

# “Three Sides to Every Story”: Living the Patient, Carer and Staff Experience of COVID

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## Abstract

In 2020, the UK's National Health Service (NHS) braced itself for the challenge of the COVID pandemic. Older, frail adults were among those at highest risk for morbidity and mortality. This study aimed to capture the lived experiences of patients, families/carers and staff on a COVID ward. Thirty participants were included, and data collected through in-depth unstructured interviews. The data were analyzed using interpretive phenomenology. Four main themes were constructed, capturing the collective experiences of the participants. The first theme, the changing and uncertain period of time, describes the shared sense of immersion in the chaotic situation, lack of control and resulting fears related to the contagion. Secondly, challenges of care, focuses on shared anxieties and guilt related to shortcomings in care delivery, and efforts to adapt to the new situation. The third theme, communication and keeping in touch, details the effect restrictions had on efforts to maintain contact and its toll on mental health. The last theme of challenging situations in end-of-life care, reflects experiences of grief and loss shared by all three participant groups. This study adds to the growing evidence base around experiences of the COVID pandemic through exploration of the profound triangulated experience of all participants.

## Keywords

COVID-19, phenomenology, nursing care, communication, frailty, grief, UK

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## Introduction

We are all aware of the immense challenge faced by health-care services worldwide from the beginnings of the COVID-19 pandemic in March 2020. In the UK, the National Health Service (NHS) braced itself to face the unknown of unprecedented circumstances. Since the start of the pandemic, over 200,000 people in the UK have died from COVID-19, with mortality rates increasing sharply with age. In 2020, the most significant rise in mortality was for those aged 80 to 84 (Raleigh, 2022).

Pre-pandemic, challenges relating to an aging population were already posing a major concern for both health and social care across the UK (Digital, 2016). COVID-19 exponentially increased pressure on healthcare systems; “do not attempt resuscitation” (DNAR) orders were pushed, with pressure on care homes in particular to ensure that DNAR orders were in place for their residents. Concerns were raised regarding a lack of discussion around such decisions, particularly at a time when COVID testing was not accessible, families were not able to visit residents and population anxiety levels were high (Sriram et al., 2021).

Controversially, some initial recommendations suggested consideration of frailty as a diagnostic assessment to identify older people not suitable for escalation to intensive care units (ICU; Hewitt et al., 2020), a reflection of the immense pressure faced by the NHS in managing an overwhelming surge in ICU admissions. The construct of frailty, which recognizes the multi-dimensional patterns of decline in older people, has been used to categorize vulnerable older adults at greatest risk of adverse health outcomes (Clegg et al., 2013) hence concerns for older people living with frailty contracting COVID-19. Since the onset of COVID there have been multiple publications describing the epidemiology and pathophysiology of COVID, including identification of at-risk groups; age and frailty have

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both been highlighted in this literature. Frailty was found to be independently associated with both earlier death and increased duration of hospital stay, with outcomes worsening with increased frailty independent of age and co-morbidities (Hewitt et al., 2020). One cohort study identified both age and frailty as being independently associated with COVID-19 mortality (Welch, 2021). There has been little research conducted on the experiences of this group or their relatives and carers during the period of time when many were hospitalized or died from COVID.

The impact of the COVID pandemic on healthcare staff has been widely investigated with a significant call to address the psychological needs and wellbeing of the workforce (Zaka et al., 2020). Stress, depression, anxiety and post-traumatic stress disorder (PTSD) are prevalent among healthcare professionals and show significant increase during pandemic situations (Arias-Ulloa et al., 2023; Fernández-Castillo et al., 2021; Tam et al., 2021). COVID-19 has had an enduring impact, with most traumatic experiences typically occurring during the earlier times of the pandemic; staff dealt with uncertainty, fear, pressures linked to personal protective equipment (PPE), limited access of families to their loved ones in hospitals, the death of both patients and colleagues, isolation and concerns for family members becoming infected (Arias-Ulloa et al., 2023; Sun et al., 2020; Walton et al., 2020). Following the pandemic, staff members have been left scarred and vulnerable with lasting effects on their mental health; many have resigned from their roles in the health service (Bitencourt et al., 2022; Cubitt et al., 2021). It is argued that COVID highlighted many inadequacies within health and social care, including health inequality, a lack of physical resources and limited access to psychological care for staff (Daniels et al., 2021). The importance of staff wellbeing has been recognized worldwide with strategies suggested to provide increased support (Tomlin et al., 2020). Studies have described the experiences of staff during the most emotionally and physically demanding times of their career (Arias-Ulloa et al., 2023; Bennett et al., 2020). The published literature regarding experiences of relatives is steadily growing, typically in relation to relatives of patients on ICU, highlighting feelings of powerlessness and abandonment (Chen et al., 2021; Kentish-Barnes et al., 2021). Experiences of older people and their relatives identify issues related to being isolated from families during hospitalization (Bundgaard et al., 2023) as well as recognizing the impact of delirium, functional decline and cognitive impairment (Kaushik et al., 2024). The importance of capturing the lived experiences of older people in particular is highly relevant, even more so for those living with dementia (Burley et al., 2023). This study was conceived by two nursing researchers who worked throughout the pandemic on a COVID ward predominantly for older people. The study aimed to capture the collective experiences of older people, their families and carers, and the healthcare professionals working in this acute hospital environment during the COVID-19 pandemic.

## Methods

To gain a deeper understanding of the “lived experience” from the participant perspective a qualitative approach was used. Qualitative research includes a broad spectrum of methodologies aligned to the epistemology of subjectivism and constructivism. Phenomenology is a philosophical approach used across many disciplines including nursing to discover and understand the meaning of lived experiences (Öhlén & Friberg, 2023). Within phenomenology there are differing philosophical perspectives which provide the basis for different approaches taken in studies of the lived experience. Interpretive phenomenology, as used within this study, is underpinned by the philosophy of Heidegger and Gadamer, predominantly in terms of hermeneutics (Frechette et al., 2020). The process of interpretation is to explore the nature of an experience as it is lived, to uncover the meaning of being a person in the world through exploration of felt sense and meaning of the phenomena under investigation (Frechette et al., 2020). Both authors (HH, SR) had previously conducted research using this methodology and therefore were familiar with the need to examine one’s own prejudices and use reflexivity throughout (Koch, 1996). This was particularly relevant as they both had worked on the ward from which participants would be recruited, aligning with the hermeneutic premise that a person seeking to understand the subject matter already has a bond to it. The process of interpretation involves creating new understanding and is situated in “being in the world” with a process of moving between the whole and the parts, often described as the hermeneutic circle (Frechette et al., 2020).

## Sample and Sample Size

Participants from three different groups were included in the study. Inclusion criteria for patients was age over 65 years, admitted to hospital with a COVID-19 diagnosis, for family members/carers was being a family member or carer of a patient admitted to hospital with COVID-19 and for healthcare professionals (HCPs) was having worked on the ward where individuals with COVID-19 were cared for. Exclusion criteria for patients were those who could not provide consent (cognitive impairment) and non-English speaking participants as there was no funding available for telephone interpretation. Family members/carers of patients already included within the study were excluded, as were family members/carers who could not provide consent due to cognitive impairment. Staff members whose relatives/friends had been patients or who had any other associations with patients on the COVID ward were excluded. The sampling strategy used was purposive to ensure that all participants had rich knowledge of the phenomena being studied (Frechette et al., 2020; Öhlén & Friberg, 2023). The setting was one hospital site of a large NHS Trust in the Northwest of England. One 65-bedded ward within the hospital was designated a COVID

ward during wave one and wave two of COVID in 2020 and 2021. Staff groups working during those time frames were approached by email including medical, nursing (including health care assistants) and allied health professionals. Patients who had been admitted during those time frames and relatives or carers of patients who had been on the ward with COVID were also approached.

Of the 274 patients admitted in two waves of COVID, 96 died and 111 were excluded due to cognitive impairment, leaving 67 eligible. Following telephone contact and information provision, 11 agreed to participate but one declined on the day of interview. All patient participants were aged over 70 years. Relatives were contacted initially by phone to inform them of the study, information was sent out for them to read with an option to contact the researchers if they were interested in being part of the study. The relatives interviewed included five daughters, four sons and one wife; of those, eight were relatives of patients who had died of COVID or within 6 months of discharge from hospital. A generic email was sent to all eligible staff members with request to contact the team if they were interested in participating. The staff cohort included two doctors of differing levels, two health care assistants, two allied health professionals and four nurses. Of the patient participants, five were male and five female; relatives six male and four female; staff two male and eight female.

### *Data Collection*

Unstructured interviews were chosen as the data collection method, to obtain rich and meaningful responses by allowing participants to talk freely about their experiences. Participants were interviewed individually; following introductions, a simple open question asked the participant about their experiences of COVID. This opening question was followed by a series of prompts if required, with the interview taking the form of a free-flowing conversation between researcher and participant based on the opening question. Duration of interviews varied between 20 minutes and 2 hours, with most lasting around an hour. Interviews were conducted by the authors, audio-recorded and fully transcribed. Due to COVID restrictions, interviews were largely conducted over the telephone although six of the staff interviews took place face-to-face; interviews took place toward the end of the second wave of COVID in early 2021.

### *Data Analysis*

Data analysis followed the four steps identified by Fleming et al. (Fleming et al., 2003) as appropriate for interpretive phenomenological methodology based on the philosophy of Heidegger and Gadamer. The steps involve: 1. Examining the text as a whole to understand the subject matter: 2. Every sentence or section is examined in isolation to expose its meaning to understand the subject matter: 3. Every sentence

section is then related to the whole, described as a movement between the parts and the whole: 4. Passages to illuminate shared understanding of the phenomena are identified (Fleming et al., 2003). This process was repeated several times as recommended as part of the hermeneutic process, taking into account pre-understandings and a movement between the whole and the parts (Frechette et al., 2020). Meaningful statements were listed as direct quotations, reflections and initial thoughts. This thoughtful and reflective process enabled the core themes to be developed, reflecting the whole across all three groups whilst being cognizant of retaining essential meaning and individual experiences.

In interpretive phenomenology, assessment of quality is through consideration of credibility, trustworthiness, reflexivity, ethics and transferability (Sin, 2010). Both researchers wrote reflective journals throughout, examining their own experiences of working during the COVID pandemic and their response to participant material (Koch, 1996). Direct quotations have been used in the text to support the interpretive narrative and provide credibility.

### *Ethical Approval Statement*

All participants provided written informed consent and the study was subject to full UK Health Research Authority ethical clearance, with approval provided by the HRA, (Wales Research Ethics Committee, REC reference (20/NE/0188). To maintain confidentiality each participant was given a unique number for analysis, all interviews were conducted over the telephone with patients and relatives, six staff interviews were face-to-face and all others were telephone. Whilst this could be seen as barrier in terms of being unable to observe non-verbal cues, it also provided a sense of anonymity. It was also a pragmatic decision due to restrictions imposed at the time. Other ethical considerations for this study included the vulnerability of the participants, due to recalling stressful and potentially traumatic experiences. Both researchers (HH,SR) were experienced clinicians with advanced communication skills, competent to manage any participant distress.

### *Findings*

Whilst each participant's experience was unique, there was enough commonality to capture the experience as a whole. Four main themes were constructed, as outlined below, to encapsulate the collective experience of all three participant groups.

#### *Theme One: A Changing and Uncertain Period of Time*

Change and uncertainty posed initial challenges within clinical areas; new teams were assembled in unfamiliar environments in an atmosphere of turmoil and fear. A sense of immersion in the chaotic situation was evident across all

participant accounts, as was the immense trial of providing care amidst the impact of COVID. This led staff to often feel “out of control” amidst the chaos. Relatives also highlighted their perception of the disorder within the healthcare setting, laughing as they described the absurdity of the situation, which they did not find humorous at the time. One relative stated, “One day I got a phone call and they said ‘your mum’s here.’ I was thinking oh right great, and it wasn’t my mum. It was someone else’s [laughs]” (R6). The confusion was also evident in the experience of another relative when staff lost track of the location of her mother, “When they lost my mum though. . . I thought she’d gone to the morgue. Maybe it’s funny in hindsight. . . it was all part of the chaos at that moment.” (R1).

Given the difficult circumstances and the chaos experienced, staff reflected on the limitations to the level of care they could provide, and the guilt they experienced as a result of feeling that “not enough” was being done for patients: “I don’t think we could do everything we wanted to do for everybody. I don’t think we did in my eyes, they were vulnerable, they were dying, and we did our best, but did we do enough?” (S10). Staff members also reflected on difficulties emerging through fear of contagion, compounded by a lack of PPE and lack of clear guidance regarding correct infection control procedures; some members of staff refused to provide care to patients with COVID due to a lack of appropriate PPE.

For patients and relatives, fear related to the implications of a COVID diagnosis along with vulnerability, uncertainty and loss of control. They referred to the emotional impact of receiving a COVID diagnosis at the time when media coverage emphasized the daily death toll and increasing burden on a struggling NHS. At this time, finding out that someone had tested positive for COVID was devastating, perhaps more so for relatives than the patients themselves: “I suppose you could say I was shocked when I was told I had COVID but my wife was devastated. . . I just thought here we go again” (P2).

Some patients described the surprise and uncertainty surrounding a positive COVID test in the absence of symptoms, a regular occurrence as COVID testing was mandatory prior to discharge to other care environments or when care was to be provided at home.

## **Theme Two: Challenges of Care**

Challenges of providing care during the pandemic linked closely to the chaotic situations and lack of control identified in the first theme; all participant groups were aware of the shortcomings in care delivery. The importance of maintaining standards of fundamental nursing care in the face of immense challenges was highlighted by both staff and patients, for example staff highlighted particular difficulties with mouth care. Ensuring that patients received adequate nutrition and hydration was also problematic, particularly

due to fears among staff about remaining in close proximity to patients. One staff member (S2) shared this sentiment, “You know drinks were put down, and then staff just left quickly. . . reluctant to be the person [who] sat with them, feeding or giving a drink. . . We saw a lot of that at first.” This had an emotional impact on other staff as it reinforced feelings of guilt, lack of control and inability to really make a difference, at times, contributed to heightened tension in the ward.

Staff highlighted the emotional impact of being unable to spend time talking to and comforting patients due to the significant pressure they were under. Whilst staff attempted to meet fundamental care needs, interactions with patients were limited due to both time constraints and infection control measures. For many staff, the initial fear did start to abate as more was learned regarding the transmission of COVID and the disease process; consistent infection control guidelines and availability of PPE also reduced the threat of infection. One of the younger medical staff described living with fellow healthcare professionals, with little concern as to the possibility of contagion. Staff who were older, living with dependents, tended to be more cautious, as reflected in this quote from a senior staff member: “I wouldn’t go near my dad because he was frightened” (S10).

Opinions differed among staff as to whether enough had been done for patients. A doctor described how medical treatment was continued for longer than would be typical, for example if the patient had presented with pneumonia prior to the pandemic. Nursing staff were saddened by limitations in the level of care which could be provided in the circumstances for example one nurse (S10) stated: “I think we didn’t really give our all to everybody.” This illustrates the difference between the levels of medical and nursing input required in the care of frail older people, particularly those at the end of their lives.

As time went on, staff described the camaraderie and team working which evolved as an attempt to meet patients’ care needs, often focusing on simple but important tasks such as providing drinks and assisting with eating. This became a shared task across the multi-disciplinary team, as explained by one staff member (S3): “not just for the HCAs (healthcare aids), [but] doctors and everyone were trying hard to help.” Maintaining adequate nutrition and hydration was a challenge due to several factors, including the physical and cognitive effects of COVID, with many patients with cognitive impairments and/or delirium refusing to eat or drink. Families who might ordinarily have visited to assist at mealtimes were unable to be present; they were also unable to provide additional food which patients may have been more tempted to eat. Obtaining information about patient’s food preferences became increasingly important. Relatives often made reference to concerns about care, in particular the meeting of nutrition and hydration needs.

The poor recall many patients had of the initial stages of their illness and hospitalization highlighted the effects of



delirium, reflecting what many staff witnessed among their patients. One patient's (P3) experience was typical:

"Who are you? Where are you?" I didn't know who I was, I didn't know where I was, I didn't know who my next of kin was, I didn't know who my family were and I said to the ambulance men, "What's wrong with me?" And, quite honestly, they took me to hospital and I don't remember the first fortnight.

For the relatives, patient amnesia regarding events was found to be comforting; having only limited recall of such potentially traumatic events was hoped to lessen any lasting impact.

Patients described how their experiences of care varied between hospitals and wards, particularly in terms of their emotional response to the care provided. For some patients, their experience of acute care in a different hospital at the very start of the pandemic was compared to later experience on the ward in question, tainting the patient's perception of the other hospital as a whole. For example, one patient (P6) stated, "I really wasn't happy there the way I was treated. I really wasn't." These "bad" experiences often meant that people did not want to go back, as reflected in the following quote:

The experience in [Hospital A] I don't wish to ever go in there again. I know the pandemic was on, but I said to one nurse after a few days, "My bottom feels a bit sore." She said, "What do you expect me to do?" And just walked away. . . I was nearly in tears (P4).

Such experiences were typically described in contrast to the care received on the COVID ward, which was praised by participants. Some experiences which particularly stood out to participants involved encountering other patients who were perceived to be "worse off," particularly when participants themselves were asymptomatic. One participant took on a caring role toward other patients, pressing the call bell on their behalf. Another participant described not wishing to disturb other, sicker patients by walking up and down the bay, even though the physiotherapist had recommended this to her. Participants also described how they were reluctant to "bother" staff, minimizing their own concerns in relation to other patients who were critically unwell:

I could never get hold of the doctor he was always tending someone else. . . I had a sore mouth. . . I would put my hand up and he would disappear. . . but then I don't think maybe a mouth that's sore and painful comes under the category of life threatening (P3).

Between patient and staff participants, the comparative experiences of care had an overarching sense of fear and chaos at the start of the pandemic, developing a sense of moving on and learning to adapt to the new situation and associated challenges. As time went on, one redeployed nurse found satisfaction in providing fundamental patient care which gave her a sense of purpose: "I could give good care and took pleasure in being able to do that" (S1).

### *Theme Three: Communication and Keeping in Touch*

Communication was a key theme affecting multiple aspects of the patient, staff and carer experience. "Keeping in touch" was vitally important to patients and their families, who described strong emotional responses, both positive and negative, relating to their attempts to maintain contact. Whilst the country was in lockdown, with limited interpersonal contact permitted, strict visiting policies were put in place across NHS hospitals; some discretion was allowed for relatives to visit under exceptional circumstances following a full explanation of the risks involved.

Patients spoke of the difficulties encountered by COVID restrictions on hospital visiting. The majority of the patients interviewed had brought mobile phones into hospital and were able to communicate regularly with relatives. Other patients found this more difficult, describing loss of battery power, unwillingness to disturb other patients and having left their hearing aids at home, among other challenges.

For relatives, opportunity to speak to the patient was variable, with some having no telephone contact, as their relative had hearing difficulties or could not use a mobile phone due to confusion. Others were able to establish regular contact. The importance of maintaining regular contact or a desire to do so was stressed by all relatives, as reflected in this quote from one participant: "My main concern was staying connected with mum. . . It was trying to remind my mum to keep her phone plugged in, and all that kind of silliness. . . These things are just terribly stressful anyway" (R1).

Patients expressed mixed feelings regarding the absence of visiting, such as resignation and acceptance and a need to "obey the rules." One patient linked this to concern around passing COVID onto their family, who he had asked to keep away until he was discharged. Other patients found the absence of visiting distressing. For example, one patient (P5) stated, "It was hard not seeing them. . . horrible. It wasn't nice at all." Another patient highlighted the apparent inequity in the ward's visiting policy, after noticing that another patient had been permitted visitors. This likely occurred after visiting restrictions had been loosened to allow visits to those approaching the end of their lives.

Patients described the effect of visiting restrictions on their family members in terms of increased anxiety for their relatives; others found it very challenging to be apart from their loved ones. Several patients described the emotional impact of being apart from their spouse, having previously had very little time apart. For example, one patient (P6) stated: "Not being able to see each other, you know, when you've been married all them years. It's hard isn't it?"

Relatives themselves described the emotional impact of being unable to visit, which was particularly difficult for those whose family members had cognitive impairments. Lack of opportunity to visit raised significant challenges in terms of being unable to monitor progress or deterioration,

and having to rely on staff to provide updates. One relative (R10) described this experience: “The last time I saw him he was really, really poorly, gasping for breath. . . . It was just not being able to see him getting better, you know, just going off what we were told [was so difficult].” Other relatives highlighted the anxiety provoked by being unable to visit, both in terms of uncertainty around the condition of the patient and worrying about their mental state in the absence of family visits.

Many relatives found themselves relying on telephone contact with staff members as the only source of information regarding the patients. Several family members discussed the value they placed on telephone updates, describing how helpful they found daily phone calls from staff. However, other relatives found this more problematic, particularly if the staff members told them the patient was feeling low or having a bad day. The process of phoning the ward was in itself found to be distressing; relatives describing having to work themselves up to make the call, feeling guilty for disturbing staff or taking them away from patient care. Updates provided by staff were felt to be guarded; relatives were aware that the course of COVID could be unpredictable and recognized the difficulties posed to staff regarding providing an accurate prognosis.

Staff members discussed the emotional impact of the regular telephone calls made to update relatives. One nurse recalled:

We had a lot of tears on the phones from relatives when we updated. . . . and then relatives crying set me off a couple of times as well. Which is unprofessional I suppose but one of them said to me, “Well at least I know you’re human,” which I thought was quite nice (S10).

The staff described the empathy felt toward the situation relatives found themselves in, along with the challenges caused by lack of visiting, including the detrimental impact on patients due to isolation.

Telephone conversations regarding resuscitation decisions were found to be particularly challenging, described in emotive terms by relatives, with one referring to the phone call as “the worst moment of all” (R1). At a time of media representation of an overwhelmed NHS with limited resources, relatives were typically unsurprised that resuscitation would not be attempted given the patients’ age and pre-morbid frailty. Relatives also expressed compassion for the staff involved, reflecting on the number of similar telephone calls the staff members would likely have made.

#### ***Theme Four: Challenging Situations in End-of-Life Care and Death***

Participants discussed the challenges encountered through end-of-life care and the death of patients, from emotion-laden telephone communications right through to staff

feeling “all they ever did was wrap a body up.” The patients’ voice within this theme is less dominant for obvious reasons. For relatives, the experience of receiving a telephone call advising them of deterioration in the patient’s condition was unfortunately common. Such conversations reinforced the severity and unpredictability of the situation. One relative’s (R1) experience was not uncommon and reflected the heightened emotional impact of these conversations: “That was the moment when I sat on my own and thought, my mum’s gone, you know, I’ll never see her again.” Relatives described the shock they felt on receiving such telephone calls, which highlighted with the rapidity at which COVID-19 patients could deteriorate. They often felt empathy for staff having to make the calls. One relative (R2) recalled, “The young doctor rang me up. . . . The poor man rang me to say he’d (her father) died. He was really nice. I apologized. He apologized.” Staff members also described finding breaking bad news over the telephone as challenging, being unable to read non-verbal cues and finding it more difficult to make a connection.

One patient described a situation in which their husband was allowed to visit, waking to find him present and being confused as to why; they later found out that staff were concerned she had been about to die. This was something to be treasured for relatives who were permitted to visit the dying patient, as reflected in this relative’s (R2) experience: “I was just so pleased to sit holding hands, and I think it was my voice he knew. I stayed there for two hours. . . . I will treasure that.” Relatives who did not have the opportunity to visit were preoccupied with thoughts of whether the patient would die alone. One relative (R4) recalled: “I just had to go to bed at night thinking, if she just dies and she’s got nobody with her, no family with her, just that would be so sad.” For some, being unable to be present at the death of their family member led to deep feelings of guilt and despair; being unable to visit their loved one had a deep and lasting impact if the patient subsequently died in hospital:

I think the most hardest thing was not being able to see my dad [crying]. And saying the final goodbye. I think that was the worst thing, really. I’ll take that to my grave that I never saw him. . . . I think it’s something you learn to live with but not get over (R3).

Staff members all described the emotional labor of encountering the unprecedented number of deaths on the ward. For one staff member, managing death seemed to be the major focus of their work on the ward: “It does sometimes feel like all you ever

do is wrap a body up. . . . all you ever do is the death paperwork” (S3). Variability of disease progression added to the uncertainty of the situation, with staff providing vivid descriptions of their patients’ sudden deterioration and unexpected deaths. Unexpected deaths were the most emotionally challenging for staff:

A couple of them, in particular, got to me; ones that weren't that old [and] were physically well, and then deteriorated and then died. . . . And then having to tell the wife after you'd previously said they were doing really well, that they were just about to pass away. I had a few wobbles where I'd end up in tears (S10).

In the difficult circumstances on the ward, a patient recovering was something to be celebrated, with several patients requesting a round of applause from staff as they were discharged.

## Discussion

Phenomenology is a methodological approach which lends itself to exploration of lived experience and as such has been used in several other studies conducted during and after the COVID pandemic (Jesmi et al., 2021). This study used phenomenological methodology to explore in-depth the experiences of COVID of staff, relatives and patients on an inpatient COVID ward; findings are interpreted as a collective experience seen from the perspective of three different viewpoints. Four themes were identified; these will be discussed, including reference to other studies highlighting similar themes from the perspective of one or more participant groups.

All participants highlighted the initial shock, fear and uncertainty, the speed of change, the “chaos” they experienced at the start of the pandemic. This has been previously identified in studies specifically of staff experience; descriptions of fear, hopelessness and chaos are common (Arcadi et al., 2021; Borges et al., 2021; Khanjarian & Sadat-Hoseini, 2021; Peng et al., 2022; Robinson et al., 2022; Sun et al., 2020), with such feelings contributing to stress, burnout and psychological distress (Alizadeh et al., 2020). The current study highlighted the immense stress many staff members experienced when feeling that the limitations imposed by the chaotic environment and their own fear were preventing them from delivering adequate care. The chaos of a busy environment combined with underlying fear led to significant challenges in providing care. This has been described as “unfulfilled care” and “incomplete care” due to the disruption and interruption to usual routines (Safdari et al., 2022). Meeting the needs of patients proved challenging due to the limited resources available; such difficulties in providing care relating to the environment, PPE, lack of resources and fear of becoming infected have been previously described (Adeyemo et al., 2022; Akkuş et al., 2022; Begum et al., 2021). Due to the limitations imposed by the pandemic it proved difficult to carry out comprehensive assessments or to provide person-centered care and emotional support. Understanding of personal preferences and collaborative care planning involving families and carers are central to the care of older people; these were particularly challenging during the pandemic. It has been suggested that the pandemic served to highlight the pre-existing pressure on and under-resourcing of the healthcare sector (Daniels et al., 2021).

In general, experiences narrated by patients related to *poor* experiences of care, when the “patient” role evoked feelings of powerlessness and vulnerability in a context of limited resource. Patients compared experiences across hospital sites, typically describing their initial management unfavorably. It is possible that the care of frail older patients was viewed as less of a priority at the acute site, which was overwhelmed by extremely sick patients of all ages and prioritized the care of those who required ICU beds. The initial shock and emotional impact of their illness and hospitalization, along with delirium in some cases, will have increased the emotional intensity of the situation. Transfer to a smaller site may have been comforting for the patients in our study, who would typically have had a short stay at an acute site followed by a longer stay on the COVID ward. This may also be an example of splitting, the mental separation of objects into categories of “good” or “bad” in order to reduce anxiety provoked by the “bad” aspects of the experience (Klein, 1932).

A collective sense of stress and anxiety has been described in studies of the patient experience, reflecting the “psychological burden” of the pandemic (Hsiao et al., 2021; Jesmi et al., 2021) which affected quality of life and level of functioning and increased fear around being discharged from hospital (Heiberg et al., 2022; Jøranson et al., 2022; Li et al., 2021). Studies of the patient experience of care during the pandemic have highlighted the constraints identified by patients regarding the environment and limited resources available, along with the psychological impact of transforming from “person to patient” (Nielsen et al., 2020; Östlund et al., 2023). In Östlund et al.’s (2023) study the participants described an acceptance that communication and shared decisions were given less importance in the face of the immense pressure staff were under, with patients expressing gratitude for the care they received (Östlund et al., 2023). In other instances, taking on the role of patient was found to be comforting. Several patient participants in the current study had limited recall of the most acute stages of their illness, when personhood was fully absorbed into patienthood and reliance on staff was at its greatest.

Whilst well-being initiatives were gradually introduced in order to support staff working through COVID, such interventions were not always appreciated (Daniels et al., 2021; Sherman & Klinenberg, 2024). Public support and acclaim including the weekly applause was typically viewed with cynicism by staff members in this study, as support from the general public was not felt to translate into organizational support. A rapid review of the psychosocial impact on staff during previous flu pandemics highlighted psychological wellbeing and the need for reasonable work conditions as major concerns (Barello et al., 2020). Sherman and Klinenberg (2024) described the “moral injury” and suffering of staff working through the pandemic, connecting this to the high levels of burnout experienced. Health care professionals have consistently stressed the need for policy makers



and NHS leadership to provide support in a meaningful way with better training, improved communication, access to equipment and safe working environments (Begum et al., 2021; Bennett et al., 2020). In particular, COVID heightened the need for strategies at individual, institutional and organizational levels to protect the psychological health of health-care workers and to improve their working conditions (Efeoğlu & Kılınçarslan, 2022; Sherman & Klinenberg, 2024). The lasting impact on all involved has been captured publicly during the UK-COVID-19 inquiry with reporting of experiences encouraged and emphasis that “every story matters” (COVID, 2022).

Despite the absence of organizational support identified in this and previous studies, several staff members identified “transformations” occurring during the pandemic. For example, staff in the current study described a shift from initial chaos to greater organization and the development of camaraderie within the newly formed team. This reflects the coping mechanisms employed by staff members, described elsewhere as a move from perseverance to resilience (Robinson et al., 2022) and in one study viewed as a shift from fear to a transcendence of feeling “superhuman” (Khanjarian & Sadat-Hoseini, 2021). These adaptive approaches are linked to individual emotional responses, team approaches and the level of support provided (Borges et al., 2021).

Unsurprisingly, communication proved to be a significant theme emerging from this study, featuring prominently in the accounts of all three groups. Limited contact between patients and their family members increased pressure on staff members to act as intermediaries, posing significant emotional challenge to the staff involved. One relative described the “void” he experienced due to lack of contact with his elderly, confused and acutely unwell mother; being unable to see or speak to her personally and relying on staff updates caused him to ruminate on worst-case scenarios during a time of already-heightened anxiety. The impact on relatives has been reported elsewhere with similar findings of distress and isolation (Bovero et al., 2021; Dennis et al., 2022). Such anxiety on the part of relatives had to be sensitively negotiated by time-pressured staff members who felt under-skilled and unprepared for multiple daily telephone conversations regarding resuscitation decisions, uncertain prognosis and breaking bad news.

A review of 26 studies exploring the effect of hospital visiting policies during the pandemic, with over half the studies from a critical care setting, highlighted that “blanket hospital visitor policies were associated with failure to address the unique needs of patients, their visitors, and health care providers in various clinical environments” (Iness et al., 2022, p. 1158). The setting for the current study initially had a strict policy of no visiting, though exceptions were quickly established to enable visiting if a patient was dying, providing the relative wore PPE and understood the risks involved. The use of mobile phones was referred to often by both patients and carers/families as

a valuable means of communication, though for several participants use of a mobile phone proved problematic.

Whilst participants expressed mixed feelings in relation to visiting, with some patients noting that they had preferred their relatives *not* to visit due to fear of contagion, overall the anxiety and isolation identified by patients, staff and families was immense. Prior to the pandemic, national campaigns were driving a move toward “open visiting” on hospital wards, in particular for older people with dementia (Campaign, 2014), with reported benefits of the impact on outcomes for older people in hospital (Hurst et al., 2019). Therefore, the issues raised in this study and others conducted during the pandemic re-enforce the need for considerations of visiting and the impact this can have, in particular due to the increased reporting of loneliness and isolation associated with lack of visiting (Bundgaard et al., 2023; Feder et al., 2021; Hsiao et al., 2021; Jesmi et al., 2021). Loneliness and isolation create a feeling of powerlessness and vulnerability exacerbated by lack of contact with relatives and limited access to personal belongings (Bundgaard et al., 2023; Nielsen et al., 2020).

Given this, it was unsurprising that participants described their experience of strained communication regarding resuscitation and prognosis. Collectively, all participants found this experience particularly traumatic, with relatives in particular describing the long-lasting impact of such conversations. In this study, whilst some relatives expressed shock at finding out their relative was deteriorating, they also had empathy for the staff delivering the news over the phone, the relentlessness of the situation being made clear. Some studies have previously described such telephone conversations, often in the context of intensive care units, with some finding comfort in remote communication (Feder et al., 2021) and others describing an increased sense of isolation through forced reliance on telephone communication (Kentish-Barnes et al., 2021).

Descriptions of encountering death, with associated experiences of grief and loss, were prominent within participant accounts. The emotional effect of such experiences was palpable during interviews and the long-term psychological impact evident. For relatives, difficulties with funeral arrangements and limited or no contact with the patient prior to death interrupted and confused the grieving process; feelings of fear, guilt and loss of control were apparent among both relatives and staff. Relatives drew particular attention to preoccupation with thoughts of the patient “dying alone” as a result of visiting constraints or insufficient staffing levels. This was something which staff themselves struggled to come to terms with, viewed as a failure to provide fundamental care; this was also identified by Sherman and Klinenberg (Sherman & Klinenberg, 2024). Similar experiences are reflected in other qualitative studies where being unable to spend time with loved ones was described as a “sacrifice” for the public good yet created despair and long-lasting grief for many relatives (Bovero et al., 2021; Dennis et al., 2022).



Palliative care teams in the UK's NHS found themselves stretched to meet the demand from many areas, prioritizing and trying to support when and where they could. In response to the pandemic, the need for a more focused palliative care framework has been proposed, including emphasis on dignity (Bausewein et al., 2022; Buonaccorso et al., 2021). The additional emotional burden for staff providing care for those who died in the absence of families has also been recognized (Castaldo et al., 2022).

Whilst this study focused predominantly on the care of frail older people, comparison of results with the wider literature has identified some commonality of experience across COVID units, regardless of patient age and acuity. For example, themes of chaos and confusion, along with psychological impact on staff, seem endemic to the COVID experience as a whole. However, this study also highlights aspects of the experience which were particularly problematic for this patient cohort, given the unique challenges of care within frailty. These included the impact of delirium on patients more likely to have cognitive impairments, increased isolation among patients who did not use mobile phones or access social media, lack of contact with family members who may previously have been acting in a caring role and challenges around collaborative care planning for discharge.

Through triangulation of the experiences of patients, relatives and staff during two waves of the COVID pandemic in one hospital setting, this paper has added to the growing evidence base around the traumatic events experienced by many during the pandemic.

### Strengths and Limitations

One strength of this study is the use of phenomenological methodology to triangulate analysis across all three groups. This allowed a combined “sense of the whole” experience to emerge, providing an in-depth insight and opportunity to highlight commonality of experience reflected across all three groups. The limitations of this study include sampling from only one hospital site and the exclusion of participants with cognitive impairments; insight into the experiences of this patient group would have been beneficial given some of the experiences described by such patients' relatives. Another limitation may have stemmed from participants knowledge that the researchers (HH, SR) had been staff members on the ward in question, however this was taken into account through the reflexive approach used in the analysis. From the staff perspective, previous knowledge of the researchers may have facilitated development of trust during the interview process, with staff recognizing our shared insight into the experience.

### Conclusion

This study adds evidence of the lived experiences of staff, patients, and carers/relatives during the COVID pandemic

to the developing knowledge base in this area. This study adds the unique interpretations of the phenomena from the different perspectives of the three groups of participants. It provides insight into vital considerations to be made in the event of a further pandemic such as the necessity to manage isolation, uncertainty and staff well-being, prioritization of communication and potential mechanisms to improve and enhance this through mobile technology or other devices; facilitating the presence of family and carers when a patient is dying should be prioritized. There is also a need for recognition of the long-lasting impact of COVID throughout all participant groups, with traumatic experiences potentially coloring future experiences of healthcare for patients and their relatives. In addition, exploration of experiences during the pandemic has highlighted the ongoing need for additional support for patients with cognitive impairments, palliative and supportive care training for staff, including communications skills, and ongoing focus on staff mental health and wellbeing.

### Data Accessibility Statement

The datasets generated and/or analyzed during the current study are not publicly available due to ethical restrictions but are available from the corresponding author on reasonable request.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Ethical Approval

Full UK Health Research Authority ethical clearance, with approval provided by the HRA, Wales Research Ethics Committee, REC reference (20/NE/0188).

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