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Pandemic narratives in stories about hospice palliative care: The impact of Covid-19 upon ideals of timely, holistic care and quality of life

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ABSTRACT

Background: Hospice palliative care aims to provide timely interventions and holistic care that focusses on quality of life for people who are terminally ill. In the first two years of the Covid-19 pandemic the national political and healthcare contexts changed significantly. Throughout this time hospices had to repeatedly adjust their approach to supporting terminally ill people, many of whom were especially vulnerable to Covid-19.

Aim: The aim of this paper was to explore hospice patients, carers, staff and senior managers stories to identify how changing pandemic narratives affected their understanding of hospice palliative care as timely, holistic and supporting quality of life.

Methods: Narrative analysis of in-depth interviews with patients, carers, staff and senior managers (n = 70) recruited from hospices across the West-Midlands, UK, in 2020–22.

Findings: We identified four ‘pandemic narratives’ (reaction; revision; resilience; (re)normalisation) in the participants’ accounts of hospice palliative care support in the first two years of the pandemic. In each narrative we explore how Covid-19 and the associated pandemic guidance affected what quality of life was understood to be; how what was considered to be timely care could change during the palliative care journey; and, how different ideas of holistic care were emphasised as the hospice and wider healthcare context changed.

Conclusion: This is the first-time stories about the first two-years of the Covid-19 pandemic from hospice patients, carers, staff and senior managers have been analysed together. We identified how the pandemic brought an existential challenge to ideas of what hospice palliative care is and could be. Our findings suggest that ‘living with covid’ will continue to affect hospice palliative care’s ideals of timeliness of care, holistic support, and quality of life left.

1. Introduction

On March 23, 2020, England went into a national lockdown as part of a series of measures designed to combat the spread of SARS-Cov-2 virus and the Covid-19 disease it generated. Although the preceding weeks had involved cancelled events and various individual and voluntary precautionary measures, the lockdown – both as a public health measure and as a socio-political event – became a significant symbol for how societies around the world were to think about transmissible diseases (Lupton, 2022). Ostensibly a measure to protect everyone, particular attention was given to mitigating the impact of Covid-19 on those with pre-existing conditions or who were clinically extremely vulnerable (CEV), which included people with life-limiting

conditions. Prior to the first lockdown people with terminal illnesses could expect to be supported by the National Health Service (NHS), along with a network of informal carers and civil society organisations, including their local hospices. However, the presence of Covid-19 and the state of exception that the public health protections initiated brought a significant challenge to the hospice palliative care approach (Davies et al., 2022; Dunleavy et al., 2021; van Langen-Datta, Driscoll, et al., 2022).

In this article we examine the effects of the Covid-19 pandemic on hospice palliative care by drawing on stories told by patients, carers, staff and senior managers about hospice care between May 2021 and February 2022. Our analysis of pandemic narratives gives form to some of the changing norms and values involved in hospice palliative care

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(Clark, 2014, 2019; Frank, 2010; Sleeman et al., 2022), and contextualises them within wider social and political discourses of pandemics (Davies et al., 2022; Lupton, 2022; Strong, 1990). By relating the changing pandemic context to different understandings of care, we also contribute to sociological discussions about the type of problem the Covid-19 pandemic became for healthcare services and society (e.g. Driessen et al., 2021; Manning, Moore, Tchilingirian, & Woodthorpe, 2023; Montgomery et al., 2023). The study may therefore be located in the specific experiences of those providing and receiving hospice care, but like the pandemic itself, we expect our findings to be able to affect healthcare around the world.

2. Background

2.1. What is hospice palliative care?

Prior to the Covid-19 pandemic hospices in the UK were providing multiple services, such as in-patient, day service, hospice-at-home, out-patient; by a range of clinical and non-clinical staff, from therapists and spiritual support to specialist palliative nurses and doctors; working with multiple other health and social care services e.g. primary care, oncologists, or social workers; to meet as many of the physical, psychological and emotional, social and spiritual needs of the dying patient, their family and those that cared for them (Hospice UK, 2021). Hospices in the UK have a broad range of financial and service models, but most are independent and charitably funded organisations (i.e. non-National Health Service), frequently led by specialist palliative care consultants to provide multidisciplinary support (Hospice UK, 2021). Although often associated with a physical location, hospice palliative care is perhaps better understood as an approach that can be provided in several locations extending to a person's home, nursing and care homes, or in hospital. Hospice palliative care can also be provided by a range of people, such as family, informal carers or volunteers; by general healthcare staff e.g. any clinician caring for a dying patient; or by specialists in palliative care, when a person's needs have become 'complex' (i.e. having multiple issues or increased severity) (Yardley, 2018).

The diversity of hospice models reflects a long and contested history around what hospice palliative care should be and who should provide it. Tensions persist between two schools of hospice palliative care, which either emphasise humanist approach, best exemplified by Cecily Saunders' total pain model first described in 1964, or those who prioritise a biomedical epistemology of dying (Clark, 2014, 2019). This tension can be found in the philosophies (Randell & Downie, 2006) and frameworks of palliative care e.g. 'Ambitions Framework' (National Palliative and End of Life Care Partnership, 2021); 'Gold Standard Framework' (Hansford & Meeha, 2007); but is perhaps best exemplified within definitions of palliative care that have developed since the emergence of palliative care as a medical speciality in the 1980s (Clark, 2019; Field, 1994). In seeking to fix an understanding of palliative care the World Health Organisation definition can be read as a compromise of humanistic language being used to describe clinical practices and goals when it says palliative care is, "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (World Health Organisation, 2002, p. 84).

What is notable across definitions and frameworks are three persistent ideals that palliative care concerns itself with. First, there is an emphasis upon the *quality of life* left, raising questions about the relationship between quality and amount of life a person has; second, attention is given to ensure there is provision of *timely* support or identifying the right support, delivered by the right people, in the right place at the right time; and, third, the problem of *holistic* support is about knowing how to balance often incommensurate spheres of psychological and emotional, social, spiritual, and physical needs. However, the

Covid-19 pandemic significantly challenged what hospice palliative care could do (Dunleavy et al., 2021), how it was experienced (APPG Hospice and End of Life Care, 2023; van Langen-Datta, Driscoll, et al., 2022), van Langen-Datta, Wesson, et al., 2022nd, as we will explore, what it was understood to be.

2.2. The effects of Covid-19 pandemic on hospice palliative care

The Covid-19 pandemic and the guidance put in place brought a novel environment that challenged palliative care structures, practices and norms (Driessen et al., 2021). It was a period that was marked by rapid, on-going change, often highly charged in purpose and ambition, but frequently ambiguous in implementation (Dunleavy et al., 2021). Surveys of hospice managers during the early stage of the pandemic identified significant changes to hospice systems, structures and services (Dunleavy et al., 2021; Hasson et al., 2021). Some hospices experienced shortages of Personal Protective Equipment (PPE), medicines and other resources that delayed or prevented patient care (Oluyase et al., 2020). Nonetheless, most hospices sought to quickly adapt to changes in need for in-place services (e.g. in-patient, day service, or out-patient) by increasing community-based offerings (e.g. online support groups, telephone check-ins, or hospice-at-home) (APPG Hospice and End of Life Care, 2023; Hasson et al., 2022; Sleeman et al., 2022). Yet changes to how, when and where hospice palliative care was delivered could leave patients and their carers with unmet holistic needs. This could be because of systemic disruption and physical separation limiting workforce capacity or because the transmissible virus challenged what hospice staff thought their role could be, with care sometimes being limited to physical needs, as staff felt unable or unsafe to provide psychological, social or spiritual support (Bailey et al., 2023; Washington et al., 2022). Such asymmetry of support could be related to the locale of care, with some patients dying in hospice being more likely to have their nursing and personal needs met, than at home (Onwuteaka-Philipsen et al., 2021). However, dying in a hospice or hospital meant separation from family members or other close-persons because of visiting limitations and therefore many carers reported worse experiences of end-of-life care than those caring for someone at home (Schloesser et al., 2021). The benefits of technology to safely connect with family and friends were also found to have limits, as it could not always replace the intimacy that in-person communication allowed, especially with some of the difficult conversations at or about the end of life (van Langen-Datta, Driscoll, et al., 2022).

The Covid-19 pandemic has been described as exacerbating, accelerating, or a catalyst for much of what is known about the pre-existing strengths and weaknesses of health and palliative care systems, processes and structures (Marmot et al., 2021; Sleeman et al., 2022). It is notable that most research into the first two-years of the pandemic's impact on hospice palliative care mostly relied upon surveys or rapid snapshot analysis of focus groups or interviews, and were only able to investigate issues involving one or two of the affected cohorts (van Langen-Datta, Wesson, et al., 2022). Those studies, along with the inquiries and reports that have followed, understandably focused on the effects upon clinical practice and processes with a view to generating recommendations for pandemic or healthcare policy (APPG Hospice and End of Life Care, 2023; Beng et al., 2022; van Langen-Datta, Driscoll, et al., 2022). There has also been little consideration of how people's understanding of the dynamic pandemic context drew on wider and pre-existing social narratives of healthcare and society, how these changed during those first two years, or what the implications of these changes were on the normative ambivalences affecting hospice palliative care (Merton & Barber, 1976). The aim of this paper is therefore to identify how the changing Covid-19 pandemic narratives affected three of the central ideals (quality of life left, holistic and timely care) of hospice palliative care for all those involved. By doing so we will be able to better understand the impact of the Covid-19 pandemic on ideas of what hospice palliative care is and can be for people with life-limiting

conditions during a pandemic.

3. Methods

3.1. Design

We used an interpretive qualitative approach (Silverman, 2011) to identify narratives in participants' stories of hospice care and support during the pandemic.

3.2. Ethics

Ethical approval was provided by University of Warwick's Biomedical and Scientific Research Ethics Committee (Ref: BSREC 98/20–21).

3.3. Setting and recruitment

The West Midlands, England, includes the largest ethnically diverse population outside of London that is distributed across a range of geographical locations, from inner city to rural areas (Medland, 2011). We contacted all thirteen non-NHS hospices caring for the adult population in the West Midlands and asked them to recruit participants for the study. A local collaborator at each hospice identified and contacted potential participants who then contacted the study team via email. We used a purposeful sampling approach to recruit a diversity of patients, carers, staff and senior managers. To be included participants needed to be over 18 years of age and have provided or received hospice palliative care since the start of the Covid-19 pandemic (March 2020).

3.4. Data collection

Between May 2021 and February 2022 in-depth interviews were conducted by AE, JF, CG and JM via telephone or MS Teams, whichever the participant preferred. The researcher recorded verbal consent before starting the interview. The interview then started with the open question, "Could you tell me a bit about your background and what kind of contact you have with the hospice during the pandemic?" Follow-up questions would be in response to the participant's story, but would include prompts on accessing services, experiences of different locations of care, concerns about Covid-19, or the impact of the pandemic on care and family.

3.5. Analysis

We approached participants' stories as living, local and specific, which contain narratives that can be understood as templates, tropes or plotlines that allow the specific stories to be heard, read or seen as a particular form of action (Harrington, 2008, pp. 24–5). Narrative approaches to analysis involve a dialogical approach to thinking *with* and thinking *about* stories (Frank, 2010). When thinking with a story the researcher seeks to sit with it, through reading and re-reading, to better understand the story as told. Stories can be polyphonic, in that they can contain more than one narrative, which can help to draw out the value of each narrative against the other (Frank, 2010). The analysis develops through the dialogical movement between narratives within stories, as well as the engagement with other stories and narratives, placing one beside the other to better understand and develop new, critical, ways of thinking about each (Frank, 2010). In this way a narrative analysis can be seen to build up-and-out of the "data analysis spiral" (Creswell & Poth, 2018, p. 181) through our iterative engagement of the interviews with the wider literature.

Recordings were automatically transcribed via MS Stream, checked by AE, JF and CG and transferred to NVivo 15. Transcripts were initially coded under descriptive headings. Several of these coded outputs (30,000 words or more) were shared with the wider research team over a series of four half-day online analysis meetings. The descriptive

thematic findings from these meetings, along with recommendations for clinical practice and health policy, were reported as part of the rapid response to the pandemic (Fleming et al., 2022; MacArtney et al., 2022a, 2022b, 2022c; van Langen-Datta, Driscoll, et al., 2022). But during this process two sociological considerations became apparent when thinking about the stories: First, that Covid-19 and the changes brought about by the pandemic affected important aspects of participants' understandings of what hospice palliative care was. Second, that these effects changed as the pandemic progressed and the social context changed. To address these areas JM re-coded the transcripts using NVivo and developed the narrative analysis.

4. Results

Of the thirteen hospices contacted, nine agreed to take part and seven successfully recruited participants. In total 18 patients, 15 carers, 25 hospice staff (clinical and non-clinical), and 12 hospice managers participated (n = 70). Most study participants identified as female (n = 58) and white British (n = 63), however this is skewed by staff and senior manager cohorts (97% White British), with 79% of the patient and carer cohort identifying as White British (see Table 1).

The stories we heard – including from patients and carers – recalled events going back before the first England lockdown in March 2020. Stories were initially collated and ordered under four temporal groups (see Fig. 1), to help explore and identify the changing nature of experiences as the pandemic progressed. It is perhaps unsurprising that the temporal context of experiences were often foregrounded in interviews, either by specific events e.g. "first lockdown", "freedom day", or Covid-19 guidance (see: Institute For Government Analysis, 2022) or through time orientated language such as journey, speed, rapid, repetition etc. Narratives relating to the earlier (Reaction) and later ((Re)normalisation) periods of the pandemic (as it was at the time of interview) were more easily identified. Further re-reading of the stories helped to distinguish two more narratives that reflected the middle period: one that was characterised by repeated changes (Revision), and a period framed by a state of exception that was felt may never end (Resilience).

4.1. Reaction narrative

"healthcare professionals were afraid, weren't they, but [they] all still had a duty of care to provide [care]" (ICOH16, Carer)

Stories with a reaction narrative described the tension in those moments or events where participants sought to maintain previously established practices, norms and values, while also recognising that fundamental context and circumstances had changed in ways that were, as yet, to be fully understood. Although a reaction narrative could be found in stories throughout the two-year period, the clearest examples were found during the implementation of the pandemic's first lockdown guidance, which was associated with a moment of rapid change and the retraction of multiple aspects of hospice palliative care. A patient described how access to hospice resources they had enjoyed previously *"Bang! Stopped"* (ICOH12) overnight. A hospice staff member recalled how many services were cancelled, *"to keep us and the patients safe"* (ICOH43). This idea of mutually ensuring each other's safety shaped many accounts as a member of staff said, *"certainly at the beginning no, we didn't go into people's houses and people didn't really want it either"* (ICOH46). As another staff participant noted *"at the beginning, relatives and patients were very understanding and they kind of got that we were in this, you know, unprecedented pandemic"* (ICOH26).

Part of the initial reaction to the implementation of pandemic guidance came from a shared understanding that, *"... Everybody was in the same boat and there was nowhere open, was there?"* (ICOH25, Patient). For staff this was reflected in comments such as, *"Everybody wanting to pull together"* in a *"Dunkirk spirit"* (ICOH31). But while there was a mutual recognition of the unique context necessitating the withdrawal

Table 1
Participant characteristics (*percentages rounded up/down).

	Patients		Carers		Staff		Senior managers		Total	
	n	%*	n	%*	n	%*	n	%	n	%*
Participants	18		15		25		12		70	
Male	7	39%	1	7%	2	8%	3	25%	12	17%
Female	11	61%	14	93%	23	92%	9	75%	58	83%
Non-binary gender	0	0%	0	0%	0	0%	0	0%	0	0%
18-29	0	0%	0	0%	0	0%	0	0%	0	0%
30-39	1	6%	1	7%	7	28%	2	17%	11	16%
40-49	1	6%	6	40%	4	16%	5	42%	16	23%
50-59	1	6%	2	13%	13	52%	4	33%	21	30%
60-69	8	44%	3	15%	1	4%	1	8%	12	17%
70-79	3	17%	3	20%	0	0%	0	0%	6	9%
80+	4	22%	0	0%	0	0%	0	0%	4	6%
Asexual	0	0%	0	0%	0	0%	0	0%	0	0%
Bisexual	0	0%	0	0%	1	4%	0	0%	1	1%
Heterosexual	18	100%	15	100%	24	96%	10	83%	67	96%
Homosexual	0	0%	0	0%	0	0%	2	17%	2	3%
Other sexualities	0	0%	0	0%	0	0%	0	0%	0	0%
White, British	15	83%	11	73%	24	96%	12	100%	62	89%
Asian or Asian British, Indian, Pakistani or Bangladeshi	2	11%	2	13%	1	4%	0	0%	5	7%
Black, African, Caribbean or Black British Caribbean	1	6%	1	7%	0	0%	0	0%	2	3%
Mixed or Multiple ethnic groups, White and Black Caribbean	0	0%	1	7%	0	0%	0	0%	1	1%

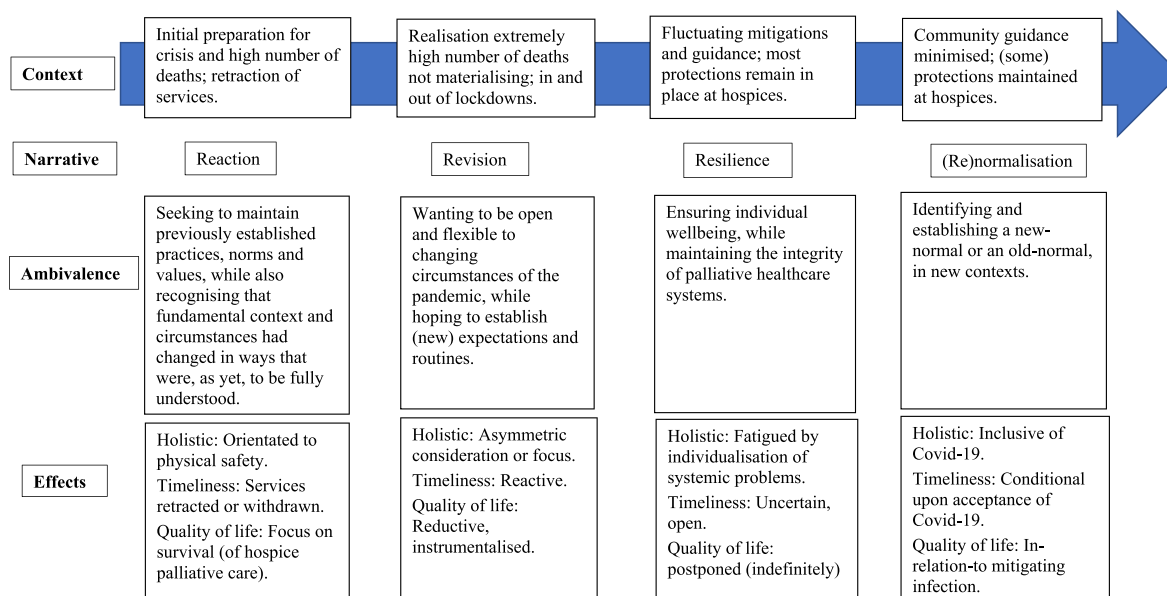


Fig. 1. Changing social ambivalence in pandemic narratives of hospice palliative care.

or reduction of many services, the palliative care and support needs of patients remained, as the following participant said,

Everything stopped as soon as we went into lockdown and it was clear what we were going to have to face. All those professionals had to put on a brave face, do an about turn and take a completely different approach from the one they usually took or take. And it was as hard for them. I think some of them were very, very, very sad at the circumstances they were put into. But, as we say for the greater good, it was necessary to do it... And I'm thinking, "Okay, so ... What do we do? Who do we ring?" ... As for the people who visited used to visit [husband], they disappeared overnight. (ICOH13, Carer).

As this carer notes, they were sympathetic to the impact upon the hospice staff of the decision to withdraw services. Nonetheless, the participant was also concerned about what this meant for them and the person they were caring for or, as another carer said, of being "quite abandoned" (ICOH16). She went on to say, "healthcare professionals were

afraid, weren't they? But [they] all still had a duty of care to provide [care]".

Hospice staff and senior managers were similarly concerned about how to interpret what the new context meant for how they could provide palliative care. A member of staff reflected how there was, "a lot of, kind of, just ambiguity about our roles" (ICOH26). Another participant recalled,

I remember the first one [lockdown] and we literally, there was about four nurses and medical director standing in the corridor going what, can we go in? Can we go in? Can we go into the patient because we just didn't know. (ICOH09, Senior Manager)

In these early reactions it was recognised that there were many conflicting tensions when seeking to fulfil any of hospice palliative care's main ideals. As the following participant reflected,

I think the main thing has been just the kind of the experience and that kind of it hasn't been as holistic probably. It hasn't been as personal and it

hasn't been as warm and I think that's what, that's what people have ... what they missed was not being able to have that human contact. Not being able to hug, hold hands, you know, pat somebody on the leg ... It's just that barrier that that has come down that, I think that's probably the single most important thing that affects the quality and the experience that people have had. (ICOH07, Senior Manager)

As this and other participants described, the start of the pandemic brought significant “barriers” that were put in place to protect the person and those around them. Stories with reaction narratives identified the tension that these mitigations created with the core ideals of what hospice palliative care can offer – holistic, timely care focused on improving the quality of life – and even how they threatened the very idea of what hospice palliative care is. But it is important to note that while there was widespread retraction of many services, hospices also rapidly devised and implemented many new ways of working. As one participant said, “We've all learned to react and adapt a lot quicker” (ICOH76, Senior Manager). We explored the effects of rapid and ongoing change under the next narrative, revision.

4.2. Revision narrative

“... it took a lot of time to get used to still being able to have that warmth and that connection with someone ... when you're not actually with them.” (ICOH56, Staff)

A revision narrative helps us to explore how participants understood the ongoing changes that the pandemic brought, including the need for adaptations to adjustments already made. There was a continuous need to make sense of people's changing roles, within the constantly shifting national, health service and palliative care environments. Revision narratives were therefore marked by tensions of participants wanting to be open and flexible to repeatedly changing circumstances, while seeking to establish (new) expectations and routines. For example, the early weeks and months of the pandemic were marked by stories of repeated and rapid changes to not yet established ways of providing or receiving palliative care, as this hospice staff participant explained,

I mean there were a few occasions when NHS England kept on changing what to do with PPE and we were just thinking, “for goodness sake. Can't they just stick to just one way of doing things?” But they did it for a reason and we changed. But yeah, I think everybody in the end sort of relished that routine, doing it all a certain way because we were all doing it the same way. (ICOH45, Staff)

A revision narrative juxtaposes understanding the need for repeated change, “they did it for a reason”, with desires to establish common routines, “all doing it the same way”. While many revision narratives contended with rapid change, we also found stories of slow revision as participants adapted to new circumstances. For example, it took time to identify how to provide holistic care and support at a distance, such as with telephone and video calls,

... it took a lot of time to get used to still being able to have that warmth and that connection with someone and having that kind of comforting, reassuring atmosphere when you're not actually with them. It took a lot of time to get used to that. (ICOH56, Staff)

For some participants revision often meant lowering expectations of palliative care. For example, as hospice staff were not able to visit patients in their homes to proactively assess needs, a telephone hotline was opened so patients and carers could call in with any developing needs. However, adapting to this reactive approach had limitations when ensuring needs were met,

... they encouraged me to call should I ever wanna talk about something but I just I never did, I just don't know why ... I always feel that I'm bothering people ... (ICOH33, Patient)

Here the revised expectation. “I'm bothering people” draws on a

longstanding narrative of healthcare as a scarce resource, not to be exploited. Similarly, by recognising the interaction of multiple narratives in stories of revision we can also explore how the reorganisation of healthcare structures, authority and capacity were related to (re)establishing palliative care concerns for timely and holistic care. The following participant explained,

... we set up a completely new clinical model up in ten days flat, which is absolutely unheard of [laughing]. If you think about all the social theory ... around organisational culture, change management. All of that kind of it all just went out the window 'cause we were like, “right we need to get this up and running”. And so and what was really, really interesting is that actually as within the NHS, within hospice organisations a lot of the sort of management normal processes were very much, “okay this is all halted now you're the clinicians, you know what is best, you go ahead and make those decisions and you offer it”, and so we did ... And we can't, we can't sort of do lots of lovely you know stroking everybody making sure they're happy with the model, all that kind of stuff which we would normally really pride ourselves in doing, so we weren't able to do any of that. (ICOH36, Senior Manager)

This account shares with the other revision stories descriptions of having to repeatedly adapt, change, and revise the hospice palliative care approach, with a recognition that the new practices were challenging many of the fundamental notions of how hospice palliative care understood itself. In this case, as this participant described, there were fewer opportunities and less impetus to engage in holistic wellbeing support, the “social theory” of “organisational culture [and] change management”, which provided space for a longstanding medicalisation narrative of “clinicians, you know what is best” to assert itself. This is recognised as a normative breach, “we would normally really pride ourselves in”, but is justified by the exceptional and immediate context of the pandemic. But as the pandemic went on, the personal, emotional and systemic effects of having to constantly revise ways of providing and seeking hospice palliative care became a focus of many stories. We explore this further in the narratives of resilience.

4.3. Resilience narrative

“... going through this journey that is difficult anyway at the best of times.” (ICOH77, Carer)

Participants' stories described the ways they maintained the ongoing state of exception that the Covid-19 pandemic brought and the consequences that this had for their experiences of hospice palliative care. By exploring these stories through a resilience narrative, we connect stories of individual flexibility with ambitions to maintain the integrity of palliative healthcare ideals. One example of this was during the retraction of many hospice palliative care support services in the first lockdown. For the following participant this meant that they became responsible for their personal and physical care of their terminally ill spouse.

And I found it quite difficult to you know this, without an income, and just well, yeah, it was extremely difficult switch from the position of providing that, you know, moral support of going through that period of somebody dying and journey with them and then switching to the role of carer. I think that was that was quite difficult for both of us. Yeah, so I think that yeah, definitely it did impact on, I don't know, the quality, the experience, going through this journey that is difficult anyway at the best of times. (ICOH77, Carer)

As elsewhere, there are a polyphony of narratives in this story: the participant's account links-up the hospice system's reaction to the pandemic – manifest here in the withdrawal of hospice palliative care support at home – with the financial and relational effects of moving from providing moral support to being a person's personal carer. The effect is that the person with a life-limiting condition continues to

receive palliative support – a form of systemic resilience – but one that both the participant and the person they are caring for are understood to find “quite difficult” and that affects “the quality, the experience”.

As the previous participant’s use of the term “journey” denotes, narratives of resilience also draw our attention to the importance of timeframes in people’s stories. As well as the impact on the quality of palliative care, there were individual and emotional costs to maintaining hospice systems and processes of palliative care. In the reaction and revision narratives the consequences of change – even when largely negative – were contextualised within the relative immediacy of the pandemic’s circumstances as something to be endured in the short term. However, the following participant described how an earlier sympathetic understanding of hospice’s changes to the care provided waned as the pandemic progressed,

Very disappointed actually, to be honest. I think initially that all medical staff were all turned into the fight against the virus weren’t they, you know? Everything was switched in that one direction, which was understandable at the time. But I can’t help feeling it’s as it’s gone on, that there I would have things would start to have been improving a little bit as far as healthcare is concerned. (ICOH12, Patient)

A pandemic narrative of resilience is one that articulates the ambivalent connections between the individual and the systemic costs of maintaining the pandemic’s ongoing state of exception. This participant’s initial reaction links the immediacy of the pandemic situation with a sympathetic understanding of why the support she is receiving is being reduced. This connection between individual and systemic resilience is maintained, “as its gone on”. However, there is an expectation that the postponement of support the participant received from the hospice would be reversed when she says, “things would start to have been improving a little bit as far as healthcare is concerned”. This concern was particularly salient when participants’ stories were contextualised within indefinite, open or uncertain timeframes, as the following participants described.

“I think it probably noted that the staff are still exhausted that they’re still tired, that we are still in the midst of change, not quite at the pace that that we were, but I think compassion fatigue is potentially, you know, an issue and creeping in.” (ICOH63, Staff)

Participants’ stories reflected upon the personal impact of ongoing state of exception, of being “exhausted”, “tired” and experiencing “compassion fatigue”, throughout the two-year period. Their accounts allow us to recognise the relationship between the need to maintain hospice’s systemic adaptations to providing pandemic palliative care and their individual costs.

4.4. (Re)normalisation

“... everybody needs to start to put a foot out of the door and start moving forward. In a very careful way” (ICOH13, Carer)

In the final pandemic narrative we identified, we explore how participants found ways to re-establish a sense of ending(s) in the ongoing changes to palliative care via a narrative of (re)normalisation. The extraordinary circumstances of the pandemic and what it might mean for the future of palliative care were reflected upon by participants throughout the interviews. This became especially evident as participants discussed the question of what ‘living with covid’ might mean for hospice palliative care. In their search for insight into what might come next, participants’ stories contended with whether to normalise the different ways of providing and receiving hospice care, or if they should find ways to renormalise pre-pandemic ways of delivering palliative care.

Stories of normalisation move between the recognition that there is a need to adapt to mitigate Covid-19, and the negotiation of the lived implications of those changes. For example, participants reflected on the

need to normalise new infection control practices, as the situation entailed, “[doing] everything they possibly [could] do to maintain a normal situation within the good clinical guideline” (ICOH12, Patient). Another participant said,

... staff there also look after very poorly patients who are in the hospice permanently. So there can’t be any worry about passing infection around. That would be totally wrong ... So they try and make [the hospice] a safe place. (ICOH13, Carer)

Having accepted the assumption that change was necessary to maintain hospices care as a “safe place,” participants described how ensuring hospice palliative care could be maintained was in-relation-to making this their “new normal”,

So now our new norm is we wear masks all the time. And you know, we’ve gone from everybody moaning, “I hate masks,” to just wear a mask and don’t moan about it and actually, I get really grumpy when people don’t wear masks ... That kind of like we learned to, just a new normal, so if you like, this new normal now. (ICOH09, Senior Manager)

This “new normal” was not a fixed experience. Stories of normalisation required adaptation of what was considered normal for different spaces and contexts. This was particularly evident as Covid-19 guidance was relaxed,

Well the thing is this: everybody needs to start to put a foot out of the door and start moving forward. In a very careful way. I think going to the hospice is okay. If you can’t go to the hospice for a day when they’re taking so much care wiping everything down ... everything’s done, and if you take, you know, you keep your distance. And if everybody’s had a lateral flow test, and they’re all okay ... That sort of thing it, should be okay, because if we can’t do that, you’re never going to be able to get out at all. (ICOH13, Carer)

This participant suggests that a normalisation narrative of living with Covid-19 includes a recognition of Covid-19’s ongoing circulation, the potential risk it poses to people with terminal conditions, and the need for some shared measures to protect them (use of “everybody”, “you”, “we”, and not “I”), otherwise they and those that care for them were, “never going to be able to get out at all”. However, in what follows we hear more stories of finding ways to restore pre-pandemic norms.

Stories of renormalisation emphasised the strangeness of the pandemic and the costs it brought to hospice palliative care,

... once things kind of go back to normal, it’s very easy to kind of slip back into old ways. I think people were so accommodating because we were in a global crisis, you know, but certainly a national crisis and people were very much about kinds of mucking in and getting on with it, weren’t they? ... And I think as time has gone on, you know that has gone, hasn’t it? And I think, I think people kind of naturally kind of drift back to the to the to the norm, don’t they. (ICOH07, Senior manager)

In stories of renormalisation, the direction of travel in the “drift back to the norm” was to view most, if not all, pandemic adaptations as artifacts of that exceptional period that did not meet expectations for hospice palliative care, as it was preferable to return to the “old ways”.

As with normalisation, a renormalisation narrative is concerned with the relationship between an individual and hospice palliative care. However, it is the normative “drift” that distinguishes these stories,

Oh it knocks your confidence a lot. You know even now, I know we can go out and we can do this that and the other. I have to think two or three times before I do anything, the only place I’ve been really is to [hospice name]. Because I feel safe there and unfortunately, other members of my family have had covid, so I couldn’t go to see them. And I don’t feel safe shopping and things like that. My younger daughter comes and does that now for me. I know eventually I’m, I’m going to have to conquer you know this feeling of, I can’t explain it, it’s a fear of the unknown really. You know you don’t know who it is that’s got it, who’s going to give it to you.

And I'm safe where I am, yeah. But eventually you know you cannot keep on intruding on other people's lives. You have to get on with your own. So it will come. It will come. (ICOH08, patient)

This participant's story of renormalisation explores the tension between her need to feel and be safe from Covid-19, and the impression that "you cannot keep on intruding on other people's lives". Foregrounded in this negotiation is the individualisation of responsibility for one's self and care, "You have to get on with your own [life]". Importantly, the participant says about the hospice "I feel safe there", suggesting that some mitigations remained in place at the time. However, through her self-admonishments for her difficulties in returning to normal life activities – going out, seeing (Covid-19 infected) family, or doing her shopping – we can witness the different normative direction of travel – of the return – in the narrative of renormalisation.

5. Discussion

We have explored the stories of hospice palliative care patients, carers, staff and senior managers to identify how pandemic narratives affected their understanding of hospice palliative care as timely, holistic and supporting quality of life. While previous studies have identified issues or themes drawing on data from defined cohorts e.g. carers or staff (Bailey et al., 2023; Dunleavy et al., 2021; Hasson et al., 2022), this is the first study to explore the effects of the pandemic across multiple actors' experiences of hospice palliative care. To do this we identified four pandemic narratives – reaction, revision, resilience and (re)normalisation – and described some of the normative ambivalences that affected understandings of hospice palliative care during the first two years of the pandemic (Fig. 1). In particular, we found that ideas of holistic, timely care and supporting quality of life left were often challenged, transformed, or even abandoned as circumstances changed.

It is not always self-evident at the start of any pandemic what the right thing to do is and people have been observed drawing on established knowledge, practices and narratives when attempting to make sense of disruption, fears and uncertainty (Strong, 1990). We found that narratives of reaction were shaped by an ambivalence drawing on established practices, norms and values, while understanding that an essential part of the palliative care context had changed in ways that were still to be ascertained. We identified how collectivising-in-the-face-of-adversity narratives, such as 'Dunkirk spirit', that had been identified in research with healthcare staff (Montgomery et al., 2023), could be identified in many of our participants' reaction stories. However, what appears to be distinct for hospice palliative care was the recognition that the quickly changing context meant that the necessary changes that were made to palliative care led hospices away from maintaining its core ideals. This was a reasonable concern, stories of reaction often emphasised the importance of the idea of bodily safety and this narrowed the focus of both holistic care and quality of life to the physical care of patients (Bailey et al., 2023). That is, in narratives of reaction there was a recognition of the value of retracting and restricting in-person care as part of ensuring the safety of all involved with hospice palliative care. At the same time the effects upon ideas of quality of life, holistic, and timely care meant that this reaction also immediately posed an existential challenge for understanding what palliative care is and should be in the Covid-19 pandemic.

It was in participants' stories of multiple, repeated and rapid changes that we identified a more dynamic narrative of revision, which highlighted the ambivalence participants faced between seeking to be open and flexible to changing circumstances of the pandemic, while hoping to establish (new) expectations and routines. This included stories that explored the pace of change, including highlighting the opportunities that the pandemic crisis brought – from changes in management style to enacting new digital services – and the hope that many of these changes might be made permanent (van Langen-Datta, Driscoll, et al., 2022). But revision stories also explored the change in expectations that this more

dynamic environment brought. This was particularly evident when hospice palliative care was described as reactive, which significantly contrasted with a pre-pandemic focus on being proactive (Hansford & Meeha, 2007) i.e. of being able to anticipate needs and ensure the right person, providing the right support is available at the right time. This revised approach meant being less able to anticipate issues, which affected the timeliness of support and increased the interpersonal, financial, physical, and emotional burdens faced by participants (Bailey et al., 2022).

A resilience narrative reflected the ongoing, open or uncertain timeframes involved in the state of exception that had defined hospice palliative care. Rather than approach participants' stories of resilience via an analysis of psychological traits or individual capacity to cope (Aburn et al., 2016), our focus on a narrative of resilience highlighted two social aspects. First, that conceptualisations of resilience should recognise its ecological and economic genealogy (Walker & Cooper, 2011). Doing so helps to emphasise the individual's place within a system of forces during a crisis, many of which are beyond any individual's capacity to effect. Second, it allows us to extend the observation that there was a "politics of flexibility" during the first years of the pandemic beyond the economy or key workers (Davies et al., 2022, p. 77), to pandemic health and palliative care policies. That is, by drawing on a narrative of resilience we are better able to understand how participants at all points in the hospice palliative care system were called upon to find capacity to accommodate or make-up for shortfalls: whether that was having to make personal assessment of rules and risks, drawing on financial, psychological and emotional reserves, or transforming identities to provide some form of palliative care. A pandemic narrative of resilience, therefore, provides a necessary social and systemic context to understand how adaptations and changes to what hospice palliative care could do in the context of Covid-19 changed, as the exceptional became routine. But as the temporal frame for living with change shifted, so did the narrative for understanding the effects of Covid-19 upon hospice palliative care.

When exploring stories about what "living with covid" (HM Government, 2022, 8) meant for hospice palliative care, we found it helpful to make the distinction between normalisation and renormalisation, so that we could identify how and when the different normative registers in the (re)normalisation narrative mattered (Ahmed, 1998; Lupton, 2022; Mol & Berg, 1998). This is important as discussions of Covid-19 and the pandemic measures put in place to mitigate the virus are frequently polarised into simplistic, winner-takes-all camps either for-or-against measures (Davies et al., 2022). However, the narrative of (re)normalisation was characterised by struggles to understand how and when Covid-19 was an issue for any individual, as well as what this new context meant for hospice palliative care.

It is important to consider the implications of the (re)normalisation narrative, as it may have consequences not only for how hospice palliative care understands itself in the ongoing pandemic landscape, but also for other healthcare services caring for populations who remain vulnerable to Covid-19 affecting the quality of their life. This is because it is inherent to the (re)normalisation narrative that there is a social acceptance that 'living with covid' means that there is a likelihood being infected at some point i.e. of 'living with *getting* covid'. But crucially, in wider society, this is now a difference that is held to be one that should not matter (to the well body) (Gurdasani & Ziauddeen, 2022). However, for a (re)normalisation narrative the hospice palliative care context included a concern for quality of life, which could still be significantly affected by contracting Covid-19, if not foreshortening that life. Therefore, for hospice palliative care normalising living with covid for people with terminal conditions held the (implicit) dilemma of 'living with *not getting* covid'. Yet how to achieve this is problematic, as stories of renormalisation document how quality of life was also significantly affected through the untimely provision of limited holistic care during the exceptional conditions of the first two-years of the Covid-19 pandemic. Posed like this, the ambivalence in (re)normalisation

narrative has the potential to be a defining issue for hospice palliative care's foreseeable Covid-19 future (Lupton, 2022).

6. Conclusion

This article is the first to identify and explore how different pandemic narratives (reaction, revision, resilience and (re)normalisation) helped give form to the norms that affected hospice palliative care during the first years of the pandemic (Frank, 2010). By contextualising these narratives within some of the wider social and political discourses (Davies et al., 2022), we were able to relate the individual stories to systemic problems experienced during the pandemic. Of particular concern was how 'living with covid' was interpolated by those with life-limiting conditions and those who care for them, and how this approach problematised what quality of life might mean for those at the end of life. These findings may continue to resonate, as the pandemic remains as a problem for people around the world at a higher risk of Covid-19 affecting the amount or quality of their life (DHSC, 2023). This study has provided some insight into the norms and histories that allow living with covid to be understood as a particular type of question (Gurdasani & Ziauddeen, 2022; Lupton, 2022), as well as provide some hope that interpretations could be opened-up to provide a more equitable future of 'living with not getting covid'.

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Supplemental material

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