 hours. Interviews provided rich and in-depth descriptions of participants' experiences of managing a hospice during the pandemic. Seven hospices sent grey evidence in at least one format (Table 2).

Table 1: Interview participant characteristics (n=12)

Gender: female n (%)	9 (75)
Age group: n (%)	
18-29	0 (0)
30-39	2 (17)
40-49	5 (42)
50-59	4 (33)
60-69	1 (8)
70-79	0 (0)
Ethnicity: White British n (%)	12 (100)

Table 2: Details of Grey Evidence Included in this review

Hospice	Covid-19 pandemic related policy documents / guidance etc.	Emergency funding info	Email correspondence
Hospice 1	✓	✓	✓
Hospice 2	✓		
Hospice 3	✓	✓	✓
Hospice 5		✓	
Hospice 6	✓		
Hospice 7			✓
Hospice 9		✓	

Two overarching themes had been identified in our previous study: 1) Impact of changes to hospice services, 2) Impact on quality of hospice care, with several anticipatory and new sub-themes (MacArtney et al., 2021).

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 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 the impact on resources and funding could be quite specific to each individual hospice. However, it was evident from interviews, and emails, that **the loss of resources was an area at the forefront of senior manager's minds**. There was acknowledgment of these being tough times for a hospice, and that hospices across the West Midlands and nationally, could be in very different or more difficult situations:

> *"I know many hospices have really, really struggled more so than us, you know, we've not had an easy ride, and you know, we really need to pick things up, but we've survived. We're still here and you know we're planning for the future."* (ICOH76).

Loss of funds was often a result of the stopping of many in-person sponsorship events and fundraising, as well as the closing of charity shops:

> *"We [hospice], obviously a lot of funding streams dried up instantly, so people who would do all these sponsored walks that take part throughout the summer, and you know, pub days and things, all that stopped*" (ICOH76).

In the early stages of the pandemic, provision and sourcing PPE was one of the biggest challenges:

> *"I took on PPE. And that was just a nightmare, an absolute nightmare. We had to try and get PPE from well… I didn't know where to start if I'm honest. We didn't really know what to do, where to go for it. I contacted the major hospitals to see if they would be able to provide us with some specialist masks that we would need. A few of us got together and got in touch with, we were given so many different numbers to call and so many different people. The public were bringing in aprons and gloves"* (ICOH39).

Hospices did have to furlough particular members of staff but received money from the government, which helped pay towards their salary. Where possible, hospices made up the difference, with one manager saying *"*we felt that wasn't the staff's fault that they weren't here and they wanted to be here, and the shops didn't have a choice. You know people didn't have a choice in that*"* (ICOH54).

Some senior managers were pleased that the pandemic brought positive steps towards more efficient use of resources, for example, better use of staff time during the pandemic due to online working. There were also some concerns from some senior managers that this might start to go back to how it was. However, if elements of this implementation stay, it has the potential to save money which can go directly back into patient services, as well as being better for the environment and saving both money and peoples' time, as one participant said:

> *"…but I know it's across the board, is the amount of money that you spent on travel and hotels and meetings, and I think the uptake of Teams meetings was brilliant and from an environmental point of view, fantastic. I'm just really cross that it's all starting to already go back. And I'm like where are the lessons that have been learned and the amount of money that was being saved that could be again, refocus back into direct patient care. That now is going to be going on, travel, hotel or…"* (ICOH58).

Hospices who adapted to the Covid crisis and supported their local NHS received **emergency funding** from the government via Hospice UK in recognition of their help. This funding was only available for *new* services, and not for maintaining existing services that were struggling due to loss of usual hospice income. Emergency funding allowed some hospices made additional bed capacity available at the peak of the pandemic, as part of an effort to prevent hospital admissions, while continuing to provide palliative and end of life care in the region, "...one of the requirements with that was that we had to provide bed status on a daily basis" (ICOH76). They went on to explain:

> *"…we had some emergency funding from the government via Hospice UK that has helped…. So we've managed to…change our service slightly, but managed to keep the money coming in enough to keep us afloat*" (ICOH76).

One hospice, who let one of its buildings out to the NHS, chose not to make a profit from doing so, thereby potentially lowering its income:

> *"We decided not to make a profit from letting out our facilities, but all of the service and utility charges will be paid by [local foundation trust] and they will pay an agreed amount to cover wear and tear on our equipment, so it will at least save us some money"* [Email 14.04.20, Hospice 7].

Four hospices provided additional information about their emergency funding. Of the hospices which provided details on the received amount, this ranged from £256,023 and £2,477,844. Participants told us that the funding enabled hospices to continue to deliver community hospice services, but also to extend the criteria in the types of patients they were caring for. Ways in which the money was used by hospices in this study included: phones and IT equipment to allow the hospice and family support to maintain their care for patients and other service users; additional hours for family support counselling; the restructuring of the Day Care Service to support the needs of patients during and after the pandemic which has included additional nursing posts. One hospice used their funding in two phases, where phase one involved making available bed capacity and phase two was for providing community support for people with complex needs, e.g. extending support from three weeks until a person was likely to die, to six weeks during the pandemic (this has since returned to three weeks). The rapid response day service geographical area also expanded during the pandemic, with plans for that to remain.

Loss of volunteers

One significant decision all the senior managers were involved in during the pandemic was to stand down hospice volunteers. The interview participants explained that this was a decision made either because day services could no longer be offered at the hospice under the pandemic protections in place; or because many of the hospice's volunteers were high risk of serious illness from Covid-19 and their safety would be compromised. Managers described how **it was a decision that was made reluctantly, and the volunteers' absence was greatly noticed**. Furthermore, managers said they were aware that for many volunteers, this role was a form of social contact and in some cases a 'lifeline' both for the volunteer and the person receiving the support, with some left feeling abandoned, despite the hospices' best efforts to keep in touch:

> "*They [volunteers] felt devastated, and so you know, we did as much as possible to keep in touch with them and, and try and support them, but they very much felt, again abandoned*" (ICOH52).

Managers were also aware of the impact that the lack of volunteers had on frontline staff, who had to then carry out the personal support that volunteers could offer patients, as well as carrying out their clinical duties:

> "*I mean it was a double whammy, I think. We really missed their [volunteers] support, because they used to do beyond reception, so you know actually a lot of*

> *the roles that they were doing, suddenly the staff were having to do all of that, so workload of paid staff increased, so that was hard. And then at the same time, the volunteers losing their role*" (ICOH52).

Unfortunately, after lockdown measures eased, the number of volunteers returning has greatly decreased and this is noticeable in the services which were provided later in the pandemic (December 2021):

> "*As soon as lockdown was lifted though, volunteers did start to come back up, but we have lost quite a few because I think people have re-evaluated their…what they want to give. We've got about 1000 volunteers prior to covid and we keep contacting. We reckon we've got about 700 that have stayed with us, but they're not all back yet, but that's mainly their choice, not ours*" (ICOH31).

While the reasons for why this is the case are speculative, this participant went on to suggest that was it partly due to age of volunteers and the risk that Covid-19 this still holds:

> *"I think a lot of our volunteers are older, so they made the decision themselves. You know we don't want to put ourselves in any great risk and that's fair enough. As soon as lockdown was lifted though, volunteers did start to come back up, but we have lost quite a few because I think people have re-evaluated their, you know, what they want to give*" (ICOH31).

One participant reflected on how the impact of standing down volunteers and the impact it had on them as individuals is something which may not quite be fully understood:

> "*I think that that impact is something that will probably never be measured. Just how many people kind of older people particularly have lost their confidence and their energy, and it's turned them into, turned them into old people when they weren't before that. I've seen a lot of that, I've seen and talked to people who were volunteers and are now not. And you know, that's definitely something that I think has been really, really sad*" (ICOH07).

Changes to visiting arrangements

Pandemic restrictions meant that hospices had to limit the number of people who could visit the hospice. Several managers described how **the hardest decisions were those made around changes to visiting arrangements**. For example, the following participant said:

> "*The biggest [change] was about visitors, which was really difficult, like, to making a decision… So that I think that was the most stressful thing to make a decision about, but also the stressful thing for staff and for me about managing expectations of visitors and supporting visitors at that time because, it just wasn't, you didn't want to stop them, but you knew you had to because we had positive patients, so we had positive staff in an outbreak…*" (ICOH59).

The communication of changes around visiting arrangements was portrayed in the interviews, and the grey evidence – in the emails sent to staff, as well as the letters given to relatives. The managers also spoke of the difficulties of further supporting staff during these changes, who would be relaying the decisions to often very distressed relatives. For example, if these changes were being explained to relatives at a time when senior management were not working (out of hours), then the nurses would have to face some difficult conversations without their support:

> *"I think the most distressing for their relatives is when you'd got, yeah, families, who weren't accepting of the restrictions and understandably wanted to be with their loved ones in their last hours of life and took all that anger and frustration out on the nursing staff. And obviously then you know, our senior leadership team would support that if we were on site, but if it was out of hours, if senior leadership team aren't on site, so the nurses were at the brunt of it"* (ICOH58).

Senior managers also described how they would also meet with unhappy relatives would ask to speak to management about the decision made:

> "*And obviously you can imagine as a relative you could be quite distressed at not being able to see your relative in the last few days or week of life. So that was really hard supporting staff and then obviously as ward manager when they've tried to do what they can, you are the person they ask to see or to speak to, or the staff say can you go and speak to this family because they're not really not happy about the visiting or, all those sort of things or patients*" (ICOH59).

Emails sent from management to staff with instructions give a sense of how difficult these decisions were for everyone involved "I appreciate this could impact on our ability to support some of our patients but again balanced with our own protection" (Email 10/04/2020 12:05 hospice 3). Similarly, the grey evidence contained a letter to relatives and visitors that detailed the strict instructions that they were to comply with:

> *"Please maintain a distance of 2 metres from your loved one and staff members . . .*
> *. . . Only one named family or friend may visit during their allocated time/ day. In the first instance the opportunity to choose a loved one will be given to the patient. This can be changed each week if the patient wishes"* (Letter to relatives and visitors, dated 13th May 2020, hospice 3).

At another hospice, communication to relatives regarding visiting were often made via letter, either to the person's home or with a generic letter at reception:

> *"…we communicated [visiting restrictions] with kept letters at reception to update visitors as they've been coming in, as you know what the restrictions are, what the guidance is, and you know, we still review it on a very regular basis"* (ICOH58).

Senior managers recalled the emotional impact to themselves and their staff on changes to visiting arrangements. One manager recalled how there was anger from staff members towards management in the enforcing of these new rules:

> *"I mean there was a period, we had a period of about two weeks where we had no visitors and that was the hardest possible time, lots of anger about, anger from staff towards leaders who had made that decision"* (ICOH52).

Changes to visiting arrangements at end of life left a lasting impact on management and staff, as one participant explained:

> "*So, I feel, I still feel deeply upset myself at some of the conversations that I had. I remember one specifically early in the pandemic where a lady was in, I think she wasn't positive when she came until she tested positive, and husband had been in contact with her just prior to coming in. I think, you know, in the, I can't remember the exact sort of logistics, but basically, he had to self-isolate and so we would have been, you know, and this was at the time where people were being fined and you know it was it was, it was far more, you know it was policed... So, this man couldn't come in and see his wife at end of life*" (ICOH76).

In the early stages of the pandemic, there was limited guidance from the government about what the rules should be and, as such, hospices were left to make their own decisions about visiting:

> "*I think the thing that this staff struggled with most was the visiting restrictions. And I think as an organisation, the guidance wasn't there soon enough and early enough in the process and a lot was left to the hospices to make those decisions*" (ICOH58).

One senior hospice manager explained that putting visitor protections in place, "was a team decision" (ICOH58) including the hospice manager, members of the senior leadership team and infection control lead. They explained that throughout the pandemic there were daily discussions would also be had, and decisions made while considering staffing levels, the rate of Covid within the local community, the risks attached and the latest government advice:

> *"It was literally a daily discussion of, you know staffing levels, what the rate of covid was within our local community, the risks attached, what government advice was being given and guidance and basing our decisions on that"* (ICOH58).

The need to balance multiple factors when assessing what visiting protections were necessary was also found within the grey evidence. However, here **the emphasis was on individual interpretation of the guidance taking into account the clinician's clinical judgement** of the patient's condition, such as when it was an essential visit (or not). One example of this can be found in the following email excerpt:

> "*As before if the patient is rapidly deteriorating and is approaching the end of life, ward staff can use their judgement and with support of the medic team if required allow visiting. At the discretion of the nurse in charge they may need to increase the number of people visiting at end of life to more than two*" (Email, 13.05.20, hospice 3).

Impact on quality of hospice 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 people with life-limiting conditions because of who they are or because of the places in which care and support were (or were not) available to them. Those people with life-limiting conditions were particularly at risk of Covid-19 severely affecting the quality of the life they had left, as well as shortening that time. As such, this part of the study investigated ways in which hospices dealt with such challenges during this time.

In some cases, hospices changed their model of admitting patients slightly, to support the system to facilitate speedy discharge from hospital into community settings. Thus, their criteria of admission to the hospice became wider, e.g. patients who were frail, elderly, or suffering with dementia. One participant explained:

> *"So, we did widen our criteria for admission, not just the super specialist. Actually, we took patients that were, you know, more of the frail, elderly, more of the patients with dementia. You know all of those kinds of patients that can easily bounce into hospital for other reasons. We took more of you know those cohort of patients"* (ICOH36).

However, the sustained demand on inpatient services that had been expected in the early stages of the pandemic did not materialise, as one participant commented, "But yeah, we didn't see the sustained demand on inpatient services that we thought we might" (ICOH36).

However, there were **reports during the second year of the pandemic of a surge of patients who had presented with late diagnoses of malignant diseases**. This was a knock-on effect of patients not presenting early enough with symptoms, or not being able to access treatment:

> *"Lots and lots of people [admitted to hospice] that even if they're having active oncological intervention actually have developed really very complex symptoms because of the high burden of disease. And lots and lots of patients with life limiting illness that actually their trajectory has been very much altered by not having proactive care for those conditions and who have then developed lots and lots of symptoms or become end of life, perhaps earlier than expected"* (ICOH36).

Although at the time of interview it was in the early stages of development, one hospice had made collective efforts to engaging poorly served communities during the pandemic and beyond, including LGBTQ, homeless, learning disabilities and ethnic minority groups. The participant explained that they had:

> *"…worked as a collective with our other hospices and as a group of community engagement development workers. We sort of shared and identified the communities that were hard to reach and took one each and then focused on that*

> *community and then shared our learning and implemented the practice across all the hospices"* (ICOH58).

Places of care: hospice care day and out-patient services
We asked senior managers about their experiences of the changes to how palliative care was delivered in the community, particularly their experiences of managing the care of people who used hospice day and outpatient services. Senior managers had to quickly adapt how they provided support to their day service users and outpatients, as well as reallocate staff to other services; they are now trying to find ways to reintroduce the services safely, in the context of no national pandemic protections.

As a result of the first lockdown and associated restrictions all the hospices that had day services had to close their doors to patients and those that care for them. **Hospices were not treated as an important and equal part of the pandemic emergency response**. A senior manager reflected on that moment and how it affected her and her staff:

> *"Well, I don't think we had a choice really [to shut day services] because I think it was when everyone was told you know, the government said that was it. …it was just the NHS that was, you know keeping going and I just. I said to the team, this is it. We need to just close, and we had to phone all the patients and say we're very sorry but, this is it for now. So that really was heart-breaking, because as I said, they come here not just for symptom management for their condition, but psychologically it matters so much to them to be with other people…"* (ICOH39).

Senior managers described how they did try to keep their staff engaged with patients who were at home but could not have a member of staff be inside their home, with door step visits and other things to keep up their morale:

> *"And when the staff could, they came back and did doorstep visits. To these patients to provide, we took them Christmas hampers out that we'd had donations given to us and made up hampers for them and took them out. We took afternoon tea. Sometimes we just made a pack of scones and jam and things like that and, and took those out. But the support calls, they say even now that it was their lifeline really. Because they couldn't get in touch with GPs. GPs weren't seeing anyone. You know in these patients, we never stopped in contact with them, and although I had to close day services, the patients were still, you know, really important. So we had to make sure that we were doing the right thing by them"* (ICOH39).

Many day services were moved to being online, with senior managers finding that digital workshops for day hospice service users could help increase the number of people attending, who otherwise would not make it due to not being well enough to go out:

> *"You know you'd have a date we'd have a day hospice with place for sort of 10 people, and you might have eight people allocated to come in that day, and only three had turned up because they didn't feel well enough to go out or, you know, they change their mind. You see all of those people now because or, or at least you have contact with all of those people because they don't have to go anywhere"* (ICOH07).

There have also been some benefits of the virtual setup that have come about. For example, some hospices are now able to provide support groups on a virtual platform, (e.g. a motor neurone disease group), improving access for those people that physically had difficulty attending the hospice before. As one manager explained:

> *"it's a way into the hospice world for some people that wouldn't have accessed those services before. The virtual platform is definitely a way forward for different client groups who physically cannot get into the hospice, or potentially don't want to meet face to face"* (ICOH58).

Although **virtual consultations helped during the pandemic, they were not always a good replacement for an in-person visit by a clinician**. As such, senior managers recognised that digital support had its place, but they also acknowledged that virtual consultations were challenging. For example, one participant described a case where a patient did not have the IT set up at home:

> *"So, from the home assessment point of view, the patients were at home. We prioritise them so if they were urgent, we would go out and see them. We try to introduce virtual consultations, but the difficulty we found, or the challenge that we found was a lot of our patients hadn't got the IT set up at home, to be able to instigate that. So, the even though we've tried it, it hasn't always worked"* (ICOH58).

Another senior manager explained that for certain services within the hospice in-person support was still preferable. But the pandemic had facilitated a move towards integrating digital technology into support services, like telephone support, where it may not have been used before:

> *"Yeah so we provided lots of [online] sessions, lots of check-in sessions, just well-being sessions. Lots of telephone support that has continued. So if people can't get in, we support them in other ways. So I think that's a real positive that's come out of adversity"* (ICOH76).

The pandemic has reinforced the need to get people accessing hospice care earlier in their journey, as one manager says:

> *"If people can really experience you know the quality and the array of things that can be on offer to them from hospice care. They need to be seen earlier, you know there's not much anyone can do if somebody comes in and then dies within 24 hours, and you know we see a lot of that"* (ICOH7).

Reaching people earlier, and ways in which to do that was therefore a key takeaway lesson from the pandemic:

> *"Saying if you get referred to the hospice it doesn't mean you've only got two weeks to live, you know it hopefully means you've got months or years to live, but there's lots of things that we can do to try and make that better. That's probably the two main things that I think you know that covid has given us a kind of a new or a renewed focus on is reaching people earlier and technology"* (ICOH7).

Considering the future of day services, one senior manager spoke of the “hybrid services” (ICOH54) that will be delivered:

> *“I think that's really positive that you know the groups on the video calls are working really well. We will definitely carry those on. We won't go back to face-to-face with that, we will offer a mix of face-to-face video or telephone calls. You know some of the stuff that we found the family support service, for example, found that men, particularly I haven't, this isn't research, but that's subjectively that the men engaged in the telephone calls, and they said how much easier they found to talk about their feelings over the phone rather than face-to-face”* (ICOH54).

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 senior managers about their experiences of delivering the service in this way, and how it affected their staff and patients. **For hospices that had ‘hospice at home’ already in place pre-pandemic, this became a busier service** once patients were no longer able to access day services or were choosing not to become inpatients due to the lack of visiting allowed and because of the perceived risk of being in a hospice environment:

> *“Well, we [hospice], weren't gonna be able to take the patient numbers, but also people weren't going to want to come there because they couldn't have visitors, you know, that happened. So consequently, we had for a lot, not huge, I think it's about 40% more or something from patients at home, so we beefed up our hospice at home service”* (ICOH07).

Increasing the hospice at home services was thought to be a positive change that benefitted patients, enabling patients who would not have accessed the unit to be cared for at home, reducing their likelihood of ending up in hospital:

> *“I think the fact that we bolstered our hospice at home service was really important because those people wouldn't have come into us to our unit. So the fact that we were able to care for more people in their home, they wouldn't have had any support if we hadn't, if we hadn't done that and they would have ended up in hospital. So I think that was an important and important change, I think we started to see and we are seeing you know people presenting to us, or coming to us much later*” (ICOH07).

Furthermore, the quality of the service was further increased, becoming more responsive due to a re-distribution of staff. For a time, registered nurses were taken off the closed day services and took on some of the hospice at home roles alongside the healthcare assistants. While this has now gone back to normal, it would be a welcomed more permanent addition to the service if funding allowed:

> “*Our hospice at home teams are generally health care assistants. And so they go out and they do personal care, they make sure that they keep an eye on people basically, and they keep an eye on the families and the carers. And if things change, they alert the relevant team you know. Whereas during covid, we were able to put nurses into those teams 'cause we had to redeploy people and there were some people that couldn't be redeployed into the ward into the other ward,*

> *so you know there was going to hospice at home. So we had registered nurses in there and say the quality was definitely, you know it was better, it was more responsive. And they were able to do more and that is something that we would like to, they've come out again now the registered nurses they had to, but we are looking at how we can do that again. It's money really, and with treatment and everything, but it certainly enhances the service that people had in their in their homes*" (ICOH07).

This contrasts to experiences one hospice had during two of the lockdowns. One senior manager spoke of how referrals dropped and patients were worried about staff going into their home, due to the spread of Covid:

> "*But interestingly, we found it [hospice at home] wasn't as busy as we were expecting the first lockdown and the third lockdown. The referrals dropped and patients and families were worried about staff going into the home, 'cause they were worried about the spread of covid, which we completely got. So actually at the very start of the lockdown, we've got all these, you know, all the staff there waiting to go out to the community things and actually sometimes we didn't even have enough work for them because it was like people didn't want us. That did change and we then being busy. But again, the third lock down there, was that dip again where people were worried about having staff in, but not as much as the first lockdown*" (ICOH54).

The senior manager also described how the criteria for supporting someone at home also changed at different times during the lockdown:

> "*But we did change our criteria as well so, our criteria for support at home was three weeks, I want to say was it three weeks? Yes, three weeks. So somebody had to be come within you know, obviously it's a it's a subjective science this, but within three weeks of the end of their life. But we extended that to six weeks [in the first lockdown], because obviously we were trying to support the hospitals, discharge people home. So we worked with the [hospital] and our local Swift community nursing to get people home for that bit longer*" (ICOH54).

However, **not all hospices had a hospice at home service in place at the time the pandemic started**, and the increased demand for hospice care at home helped the following participant make the case to introduce a service: "Again, we have to provide the service when and where the people need it and I think there has been a slow but definite trend for people to want to stay at home" (ICOH76).

A participant in another hospice described a similar situation:

> *"Yeah, well we don't have hospice at home at the moment, and that's one area, very sort of focused, as that's our sort of next move really… So anything that we, we do external, we've got to raise money over and above what we what we get now. And that's quite a tall ask, but that's our that's our direction of travel [hospice at home]. Definitely I do think covid as accelerated that"* (ICOH76).

Digital and remote palliative healthcare

With the closure of day and out-patient services, hospices sought to find ways to stay in touch and support patients and those that cared for them. As the following manager explained:

> *"We found ways to be able to link patients up with their families, so you know lots of facetiming, WhatsApp, so again the technology just got better straight away so that we could all communicate. Video consultations, that all got sorted out really quickly"* (ICOH52).

One manager said that there was some support from NHS Digital, including the allocation of tablet computers. They explained how their hospice IT teams were able to support staff in setting up WhatsApp groups for patients, who had never used these before:

> *"But we did sort of have a procedure in place eventually from NHS digital, where we had allocated tablets and we, our IT team were very good at supporting with, setting up WhatsApp for patients that had never used it before and providing them with either a mobile phone [or tablet]"* (ICOH59).

Another hospice manager explained how they set up a new family liaison role, due to reduced workload in social work team, to help with things such as IT (emails and setting up virtual calls), amongst other things:

> *"We set up like a family liaison team, so with the social worker team that were, they didn't have as much demand 'cause people weren't leaving the hospital coming in and they weren't able to do home visits and things. So we set up like a team of three family support members that did the virtual phone calls and make sure that they said they helped set up the tablet with them and arrange the times for a member of staff to be there if they needed it and that lasted for a good few months"* (ICOH59).

Some hospice managers explained that identifying ideas to try and mitigate the changes to visiting arrangements was a priority, including setting up virtual meet-ups, or having other ideas in which to connect an inpatient to families and friends. However, as one manager explained, there were some significant limitations to these approaches:

> *"…we introduced a virtual technology to do virtual telephone or FaceTime and zoom and all those sort of things. But it wasn't the same and you couldn't really do a zoom call with an unconscious person to a family member, and so I think that probably that's the one thing that sticks with me"* (ICOH59).

How technology is to be used in the future in hospices is under consideration. As **one hospice reported, they are now in the process of writing a digital transformation strategy** in light of these changes, and the advantages it will bring:

> *"That's one of my jobs now is, is writing our digital transformation strategy because we recognise that, there is a huge amount of technology out there that can help us do more achieve more reach more people, record better information, make us more accessible to different groups and communities. So I think, and we're not a very, we're not a very digitally confident organisation and so I think*

> *that's a huge area of workforce now is to is to focus on how we can embrace that, how we can, how past staff and our teams embrace that"* (ICOH07).

Management felt Covid-19 had allowed hospices to think about ensuring a more varied and versatile way of communicating with patients in the future, through the use of digital and remote palliative care:

> *"I think ensuring that the way that we can communicate with our patients is really versatile so that we have got…you know if we have a patient out in the community, being able to speak to them on the phone, offer them a video call or visit them. There's different ways you can interact with them. Texting, you know, emailing that sort of thing. I think it's ensuring that we build in a whole suite of those, so that we can really cater for the person, because so for some people they just want to be texting with health professionals, while other people they need a face-to-face and I guess it's ensuring that we're using everything that we've learned through covid to be able to build in that whole suite of communication methods and not go back to how we did things before"* (ICOH52).

Interviews with senior managers highlighted how the pandemic has pushed hospices to develop their digital capacity to provide more effective services and support:

> *"So it's without doubt we've moved on, probably five years, if not a decade in our practice. You know, in our use of technology to back up our practice without a doubt. So, and accessing external expertise, you know that that has backed that up as well. So now you know if we wanted to see a heart failure consultant for a particular patient, we would get them on Teams or Zoom now and then we would have never done that"* (ICOH76).

Changes to services that worked, changes that did not work

The pandemic brought a range of changes to how hospices worked, with hospice managers continually having to find ways to adapt as the pandemic situation and protections changed. We asked participants about what had changed – for better or worse – at different points during the pandemic. Two sub-themes were identified, how participants sought to manage decision-making and the communication of rapid changes, and the issues they faced with staff morale and wellbeing.

Throughout the interviews with senior managers they explored the issues they faced **making key decisions and communicating rapid changes to staff** in a period of complex change, which provided its own communication challenges. Different ways to communicate this information to staff was sought from senior management, including notice boards in hospice corridors, emails, network groups, WhatsApp, guidance, policy documents and meeting minutes. We found that information in emails could be very text heavy, with detailed information, or conversely, quickly written in the form of bullet points, or with many attachments. The senior managers reflected on the difficulty of embedding change in the early stages of the pandemic:

> *"…it's really, really hard to embed constant change. That's one thing I would say it's hard to embed change anyway, but when the guidelines and the requirement change almost on a weekly basis"* (ICOH 76).

> *"…exhausting, completely, completely exhausting, and again because I think, you know, it was all so all-consuming at work, that when you went home you didn't escape it because it was on the news, it was everywhere. It consumed every moment"* (ICOH52).

Senior management found it difficult at times to communicate these rapid changes, without also feeling a high level of stress or overwhelmed, as this was not their usual way of working with their staff. They felt the need to be on top of the constant changes in guidance:

> *"It was just a bit overwhelming, because you were you completely absorbing new information for hours every day and then, you know, as a leader you felt you needed to know what was happening…"* (ICOH52).

Senior managers described how this constant change could leave staff feeling anxious about the uncertainty in their decision-making. The struggle was a constant problem that managers faced with top-down communication from government:

> *"…things were changing all the time, so we'd say, okay, this is what we're doing, this is to keep us all safe. This is what PPE [Personal Protective Equipment] you need and then the next day it would change and then we go back to the staff and say that and then they were like, 'well you said yesterday it was this', and we're like, 'well yeah but today it's this'. So, you can understand why they would feel anxious and nervous about it because it's like, well, you're telling us and then you changing your mind. But that was like literally daily things were changing, the advice that we were being given by the government and yeah it was, it was very, very stressful"* (ICOH54).

One participant recognised that with a lot of their time being taken up with emergency Covid-19 meetings there could be a feeling amongst staff of a lack of leadership, as they struggled with having the presence that they would usually have within the hospice:

> *"So many of the senior people were in just back-to-back meetings for hours and hours every day trying to do all the structural stuff. But of course, the people on the ground didn't see that, all they saw was the seniors had disappeared"* (ICOH52).

We also saw evidence of managing rapid change in the grey evidence, with many different versions of a policy document being produced within a short space of time. In one example we were sent a senior manager used different coloured text to highlight new additions and changes.

With so much new information being made available daily, there was a need for ensuring information came from reputable sources, with email requests from management asking that no staff share any outside advice about Covid-19. As the following email excerpt demonstrates, there was a need for a level of gatekeeping in the information that was being shared:

> "*It's important that you all get the most important messages at this time – they will come from me. Please can I ask that everyone else doesn't send everybody*

> *emails about the Coronavirus even if it’s just to share thoughts and ideas you think will be helpful”* (Email. 19.03.20, hospice 7).

An important and ongoing issue for the senior managers we interviewed was **staff morale and wellbeing.** Emails sent my management from the first days and weeks of the pandemic included sentences relaying gratefulness to their staff and apologies for the situation they were in. Managers looked to portray a sense of camaraderie and ‘pulling together’, as well as seeking to continue ‘business as usual’ as much as they could. As one email opened:

> *“Firstly I want to say a massive thank you to everyone for the amazing response to the challenges of the ever changing Coronavirus–Covid-19 situation. As always, I have been impressed by everyone’s commitment to our patients and their families, the determination to carry on and the general willingness to help out where and whenever possible – Thank you”* (Email 17.03.20 hospice 7).

However, as the sense of permanent urgency and the longer-term nature of the pandemic became more evident, the emails started to have slightly greater focus on ‘keeping the team going’:

> *“I could see yesterday when I was there, there was a great feeling of everyone working and pulling together. It has been an emotional and unsettling time for a lot of you and I do appreciate how difficult it has been, it was lovely therefore to see people smiling and laughing”* (Email 16.04.20 hospice 7).

Indeed, in emails dated almost one year into the pandemic, the acknowledgement of the strain staff were experiencing and management wanting to help comes out strongly:

> *“I firstly want to acknowledge and thank all of the staff on IPU who had a challenging weekend, and to [names] also for their support. The pressure and psychological stress on the staff seems to be relentless, but you all still amaze me with your professional approach and resilience. If there is anything you think we could be doing differently to make it easier for you please drop me an email and I can try and meet with you to discuss it further”* (Email, 25.01.21, hospice 1).

One manager noted how staff members were getting tired and wondering when the situation was going to end. As such, the managerial role of keeping staff members motivated was a challenge:

> *“It's [the atmosphere] a bit tense at the moment I would say because as I say, we're still having to self-isolate. It's becoming a bigger problem and people are tired and you know we're all starting to think, when is this going to end? And trying to keep people motivated in that situation is quite challenging”* (ICOH31).

The senior manager interviews also contained concerns about the lasting impact of staff after all they have worked through during the pandemic, risking burnout or possibly leaving of the caring profession. The following concern for their staff, who describes the situation they feel we are now in:

> *“People talk about the impacts on staff in healthcare, I'm not sure that people really get it. Because I think for people who have, I mean, we're not the NHS, but*

> *for people who are in a caring profession, to have that changed has a massive impact on people. It isn't just being tired, fed up, it's an emotional thing and I think that's quite hard to quantify, but I think that has to be, I don't, I don't think I don't think it's fully appreciated… and I think we're gonna see some more fallout. I think people will leave the caring professions"* (ICOH31).

The emotional work involved can be seen in how one senior manager listed the issues she had to address in a hierarchy of distress:

> *"So probably within the hospice, the most distressing things were, the visiting, the working out the PPE and people not knowing what they're doing, and then the smaller part of it was looking at working out how to care for patients who were dying of covid"* (ICOH52).

The senior manager interviews and grey evidence show how managers sought to keep staff morale and wellbeing high, even when their own wellbeing may have been suffering:

> *"I think particularly as a leadership team that's [organisational change] been incredibly hard, and it's felt quite isolating at times in terms of, you know, we're the ones with the fixed smile on our faces. 'It'll all be fine' (laughter). Whereas internally you're sort of thinking. 'Ahh help!'"* (ICOH36).

Summary of key findings

Interviews with senior management and grey evidence from hospices across the West Midlands showed how the Covid-19 pandemic impacted on what and how decisions were made, how they were communicated and the knock-on effect of having to put those decisions into action. It was a difficult, stressful and often upsetting time for management, who felt the responsibility of their actions on staff and ultimately patients and relatives. It is clear that pathways for delivery of fast-moving changes, from government through to frontline staff, patients and relatives is an area for improvement. Clarity of communication and guidance from management were identified as an important factor to members of staff understanding appropriate conduct within the pandemic context (see also staff cohort report). Changes were made to service delivery which may have taken much longer to happen without the pandemic, and there is now a need to adapt the elements which worked well, e.g. incorporation of digital technologies to reach a greater diversity of patients, into hospice care going forward. The hospice at home element of hospice care has potential for expansion, given its benefits in a pandemic and non-pandemic situation.

Summary of the implications for practice and recommendations for policy

The pandemic has changed the shape of hospice care into one that uses more digital technologies as well as hospice at home services, thereby reaching a wider number of people. As such, hospice managers will require further support and resources as they seek to adapt their services to these emerging demands. This is also true of the volunteer sector, which was severely disrupted during the pandemic and strategies are required to build it back up to where it was. This could be achieved by engaging a more diverse volunteer demographic, which is more representative of the local population for which the hospice serves. Further resources will be required for employment of volunteer coordinators who have the skills and experiences to carry out this role. Visiting restrictions imposed during the pandemic were a particularly difficult time for senior managers to work through. Should national restrictions need to be applied again, hospice leaders will need to collaborate in designing guidance for visitor limits and protections for in-patient settings. Providing senior hospice managers with resources so that they can ensure they can take a pro-active approach for staff health and wellbeing is important, as well as accessing such services themselves.

The fast-moving changes at the start of the pandemic were a difficult time for hospice senior managers to navigate. Looking ahead, it is important that hospice leaders have a meaningful voice in national and local conversations about the ongoing Covid-19 response, and that any changes to government policy arising are communicated in a sensitive and professional manner. In addition, hospice leaders need a long-term, sustainable and resilient funding settlement with additional statutory funding that recognises hospices as a core part of the health and care system, so that they can plan better for the future. The pandemic has shown that hospice services should no longer be regarded as a service to be overlooked.

Conclusion

This is the only study to report on the experiences of senior management of hospices during the Covid-19 pandemic, while also sharing the findings from the grey evidence documenting hospices' activities during this difficult time. We have identified key areas of learning, particularly the things that worked well – roll our of hospice at home and use of video calls – and things that did not, such as communication of visiting limits. We have identified several implications for policy and practice including the need for hospice leaders to be included in discussions around adapting Covid-19 guidance to accommodate end of life care, as well as future need for better integration of hospice services in community palliative services.

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