Compromised Connections

The impact and implications of Covid–19 on hospice care in the West Midlands and nationally.

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Executive Summary

People with life-limiting conditions are some of the most vulnerable to the Covid-19 pandemic. In the West Midlands and elsewhere, the pandemic has significantly affected both the quality and quantity of life remaining for them and for those that cared for them.

Until relatively recently, hospice care in the West Midlands and nationally has often been viewed as in-person and involving specialist palliative care, often provided in a hospice building. Covid-19 has catalysed changes to this traditional model of hospice care that had already begun to take shape before the pandemic.

These changes include a shift towards supporting more people dying at home, in response to patient preferences for home over hospital as their place of care at the end of life, and also NHS efforts to minimise unnecessary and costly hospital admissions. This has led to hospices working in a more integrated way with primary care and social care services in community settings.

Despite these steps forward, hospices have long faced significant challenges in their quest to ensure everyone has the best possible end of life experience. Their funding model relies heavily on charitable fundraising and makes it difficult to address inequalities in end of life care and meet rising demand for end of life care due to our ageing population.

This new research explores the impact of the Covid-19 pandemic on different aspects of experiences of hospice care in the West Midlands from the perspective of patients, carers, hospice staff and senior managers. It is first study in the UK to provide an in-depth exploration of the experiences of all four groups in hospice services during the pandemic.

By exploring the impact and implications of the pandemic on experiences of hospice care in the West Midlands, the study offers important lessons to inform current government plans for people with life-limiting illnesses to 'live with Covid', and future plans for hospice care as part of the wider health and care system.

The study findings arrive at a critical moment of opportunity for hospices. The new Health & Care Act has introduced for the first time in the history of the NHS a legal responsibility to commission palliative care in every part of England. Social attitudes to dying, death and bereavement are also changing, with compassionate communities emerging across the country.

The West Midlands is an ideal context in which to explore some of the wider challenges of ensuring everyone has equal access to and experience of palliative and end of life care. Most areas have a greater level of deprivation than the national average. Almost a third of residents are from ethnic minority backgrounds. The average life expectancy in the West Midlands is shorter than in the rest of England due to above average rates of premature death from preventable causes.

People with life-limiting illnesses in the West Midlands are supported by 22 hospices. 13 of these are charitable hospices, two are NHS hospices, and seven are dedicated to supporting children. Each of these local hospices has a proud history and present day record of providing outstanding care and support to people with life-limited conditions, and helping to ensure they and their loved ones have the best possible end of life experience.

These hospices play a vital role in the local health and care system as the main providers of specialist palliative and end of life care, working with other parts of the local health and care system (such as primary care and social care providers) to help ensure everyone has the best possible end of life experience.

Key research findings

Many of the in-patient, day care and outpatient services provided by West Midlands hospices had to be stopped altogether or adapted at speed when the pandemic began. One study patient described such services as "Bang! Stopped" at the start of the pandemic.

Hospices are well-known for the 'gold standard' of personalised and holistic care they provide to patients and families, and for the role they play in connecting communities through volunteering. Our study shows that during the pandemic some aspects of this model were unfortunately compromised, despite the best efforts of hospice staff to maintain it.

Guidance for hospices was insufficiently tailored to their needs, and updated frequently, causing significant stress for managers. Some hospice staff faced difficult dilemmas about patient care, and Personal Protective Equipment (PPE) presented major challenges for the personalised care conversations that hospices normally provide. Hospice care was compromised for patients with communication challenges, such as people with dementia or those with English as a second language. Volunteers in hospice services were badly missed, resulting in increased workload for nursing staff who had to cover these roles.

Limits on visitors to patients in hospices were unclear and enforcement was inconsistent, causing emotional distress for the people involved. Visitor limits to reduce the risk of infection resulted in vital social contact at the end of life being compromised. Those limits sometimes drove decisions by patients and their families about preferred place of care at the end of life, with some opting to remain at home because social contact with loved ones was a top priority at the end of life.

There was a significant increase in the number of people dying at home during the pandemic, and they and their carers did not always receive the care and support they needed. Some patients dying at home were left unsupported for long periods of time. Primary care services were under significant pressure, and some were unable to provide the end of life care patients needed. Carers found themselves covering gaps in community services at significant personal cost.

West Midlands hospices played a vital role in supporting the increased numbers of people dying at home by expanding their 'hospice at home' services to reach more patients. The high standards of patient care they provided were highly valued in community settings, but also compromised at times due to the pressures of the pandemic.

As well as caring for patients and families, specialist hospice staff helped provide training and education in end of life care to generalist health and care workers in community settings. Hospice staff also played a vital role in achieving integrated care for patients by working closely with other parts of the health and care system such as GPs, district nurses, and care home staff.

Hospices rapidly deployed technology to replace and supplement in-person service delivery during the Covid-19 pandemic. The pandemic has catalysed the adoption of technology by these hospices and how such technology will be used in future remains under active consideration.

The study found that technology brought valuable opportunities to save time and extend access to services, but it also had significant limitations, especially for conversations about patient care at the very end of life. Some patients and carers valued technology, whereas others lacked the confidence, skills, equipment and contacts to be able to use it effectively.

The pandemic has had a major impact on the health, wellbeing and bereavement experiences of carers and staff. Despite some measures to support staff wellbeing, Covid-19 has been physically and emotionally exhausting for staff working in hospice services, leaving some at risk of long-term burnout and leaving the caring profession.

Carers have experienced bereavement in extremely difficult circumstances during Covid-19, and often received very limited bereavement support, despite some innovative use of technology by hospices to maintain and adapt bereavement support services during the pandemic.

This study has implications for both current plans for people with life-limiting illnesses to 'live with Covid' and for longer term plans for hospices as part of our wider health and care system. In this report, we explore these implications further.

Key policy recommendations

For hospice care in our health and care system:

- Commission hospices to provide palliative care services in community settings, on a 24/7 basis, by telephone and in person, and accessible through a single point of contact.

- Make end of life care training a compulsory part of initial training and continuing professional development for all health and social care workers in community settings.

- Publish annual, independently verified projections of the future demand and supply of the palliative and end of life health care workforce in England over a five and ten year period, and invest in a plan for ensuring this workforce is fit for the future.

- Make more and better bereavement support services and specialist mental health services available to everyone who needs them.

- Ensure carers of people with a life-limiting illness can have their needs assessed and met in full, including for financial support.

- Recognise the vital role played by hospices in connecting communities, by supporting the restoration of volunteer-led services providing holistic patient care.

- Ensure that patients and carers can exercise choice about care by providing traditional and digital options at all stages of their journey through hospice services and in all settings.

- Invest in supporting hospices to continue their digital transformation to improve the efficiency, effectiveness and reach of their services.

For 'Living with Covid':

- Ensure that future infection control guidance is tailored to the specific needs of hospices by involving hospice patients, carers, staff and managers in its design and development.

- Consider flexible application of infection control measures (such as visitor limits and PPE in hospices) if required to meet patient and carer preferences for social contact at the end of life, whilst also ensuring hospice staff are supported to work safely.

- Proactively support patients and carers with English as a second language to participate in conversations about patient care at the end of life by recognising and respecting the importance of non-verbal communication.

- Adopt a more proactive approach to supporting staff wellbeing as a central component of the ongoing pandemic response.

1. Introduction

Until relatively recently, hospice care in the West Midlands and nationally has often been viewed as in-person, specialist palliative care provided in a hospice building. Covid-19 has catalysed changes to this traditional model of hospice care that had already begun to take shape before the pandemic.

These shifts in models of hospice care respond in part to the personal preferences and choices of patients and their close family and friends at the end of life. Most people express a preference for home over hospital as their place of care at the end of life, and hospices have sought to respond to this by growing their 'hospice at home' services.

Hospices are also responding to wider challenges confronting our health and care system. As pressures on NHS budgets have grown in recent decades, there has been a drive to reduce unnecessary hospital admissions and support speedy discharge of patients in hospital who could be cared for at home. This has helped increase demand for end of life care in community settings, and hospices have been working with primary care and social care providers to try to meet this demand.

Despite all this, hospices would be the first to admit that there is still unmet need for palliative and end of life care. Estimates suggest that while as many as 90% of people who die may have palliative care needs, only around 50% of people who die receive any palliative care (Etkind et al, 2017). These inequalities are especially acute for certain groups such as people living in deprivation, minority ethnic and LGBTQ+ communities, and people who are homeless or in prison.

In seeking to rise to this challenge, hospices are hindered by a funding model that is neither resilient nor sustainable. Charitable hospices are the main providers of palliative and end of life care, yet they only receive around one-third of their funding from the NHS and statutory sources, with the remainder raised largely through charitable fundraising. Like the NHS and social care, hospices are also experiencing significant difficulties with recruiting and retaining the right workforce.

The major long term challenge confronting hospices is our rapidly ageing population. In twenty years' time there will be 100,000 more people dying each year in the UK. This is resulting in rising demand for palliative and end of life care, and the number of people dying with a palliative care need in the UK is projected to increase by up to 42% by 2040 (Bone et al, 2018).

At the same time, some important opportunities are opening up for hospices to help ensure everyone has the best possible end of life experience. Social attitudes to dying, death and bereavement are changing, and compassionate communities committed to ensuring more people experience a good death are growing across the country.

In response to a campaign led by Marie Curie and other charities, the Government has just introduced in the Health & Care Act the first ever legal responsibility for commissioning palliative care services in every part of England, which is likely to result over time in more and better statutory funding for hospice services at local level.

The Covid-19 pandemic came to prominence in the UK in early 2019 and remains ongoing in the present day. People with life-limiting conditions are some of the most vulnerable to the pandemic. In the West Midlands and elsewhere, Covid-19 has significantly affected both the quality and quantity of life remaining for them and for those that cared for them.

During the Covid-19 pandemic emergency response, hospices across the country played a vital role in supporting the pandemic emergency response, and many of their services were busier than before, especially in supporting people who were dying in community settings (Sleeman et al, 2021).

There was a sustained and significant increase in the number of people dying at home instead of in hospice and hospital settings during the pandemic. This was likely due to both government changes to hospital discharge policy and patients and families feeling discouraged from entering in-patient settings due to visitor restrictions and fear of Covid-19 infection.

The increase in numbers of people dying at home created significant challenges and pressures for primary care and other community services as people at home at the end of life and their carers sought out end of life care from GPs and district nurses (Mitchell et al, 2021).

Hospices responded by expanding their hospice services in the community at speed, while closing in-patient beds and day and outpatient services, and restricting access for visitors to their in-patient units. Hospices also rapidly deployed telephone and digital technology to replace and supplement in-person service delivery.

Some hospices received emergency grant funding from the government to support them to expand new activity at a time when many of their normal fundraising activities were suspended.

The research shows that these changes created both challenges and opportunities for patients, carers, staff and service managers providing and receiving hospice care in the West Midlands.

This new study explores the impact of the Covid-19 pandemic on different aspects of experiences of hospice care in the West Midlands from the perspective of patients, those that cared for them, hospice staff and senior managers.

By exploring the impact and implications of the pandemic on experiences of hospice care in the West Midlands, this study offers important lessons to inform current government plans for people with life-limiting illnesses to 'live with Covid', and future plans for hospice care as part of the wider health and care system.

2. Method and context

The study examined the effects of the changes to West Midlands hospice services during the pandemic, how they have affected people's experiences of providing or receiving care, and if these changes were experienced unevenly by different groups.

Study method

The study was conducted by a team of expert academics, clinicians, practitioners, and people with lived experience of hospice care. The study team was led by Dr John MacArtney of University of Warwick, funded by ESRC, and included individuals with experience of both receiving and providing palliative and end of life care in hospices, hospitals, and community settings.

The study team collated and provided an expert review of over 225 'grey evidence' documents from seven hospices which included emails, guidance, procedures, updates, bulletins and data. These described how seven local hospices in the West Midlands have adapted their hospices in response to the pandemic, including how they used the emergency funding.

They also conducted a series of qualitative interviews with seven hospices, with individuals with an in-depth understanding of the experiences of providing and receiving hospice care during the Covid-19 pandemic, and the social factors which are affecting these experiences. The interviews were conducted with a total of 70 people including 18 patients, 15 carers, 25 hospice staff and 12 hospice managers.

It is likely that the pandemic affected study recruitment, with recruitment relying on already overworked and pressured hospice staff who wanted to support the study, but who had limited time to do so. This may have led to recruiting staff approaching patients who would be more amenable to taking part in the study, with patients who had had more difficult or complex experiences less likely to be approached. This may also account for the less ideal representation of ethnicities and gender, with 21% from ethnic minorities and 24%

of male participants across the patient and carer samples.

Despite these limitations, the study team was able to document experiences of hospice care from a range of perspectives (see Flemming et al., 2022; MacArtney et al., 2022a, b & c). Recruitment took place between May 2021 and January 2022. This included people who had life-limiting conditions diagnosed at the time of the first lockdown, as well as those who experienced the relaxation of protections and 'freedom day' in July 2021.

West Midlands context

The West Midlands is an ideal context in which to explore some of the wider challenges of ensuring everyone has equal access to and experience of palliative and end of life care.

The West Midlands has an incredibly diverse population of approximately 2.9 million. 30.6% of residents are from ethnic minority backgrounds, compared to the average in England, which is 14%. 16.6% of inhabitants are born outside the UK, compared with the England average of 13.8%. 5.7% of households have English as a second language, compared with the England average of 4.4% (West Midlands Combined Authority, 2020).

In the West Midlands, the majority of areas have a greater level of socioeconomic deprivation than the national average. Gross Disposable Household Income per person in 2017 was £16,479, the national average for the UK was £19,514 (West Midlands Combined Authority, 2020).

Life expectancy is also shorter at 82.2 years for females and 78.0 years for males, both lower than the national average. Women spend around 22 years in poor health and men spend around 18 years in poor health. There are above national average rates of premature death from preventable causes such as cardiovascular disease, cancer, liver disease and respiratory disease. Almost one in five people in the West Midlands has a life-limiting or long-term illness or disability (West Midlands Combined Authority, 2020).

The highest rates of Covid-19 deaths in the West Midlands were in more deprived areas and areas with minority ethnic communities, reflecting the national trend. In March 2020, 64% of Covid-19 deaths in Birmingham City Hospital were from African and Asian communities and in April, the figure was 50% (West Midlands Combined Authority, 2020).

People with life-limiting illnesses in the West Midlands are supported by 22 hospices. 13 of these are charitable hospices, two are NHS hospices, and seven are dedicated to supporting children. Each of these local hospices has a proud history and present day record of providing outstanding care and support to people with life-limited conditions, and helping to ensure they and their loved ones have the best possible end of life experience.

These hospices play a vital role in the local health and care system as the main providers of specialist palliative and end of life care, working with other parts of the local health and care system (such as primary care and social care providers) to help ensure everyone has the best possible end of life experience.

3. The pandemic emergency response challenged the 'gold standard' of personalised and holistic care that hospices provide

Many of the in-patient, day care and outpatient services provided by West Midlands hospices had to be stopped altogether or adapted at speed when the pandemic began. One patient described such services as *"Bang! Stopped"* at the start of the pandemic.

". . . the Government said that was it. ...it was just the NHS that was, you know keeping going . . . 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 . . ." (Staff)

Hospices are well-known for the 'gold standards' of personalised and holistic care they provide to patients and families, and for their role in connecting communities through volunteering. This study shows that during the pandemic some aspects of this model were compromised, despite the best efforts of hospice staff to maintain it.

Guidance for hospices was insufficiently tailored to their needs, and updated frequently, causing significant stress for some managers.

As hospices sought to quickly adapt their in-patient units to the new reality, they sometimes found that government guidance on infection control was insufficiently tailored to the needs of

hospices, and risked compromising their service models, which depend on a strong commitment to personalised and holistic care for both patients and their carers.

The first weeks and months of the pandemic involved frequent updates to the guidance on how hospices should respond to the Covid-19 pandemic. One consequence of the updates was that some hospice managers felt anxious and uncertain about the decisions they were making about services.

". . . things were changing all the time, so we'd say, okay, this is what we're doing, this is to keep us all safe.... and then the next day it would change . . . literally daily things were changing, the advice that we were being given by the Government" (Senior Manager)

"It changed almost weekly. It felt like 'cause I think we were trying to work out what to do" (Senior Nurse)

Some hospice staff faced difficult dilemmas about patient care.

This guidance also presented major clinical dilemmas for some staff providing patient care. One nurse reflected on a situation she faced with a patient at the hospice who needed suction to help remove phlegm, which if it was not removed could

result in the patient choking and dying. Suction was an aerosol-generating procedure and the guidance in place at the time did not permit the use of suction unless the person providing it was wearing a type of mask that was unavailable to her at that time.

"So you're giving me a choice that I'm in this situation, this man choking, and I don't know if you've got Covid or not. If I suction him, I could potentially catch it, but if I don't, he could choke to death. That's a very difficult. Putting the choice on you" (Nurse)

Personal Protective Equipment (PPE) presented major challenges for the personalised care hospices provide.

Sourcing PPE was a particular challenge for some hospices due to lack of availability.

"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 . . ." (Staff)

"But again there was that fear, I think, I'm going into houses with, you know, very little PPE. You know, we just really had, these masks and the visors and an apron. And yeah, you were going into a house." (Nurse)

Strict requirements for staff and carers to use PPE caused significant disruption to some of the personalised conversations between the patient, their carers, and staff about patient care at the end of life. For some patients at the very end of their life, PPE had a major impact on final moments with their closest carers.

"I still think a lot of people missed the human connection and you know being able to sit here and, you know, we felt it too, being able to hug people and hold their hand . . ." (Staff)

"There was a very, very strict way of doing everything... You had to enter the ward at a certain place. You had to leave it at a certain place, you had to wash your hands. You had to be assessed for washing your hands . . ." (Senior nurse)

"She was so confused because everybody around her had masks then she wouldn't be able to tell us apart from other people . . . that was quite distressing . . . I think she wanted to say something and then she died, but . . . we had the masks [on] and I hope, I hope that she realised it was us." (Carer)

Hospice care was compromised for patients with communication challenges, such as people with dementia or those with English as a second language

For some patients with English as a second language, communication challenges were made much worse by PPE, which made vital non-verbal communication between patients and staff virtually impossible. Patients with dementia were particularly affected by services stopping, because this removed a great deal of their social contact.

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

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

"When that stopped and I think everybody with dementia who couldn't have contact with other people, that made things worse." (Carer)

Visitor limits were unclear, and enforcement was inconsistent, causing a great deal of emotional distress.

Some participants in our study described both a lack of consistency in the way rules about visitors were applied to patients inside hospices, and an excess of responsibility placed on senior staff and hospice leaders who were tasked with making very difficult decisions about exceptions to those rules. As the pandemic progressed, different hospices applied different rules on who could visit, if any visitors were permitted at all, and how many people could visit at one time.

Some staff found it challenging to enforce visiting protections as guidance was unclear and they had to exercise their own judgement when applying it to individual cases.

"I think the thing that 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." (Senior Manager)

"So wide for interpretation because what my discretion is completely different to another nurse's discretion and also that is a reflection on your view of the pandemic." (Staff)

Several patients and families being cared for in hospices, and some staff and managers providing that care, found limits on numbers of people visiting at the end of life extremely distressing.

". . . 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." (Senior Manager)

"So, I feel, I still feel deeply upset myself at some of the conversations that I had. I remember one specifically. . . 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. . .he had to self-isolate and so we. . .So, this man couldn't come in and see his wife at end of life." (Senior Management)

". . . 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." (Senior Management)

Visitor limits sometimes drove decisions about preferred place of care at the end of life.

Due to fear of visitor limits, many patients and their carers did not want admission to the hospice and instead opted for home as their preferred place of care during final weeks and days.

"One of the reasons why I wanted to keep [my mother] at home and not into the hospice because at the hospice there were [visiting] restrictions." (Carer)

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

"A lot of our patients have not wanted to come in because of the restrictions, because we still obviously

have some restrictions for visiting. So, it's meant that more of our patients that would normally have come to us are staying in their community."* (Staff)

Visitor limits to reduce the risk of infection resulted in social contact at the end of life being compromised.

Participants in our study recognised the need for protections to reduce the risk of infection but were upset that this sometimes resulted in social contact being compromised for people at the end of life. This is because social contact at the end of life is a vital component of the holistic care hospices normally provide.

"We've had to put our patients first and discuss and protect everyone from Covid. So, we understand why it's been done, but obviously it's still cruel doing that." (Support Nurse)

"The last thing we want to do is, you know, take Covid in there so you know understood it, didn't make it that much easier, but it's what had to be done." (Carer)

"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." (Patient)

Some patients in the hospice felt unhappy about visitor limits reducing their social contact at the end of life. For those relatives that did visit, the strict regulations around infection control and personal protective equipment gave patients and carers the sense "very much that we were being watched" (Patient). The quality of carers' experiences of visiting patients was compromised, as some visitors had to remain in the patient's own room at all times, which made it difficult to speak to staff.

"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." (Patient)

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

Volunteers in hospices were missed, and at times felt less connected to the hospice.

Volunteering in hospices was halted during the pandemic and this has a major impact on frontline staff who had to carry out extra duties which were previously undertaken by volunteers. Volunteers themselves were also personally affected as some benefitted previously from volunteering as a way of forging their own social connections. When this was no longer possible, some felt abandoned.

"As things went on, there was certain things that you know, we were like, actually we really need some volunteers to support us with this 'cause we just haven't got enough staff and so there was certain roles that we, certain roles that kind of came back." (Staff)

"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" (Senior Manager)

"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." (Staff)

Key policy implications:

- Ensure that future infection control guidance is tailored to the specific needs of hospices by involving hospice patients, carers, staff and managers in its design and development.
- Consider flexible application of requirements to wear PPE and limit visitors in hospices if required to meet patient and carer preferences for social contact at the end of life, whilst also ensuring hospice staff are supported to work safely.
- Proactively support patients and carers with

English as a second language to participate in conversations about patient care at the end of life by recognising and respecting the importance of non-verbal communication.

- Recognise the vital role played by hospices in connecting communities, by supporting the restoration of volunteer-led services providing holistic patient care.

4. Hospices played a vital role in supporting people dying at home

There was a sustained and significant increase in the number of people dying at home during the pandemic, and they and their carers did not always receive the care and support they needed. Hospices responded by expanding their 'hospice at home' services and also by supporting other parts of the health and care system to provide integrated end of life care in community settings.

Some patients dying at home were left unsupported for long periods of time.

Staff and carers in our study described patients dying at home who had been unable to access the care and support they needed from services in the community for considerable periods of time, especially during the first lockdown.

"We had no support as soon as that day when they, you know, they put us into national lockdown, we had nothing at all . . . It was just an occasional phone call, 'are you okay?' Well, and that was it." (Carer)

"I've lost count of the times I've gone into the house and I'd have to tell the family that that person is probably going to die tonight. A couple of people have actually died while we were there, because they accessed nobody because of Covid. District nurses weren't going out, the clinical nurse specialists weren't going out, GPs weren't going out and still aren't." (Senior Nurse)

"So patients, I've gone to the house and the family are saying, I'll say have you seen the GP? 'No no he's phoned, he facetimes or so we could show him Dad and then he could say yeah, dad's dying'. So, you know, and that there's a lot of people or they haven't seen anybody for weeks and weeks. So nobody has had that conversation about death and dying to them. (Staff)

Primary care services were under significant pressure and some were unable to provide the end of life care patients needed.

GPs and district nurses had an enormous workload during the pandemic, and our study participants described them struggling to respond to the significantly increased demand for end of life care in community settings.

"GPs are overwhelmed and it's not it's not their fault . . . they really do care about people and they're willing to give more time to them, but they are under a lot of pressure and they are measured on the time that they spend with the patient." (Patient)

"The district nurses, [but] they just didn't want to know . . . they'll come back give him a top up and then that was it and they'd go." (Carer)

"The district nurse would just check the medication and whatever, but they would not provide care." (Carer)

Hospices expanded their support in the community for people dying at home

Some hospices in our study received emergency grant funding from the government to develop new services during the pandemic and used this to expand their services in community settings. This was achieved through more and better 'hospice at home' support provided by community palliative care nurses, allied healthcare professionals such as physiotherapists, and healthcare assistants.

There were hospices that initially pulled back from providing 'hospice at home services' due to infection risk, but then rapidly expanded these services to respond to increased demand for support from people dying at home. Other hospices developed brand new 'hospice at home' services.

". . . 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" (Senior Manager)

"One of the few good things that has come out of the pandemic is that the hospice now has a hospice at home team, which, you know, they are the nurses and health care assistants who go out to provide personal care for patients in the last days of life." (Doctor)

"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." (Senior Management)

One hospice improved the reach of its 'hospice at

home' services by re-deploying nurses who would normally work on hospice wards.

"During COVID, we were able to put nurses into those teams 'cause we had to redeploy. . . 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. . .we are looking at how we can do that again." (Staff)

'Hospice at home' enabled some patients who would not normally have been able to access the hospice as in-patients to be cared for at home, which some staff felt helped to prevent unnecessary hospital admissions.

"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." (Senior Manager)

The 'gold-standard' care hospices provide was highly valued by patients and carers in community settings, but also compromised at times.

Hospice staff providing care in community settings were perceived by some patients and carers in our study as patient, sympathetic and not dismissive of worsening symptoms for people with life-limiting conditions. During the pandemic, staff found innovative ways to ensure they were able to visit patients. This included doorstep visits and delivery of gifts during festive periods.

"And when the staff could, they came back and did doorstep visit . . . we took them Christmas hampers . . . We took afternoon tea. Sometimes we just made a pack of scones and jam and things like that and took those out." (Senior Management)

This holistic care helped patients and carers to feel less isolated during the pandemic as for some it was their only form of social contact.

"They made us feel secure and wanted all the time." (Patient)

"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 your friend tapping outside being silly, you know?" (Patient)

"I think it's made [husband] feel very happy. I think it's that part of, I mean all through our lives, wherever we go, we rely on our networks don't we?" (Carer)

However, staff sometimes felt unhappy at being unable to provide their usual high standard of personalised and holistic care for people dying at home.

"A sense of real dissatisfaction that this is just this just isn't palliative care. This isn't what we , are specialised at doing. This is just care. This is, you know, we doing basic care. Nobody got neglected. Nobody got, you know there was no malpractice or harm. But that's not what we're about. We're not about firefighting. We're about providing like an excellent service for people. And we're about providing a service that doesn't just accept kind of the status quo but goes beyond that" (Senior Nurse)

Carers of people dying at home covered gaps in community services at significant personal cost.

Some close family and friends of people dying at home worked hard to ensure their loved ones received the care they needed when dying at home, but they sometimes found this exhausting and emotionally distressing.

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

"That was it then. It was just an occasional phone call are you okay?" (Carer)

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

A nurse described the impact on carers and patients of no longer providing night sitters at a time when less support was available from professionals during the lockdown.

"I felt that we were letting down these people these people were still in need of our services. That was these services, which . . . our service users and their families

really rely on . . . that they actually had less support, their own support networks had been diminished, that for us to also withdraw our support I felt was an extremely, that was a very wrong decision to have made."* (Support Nurse)

Hospice staff helped provide key training and education to upskill other health and care workers in palliative and end of life care.

Some hospice staff trained and supported health and care workers to deliver end of life care in community settings. They provided webinars on key topics such as advance care planning and symptom control for GPs and other clinicians in the community. They also provided palliative and end of life care education and programmes for care homes.

"And [providing] that [training] was possibly the best decision that we ever made . . . because it was really needed, and so the evidence from it was the loads and loads and loads of people showed up to it." (Senior Nurse)

"We probably reached into more practices where GPs were concerned and more care homes and that doing sort of virtual contact than we could have ever imagined had we just said come to the classroom and here we are. So that certainly made it an impact, so that was, that was a huge sort of investment really as regards the sustainability and embedding where other services are concerned." (Staff)

Hospice staff played a vital role in achieving integrated care for patients by working with the wider health and care system.

Some hospices also worked to connect patients to other services they needed in community settings, helping them navigate through the system. One patient described how the hospice staff would *"contact the GP for you, if you if you felt you weren't getting anywhere."*

Communication between some hospices and some GPs improved during the pandemic as although several GPs were not doing home or in-person visits, they were more available through video and telephone calls.

"So there's more flexibility is the more modern take of that, and I think that probably won't return back to the traditional [ways of working]." (Staff)

"[video calls, telephone calls]...certainly improved communication.." (Staff)

Some hospices also worked more closely with hospitals throughout the pandemic, for example by dialling in to each other's meetings about availability of beds. One hospice took on responsibility for caring for a cohort of patients in the community which helped to *"free the district nurses up and they were grateful of that."* (Senior Nurse)

Key policy implications:

- Commission hospices to provide palliative care services in community settings, on a 24/7 basis, by telephone and in person, and accessible through a single point of contact.

- Make end of life care training a compulsory part of initial training and continuing professional development for all health and social care workers in community settings.

5. Hospices adopted technology at speed and scale, with mixed results

Hospices rapidly deployed technology to replace and supplement in-person service delivery during the Covid-19 pandemic. The pandemic appears to have catalysed the adoption of technology by hospices at scale and at pace, and how such technology will be used in the future for hospice care remains under active consideration. Our study found that technology brought valuable opportunities to save time and extend access to services, but also had significant limitations for patient care at the very end of life.

"It has pushed some of the services into using technology in a much more robust way." (Senior Nurse)

Some hospice staff valued phone and digital technology for time savings and extending access.

Some hospice outpatient services were moved online, with senior managers finding that digital workshops for hospice day service users could help increase the number of people attending. One manager described digital platforms as also increasing access to support groups for people with conditions causing mobility challenges, such as motor neurone disease.

". . . I think the telephone support has been really, really useful because it's widened our geographical offer. You know cause anyone can access us now and we used to be governed by our boundaries." (Hospice Staff Member)

"In fact in some situations it's better actually seeing someone remotely is better than not seeing them at all or seeing someone remotely who might otherwise be greatly fatigued, for example, coming to see you, you know. Again, it's giving us the tool and that that kind of balance . . . we've worked with people in London, Wales, Germany. So that is fantastic. I love the fact that if we've got a mum . . . and her daughter lived in Germany, we [can] work with the daughter as well because we don't have that restriction anymore." (Hospice Staff Member)

"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". (Hospice Senior Manager)

Technology had mixed results for patients, especially at the very end of life.

Patients, families and staff acknowledged the need to use technology to maintain services during the pandemic, but also had mixed experiences of it, with some reporting that it was a poor substitute for face-to-face conversations with patients at the very end of life, and about patient care.

Video calls and telephone check-ins were seen by some as inadequate substitutes for in-person conversations because they resulted in much less nuanced communication, and some patients being unable to participate directly in conversations about their own care.

"You can't tell through the phone if someone is dying can you?" (Senior Nurse)

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

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

". . . 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." (Senior Manager)

Some patients and carers valued technology, but others lacked the confidence, skills, equipment and contacts to use it effectively.

Some patients and carers in community settings valued technology as a way of continuing to connect with hospice staff after out-patient services were suspended at the hospice due to Covid-19, and for the time saved by not having to travel.

"I really do not know what I would have done without their weekly phone [calls]." (Patient)

"Right through lockdown I was housebound. The conversation was very, very helpful and useful. And they did it regularly and they were lovely." (Patient)

"that [it] saves an awful lot of traveling and the stress out of the traveling . . . So now being able to do this in the comfort of your own home is actually, I think it's a positive." (Carer)

Other patients and carers were not able to access virtual support groups and services due to not feeling confident in using technology or having the right equipment set up in their own home.

"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." (Senior Manager)

The right equipment meant more than having a device with camera and microphone which

could access the internet, but also devices that accommodated particular disabilities, such as hearing loss or visual impairments. One patient described himself as *"not very technical"*, lacking a computer, and not having anyone available to show him how to use Zoom on his phone.

Support offered by phone was unhelpful for one carer seeking bereavement support for their child.

". . . just too young to do stuff online or understand on the phone what's going on" (Carer)

How technology is to be used in the future of hospice care is under active consideration.

The advantages and risks of technology have been highlighted throughout the pandemic and many hospices are considering a hybrid approach moving forward.

"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." (Senior Manager)

"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." (Senior Manager)

Key policy implications:

- Ensure that patients and carers can exercise choice about mode of care by providing traditional and technology options for all stages of their journey through hospice services and in all settings.

- Invest in supporting hospices to continue their digital transformation to improve the efficiency, effectiveness and reach of their services.

6. The pandemic had a major impact on the health, wellbeing and bereavement experiences of carers and staff

Covid-19 has been physically and emotionally exhausting for staff working in hospice services, leaving some at risk of long-term burnout, despite the efforts of managers to deploy measures to support staff wellbeing. Carers experienced bereavement in extremely difficult circumstances, yet often received very limited bereavement support, despite some innovative use of technology to maintain and adapt bereavement support services during the pandemic.

"There's just the sense of absolute fatigue within the team of, like their resilience to just keep going during the, you know stresses of it." (Senior Nurse)

"And the [management] were burned out as well, you know, and there's gotta be that understanding as well. It cant have been easy for any of them either." (Staff)

Staff felt emotionally and physically drained by the pandemic.

Staff reported extreme fatigue due to the physical and emotional impacts of the pandemic, and this made it difficult to remain resilient and motivated.

"But you know, they are worn out, staff are worn out, because we've had you know staff off with covid and other sicknesses. And the girls have stepped up and done extra shifts and everybody's knackered. For want of a better word, everybody is knackered, emotionally and physically yeah." (Staff)

"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." (Senior Manager)

Some clinical staff felt the psychological effects of working in isolation from colleagues and decided to restore joint working together after a period of working alone from home.

"We recognised fairly quickly that without the support of each other being back in the office, they were

suffering the psychological effects of isolation. So we brought them back into the office . . . anybody that was an administrative role, went out and worked from home, but actually we still kept the clinical staff in and together, and we took over a lot of the admin buildings to be able to be covid safe within the workplace." (Senior Nurse)

Some staff felt their needs were neglected, creating challenges around staff retention.

Some staff felt their own welfare had not been prioritised during the pandemic.

". . . I think their attention was on, how are we going to get the money? How are we going to keep everyone safe? So I think that was quite right, but I think in hindsight we should have been looking after people, staff earlier . . . I mean just kind of keeping that connection with people on a daily basis and having those kind of social calls and the importance of doing that" (Staff)

Some senior managers feel concerned about the lasting impact the pandemic had on staff, which could result in burnout or leaving the caring profession.

"People talk about the impacts on staff in healthcare, I'm not sure that people really get it....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... 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." (Senior Manager)

Some managers developed measures to support staff wellbeing.

One hospice sought to support staff by creating Schwartz rounds, a multidisciplinary forum for staff to share experiences of the emotional and social impact of their jobs which was previously held in-person pre-pandemic.

". . . we've actually now opened that out to wider teams

across the organisation, so our nursing teams in the community, and other fundraisers who weren't attached to the hospice. So its just been quite a nice way to bring more people together 'cause obviously anyone can join it online now. So, I think that's been another small benefit of the pandemic."* (Support Services)

Some carers faced difficult experiences of bereavement, yet received very limited bereavement support.

Some people were unable to arrange funerals and other death rituals in the normal way and this caused a great deal of emotional distress.

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

Both pre and post bereavement services were under severe pressure during the pandemic and some of these services were suspended. This resulted in some carers feeling they received very limited support.

"I haven't been offered, you know the I mean [hospice], nobody's offered anything. We might have had one wellbeing call and then that was it. So no. But it is something that I think probably that we that we will explore" (Carer)

". . . they said they would call me back and they never did." (Carer)

"And I think if I had had more support . . . then maybe that would have helped me and my family with their grieving process, there's a lot of unanswered questions... I don't know if you've ever had a child but you know when you have a birth debrief, I think almost like a death debrief." (Carer)

Some bereavement services were adapted using technology, this included online support groups, video calls and telephone calls.

New services offering telephone calls to bereaved relatives from inpatient units were created, and some of these remained in place after the pandemic.

"So we started sort of making those calls to people, which was a new thing from the from the pandemic and, actually, that's another thing that's carried on" (Staff)

Online bereavement support groups via video calls were also created, increasing access for carers who may not have been able to attend such services pre-pandemic.

"I think that's fantastic because again, would people have come to it? And I'm not sure. Would people have made that physical journey? It just makes it so much easier 'cause it's on Zoom." (Staff)

Key policy implications

- Adopt a more proactive approach to supporting staff wellbeing as a central component of the ongoing pandemic response.
- Make more and better bereavement support services and specialist mental health services available in future to everyone who needs them.
- Ensure every carer of a person at the end of life can have their needs assessed and met in full, including for financial support.
- Publish annual, independently verified projections of the future demand and supply of the palliative and end of life health care workforce in England over a five and ten year period and invest in a plan to make this workforce fit for the future.

7. Conclusions

This is the first UK research study to explore the individual and collective experiences of patients, carers, staff and managers in hospice care during the Covid-19 pandemic. Its fascinating findings capture the painful yet life-affirming experiences of people in the West Midlands who have experienced dying, death and bereavement while in hospice services during a global pandemic.

Restrictions on socialising in England are now largely lifted and much of the national conversation is focused on 'living with Covid', yet people with life-limiting conditions remain highly vulnerable. Covid-19 continues to affect both the quality and quantity of life remaining for them to spend with the people they love and doing what matters most to them personally.

This study has implications for how the UK government protects patients in hospice services and those around them from infection. The Government has already acted to ensure infection control guidance is more tailored to the specific needs of hospices, instead of generic care providers. By involving patients, carers, staff and managers directly in the design and development of future infection control guidance for hospices, they could take this tailoring to the next level.

A recent survey of UK public attitudes to dying, death and bereavement identified social contact as a top priority for people at end of life (Nelson et al, 2022). Our study illustrates clearly that social contact is a key component of the holistic and personalised care that hospices provide, and they need support to strike the right balance between managing infection risk and supporting relationships.

Our study points to a need for future guidance to consider flexible application of infection control measures such as visitor limits and PPE in hospice services, if this is required to meet patient and carer preferences for social contact at the end of life, whilst also ensuring staff are supported to work safely.

The study also underlines the importance of ensuring infection controls do not penalise patients and carers with English as a second language, whose ability to participate in conversations about patient care at the end of life can be particularly compromised by use of PPE. Patients and carers in hospice services with English as a second language may require special measures to preserve the use of non-verbal communication for vital conversations about patient care.

This is just one of many actions needed to address wider challenges of unequal access to and experiences of hospices services, both in the West Midlands and nationally.

This research also has significant implications for the future of hospice services as part of our wider health and care system. The study clearly demonstrates both the 'gold standard' of patient care hospices provide, and the need for all parties to work together to prevent a repeat of these standards being compromised in the way they inevitably were at the height of the pandemic.

The new Health & Care Act has introduced for the first time in the history of the NHS a legal duty to commission palliative care in every part of England, in response to a campaign led by Marie Curie and supported by other hospice charities.

This new duty presents a critical opportunity to address the lack of a resilient and sustainable funding model for hospices in the West Midlands and nationally. With demand for palliative and end of life care set to rise sharply in coming decades, and the trend towards more deaths at home set to continue, statutory funding should focus especially on care in community settings.

By documenting the distressing experiences of patients struggling to access care and support while dying at home during the pandemic, this research underlines the need for concerted action to fill this gap. Integrated Care Boards should commission hospices to provide palliative care services in community settings, on a 24/7 basis, by telephone and in person, and accessible through a single point of contact.

However, hospices alone cannot meet the rising demand for end of life care in community settings, and GPs, district nurses, social care workers and other professionals will all need to play their part. Every health and social care worker is likely to be involved in caring for people experiencing dying, death or bereavement at some point in their career. End of life care training should become a compulsory part of initial training and continuing professional development for all health and social care workers in community settings.

During the pandemic, carers of people dying at home had to cover gaps in services at great personal cost to their own health and wellbeing. The Government should ensure that in future every carer of a person with a life-limiting illness can have their needs assessed and met in full, including for financial support through Carer's Allowance.

Social attitudes to dying, death and bereavement are changing both in the West Midlands and nationally, with compassionate communities emerging across the country. Hospices play a vital role in connecting communities and they should be supported to restore the volunteer-led services that are a vital component of the gold standard of holistic and personalised care they provide to patients and their carers.

This study highlights the heroic efforts of hospice staff to maintain high standards of care for patients and their carers during Covid-19, yet this work was often carried out at great personal cost. A much more pro-active approach is needed to supporting staff wellbeing as a central component of the ongoing pandemic response in future.

Charitable hospices are the main employers of the palliative and end of life care workforce in this country, and chapter five of the Ambitions national framework for palliative and end of life care sets out a clear vision for how staff in this sector should be supported to do their job well, while also safeguarding their own health and wellbeing.

Unfortunately, this vision has yet to be matched by a clear plan for recruiting and retaining the workforce hospices need to meet current and future challenges. The Government should publish annual, independently verified projections of the future demand and supply of the palliative and end of life health care workforce in England over a five and ten year period and invest in a plan for ensuring this workforce is fit for the future.

This research includes exploration of bereavement experiences during the pandemic. Carers and staff have experienced bereavement in very challenging circumstances during Covid-19. Some of them will require bereavement support services or be at risk of developing complicated grief and other conditions that require intervention from specialist mental health services. These services should be made available to everyone who needs them.

For every challenge reported in this study, there is also an opportunity grasped by West Midlands hospices to do their work in bigger and better ways. During the pandemic, hospices adopted technology at scale and at pace and our study points to both the potential and limits of telephone and digital services for end of life care.

Patients and carers should be able to exercise choice about their care and this requires providing traditional and digital options at all stages of their journey through hospice and other health and care services, in all settings. This will require further investment in supporting hospices to continue their digital transformation to improve the efficiency, effectiveness and reach of their services.

Taken together, these key changes can help ensure that both now and in future, everyone has the best possible end of life experience.

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