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# Delivering compassionate NHS healthcare: A qualitative study exploring the ethical implications of resetting NHS maternity and paediatric services following the acute phase of the COVID-19 pandemic

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#### ABSTRACT

A distinction can be drawn between healthcare, where compassion is evident, and the functional delivery of health services. Measures to curb the spread of COVID-19, such as personal protective equipment, telehealth, and visiting restrictions created barriers to service delivery and put pressure on healthcare. Through 37 qualitative interviews with NHS senior managers (n=11), health professionals (n=26), and 5 focus group discussions with members of the public (n=26), we explored experiences of the everyday ethical tensions created as services were being re-established following the acute phase of the COVID-19 pandemic in England. Our analysis enriches an understanding of compassionate care as outlined in NHS operational documents - covering the emotional, moral, and relational components of healthcare beyond the functionalities of treatment. From this analysis, we consider the normative standards underpinning NHS healthcare, concluding that, wherever possible, offering compassionate healthcare to patients and their families should be facilitated, and health professionals should themselves be compassionately supported in the workplace. Our findings foreground the need to consider the consequences of the short-term adoption of a functional treatment approach, including strategies that support health professionals and inform the public, to avoid the long-term damage caused by the fracturing of compassionate healthcare.

# 1. Introduction

The COVID-19 pandemic disrupted healthcare delivery globally. In England's National Health Service (NHS) this included redeploying health professionals, establishing temporary hospitals to treat those with COVID-19, and suspending non-urgent treatment, including elective surgery. Alongside these visible effects, COVID-19 prompted (ongoing) shifts in *how* health services are delivered. Most obvious were the infection prevention and control (IPC) measures, including personal protective equipment (PPE), visiting restrictions, and virtual interactions. Healthcare is a descriptor of health practice with two interrelated dimensions. It describes clinical management - diagnostics, interventions etc: the functional dimension of healthcare (see e.g. Frith et al., 2021 for a discussion of 'functional' care.). Alongside this functional element is the expectations of patients, professional bodies and

funders that delivery will be caring – or in the terminology of the NHS constitution, "compassionate". These elements go hand-in-hand, and the failure of either dimension would constitute of failure of care. Our research revealed that the necessary response to COVID-19 pandemic fractured the interconnection between these two dimensions, as the NHS struggled to maximise the functional dimension (to treat as many patients as possible), constrained by IPC measures which themselves presented a barrier to elements usually associated with compassionate delivery.

In this paper we use 'healthcare' when referring to functional care delivered compassionately, recognising that function delivery, including during pandemic conditions, is not necessarily care-less (Harrison et al., 2022). Rather, we highlight that measures such as IPC hinder(ed) health professionals' abilities to offer compassionate care to patients and families. These impediments to healthcare placed significant physical

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and emotional demands on health professionals (Harrison et al., 2022; Hoernke et al., 2021), raising a concomitant need for health professionals to be compassionately supported. The resulting ethical challenges for managers, health professionals, patients, and members of the public, are the focus of this article. We seek to contribute to a longer-term understanding of the everyday ethical issues that continue to arise in healthcare settings following the COVID-19 pandemic (hereafter 'the pandemic'). Whilst situated in England's NHS health services context, our findings have relevance to diverse global settings for their attention to the everyday working conditions of healthcare professionals. In all global settings, these working conditions were exacerbated during the COVID-19 pandemic due to rapidly increased workloads, increased occurrence of moral dilemmas in decision-making, and managing the anxieties and fears of patients, families, and colleagues. This context contributed to acute and chronic stress environments for healthcare professionals across the globe, with impacts on the delivery of healthcare, and raising the importance of compassionately supporting healthcare practitioners (Deng and Naslund, 2020).

In this article, we draw upon qualitative interviews with NHS senior managers and health professionals, and focus group data with patients and their families, to examine the impact of enduring measures to curb the spread of COVID-19 on everyday experiences of offering and receiving compassionate care. Our analysis contributes to broader conversations about the boundaries of healthcare in the context of pandemics or emergencies (Alfandre et al., 2021, Frith et al., 2021, Chiumento et al., 2021; Erwin and Klugman, 2021; Draper and Jenkins, 2017) and beyond. We argue that the dissonance between the functional delivery of health services, and the offer of healthcare where compassion is evident, is of moral importance to health professionals, patients, and their families; including (and, maybe, particularly) during the extreme circumstances of a pandemic. Our findings indicate the importance of supporting health professionals to return to offering compassionate healthcare instead of purely functional treatment, as soon as possible; and to ensure adequate support for health professionals throughout any necessary transitions between the two in exceptional circumstances (including non-pandemic emergencies).

# 2. Theoretical framing

## 2.1. Changing conceptions of care

There are multiple meanings inherent in the term 'care' (see e.g. Zhang, 2016, Puig De La Bellacasa, 2017; Mol et al., 2010; Chatzidakis et al., 2020; Tronto, 1998; Thomas, 1993; Lopez and Neely, 2021). During the pandemic, 'care' became a 'buzzword ... its meanings frequently drained in its constant evocation' (Chatzidakis et al., 2020, p.889). Acts of 'care' were encouraged; from 'clap for carers' (encompassing NHS and essential workers (BBC, 2020);), to public promotion of self-care to protect individual health, and volunteering to offer acts of care to others (Jones et al., 2020). These were packaged as expressions of solidarity to protect the NHS, encapsulated in the UK Government's slogan 'Stay home. Protect the NHS. Save Lives' (Prainsack and Buyx, 2017; Tomasini, 2021; Hendley, 2020, Redhead et al., 2023).

Health*care*, as we define it, *consciously* embeds emotional and moral components. Care is constructed as a way of expressing concern and interpersonal attachment; an acknowledgment and affirmation of a patient's situation (Jennings, 2018; Kleinman, 2015; Kleinman and van der Geest, 2009; Prainsack and Buyx, 2017; Tronto, 1998). This definition is distinct to the policy application of healthcare, which emphasises the *functionalities* of health service delivery: '[The NHS] is there to improve

our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives' (NHS, 2021). As a result, in everyday practice, health professionals develop 'care plans' which explicitly formulate functional service delivery, whilst the emotional and moral elements are left implicit and undefined. In contrast, health professionals champion caregiving as a core component of their professional identity and status (Kleinman, 2012; NHS, 2021, Commissioning Board Chief Nursing Officer & Department of Health Chief Nursing Adviser and BOARD, 2012), with everyday acts of care providing ways to animate and enact moral values inherent to healthcare (Kleinman and van der Geest, 2009). Following Kleinman and van der Geest (2009), we identify 'healthcare' as encompassing an emotional and a technical/practical component; a position echoed in NHS operational documents (Commissioning Board Chief Nursing Officer & Department of Health Chief Nursing Adviser and BOARD, 2012).

We engage with the experiences of NHS senior managers, health professionals, and patients and their families to consider the local moral worlds that were created (Kleinman and van der Geest, 2009). Our analysis draws attention to healthcare, where care is understood as moral experience, a foundational and omnipresent human practice; 'those quintessentials of caregiving that speak to what is most deeply human in medicine and in living' (Kleinman, 2012, p.1550). Our use of the term 'healthcare' thus attends to the moral, emotional and relational dimensions of offering care and supporting caregivers, elements that are the core of the 'compassionate care' that healthcare enacts.

#### 2.2. Compassionate care

By exposing the difficulties of providing healthcare during COVID-19, we contribute to an empirical understanding of compassionate care. We situate our analysis within England's NHS Constitution and associated operational documents and strategies to ground our exploration of the emotional and relational components of compassionate care in the context of the normative aims of the NHS (Redhead et al., 2023). Whilst emphasising the functionalities of health services, the Constitution in its Values section also recognises compassion as core to healthcare:

We ensure that **compassion is central to the care we provide** and **respond with humanity and kindness** to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. (NHS, 2021 - Fourth NHS Value; emphasis added)

Further, NHS operational principles explicitly embed the wellbeing of health professionals:

Respect, dignity, compassion and care should be at the core of how patients *and* staff are treated not only because that is the right thing to do but because patient safety, experience and outcomes are all improved when staff are valued, empowered and supported. (NHS, 2021 - Principle 3; emphasis added).

NHS England has also adopted a set of six values: care, compassion, competence, communication, courage and commitment from the *Compassion in Practice* report, which sets out a 'vision and strategy' for nurses, midwives and care staff (Commissioning Board Chief Nursing Officer & Department of Health Chief Nursing Adviser and BOARD, 2012). This report defines compassion as 'how care is given through relationships based on empathy, respect and dignity', involves 'intelligent kindness', and is 'central to how people perceive their care' (p.13). Foregrounding the role of care in professional and organisational identities, it declares that 'caring defines us and our work' (p.13).

Our notion of compassionate care recognises the importance of the emotional, moral, and relational components of offering health*care* beyond the functionalities of treatment, explicitly including

 $<sup>^{1}</sup>$  We use the term 'family' or 'families' as shorthand for the caregiving relationships surrounding a patient, be those partners, parents, spouses, siblings, significant others, or close friends providing support during a patient's healthcare experience.

**Table 1**Interview participants' demographics.

Interview (SM or HP)		Trust	Participant role	Self-reported gender	Ethnicity (self- report)
Senior Manager Childr		Children's	Medical Director/CMO	M	White British
			Medical Director/CMO	M	White British
			Medical Director/CMO	F	Caucasian
			Director of Medicine	M	White British
			Director of Nursing	F	White British
		Women and	Deputy Chief Nurse	F	White British
		Children's	Chief Operating Officer	M	White British
			CMO	M	White British
			Deputy Chief Exec	M	White British
		General	Head of Midwifery	F	White EU
			Medical Director	F	White British
Health Professional	Doctor	Children's	Consultant: Paediatric Emergency Medicine	M	South Asian
					descent
		Women's	Consultant Neonatologist	F	British Asian
			Consultant Neonatologist	F	White British
			Consultant Neonatologist	M	Indian
		Women and	Consultant Neonatologist	F	Indian origin
		Children's	Consultant in paediatric intensive care	F	White British
			Paediatric surgeon	M	White EU
			Consultant: General paediatrics	M	Indian Asian
	Nurse	Children's	Advanced nurse practitioner	F	White British
			Paediatric intensive care nurse and educator for advances in paediatric intensive care	F	White British
			Advanced nurse practitioner in HDU	F	White British
			Neonatal community liaison specialist – qualified nurse and midwife	F	White British
			Consultant nurse in paediatric critical care	M	White British
			Sister on neonatal surgical unit	F	White British
		Women and	Ward manager	F	White British
		Children's	Advanced Nurse Practitioner, paediatric intensive care	F	White British
			Associate Director of Nursing for Surgery	F	White British
			Ward manager and lead nurse for haematology oncology services	F	White British
			Cardiac specialist nurse	F	White British
	Allied HP	Children's	Specialist paediatric physiotherapist	F	White British
	Midwives	Women's	Community midwife	F	White British
			Midwife (twin clinic) and research	F	White British
		General	Community Midwife team leader	F	White British
			Consultant midwife	F	White non-EU
			Matron for community midwives	F	White British

compassionately supporting for health professionals as they care for others. We analyse the everyday lived experiences of health professionals, patients, and the public as the NHS started to resume routine services whilst continuing to adhere to IPC measures, building on studies exploring emotional and moral tensions experienced by UK health professionals in the acute phases of the pandemic (Dowrick et al., 2021; Faux-Nightingale et al., 2023; Hoernke et al., 2021). The data we collected identifies and exposes the everyday ethical tensions experienced in exceptional circumstances, and the local moral worlds of compassionate care described by NHS senior managers, health professionals, patients and patients' families (Mol et al., 2010; Kleinman, 2015; Kleinman and van der Geest, 2009).

# 3. Methods

Data collection commenced after the UK Government had declared that non-COVID-19 clinical services had to resume alongside managing subsequent waves of COVID-19 infections (Stevens and Pritchard, 2020). We conducted qualitative individual interviews with senior managers (SMs; n=11) and health professionals (HPs; n=26) in five NHS England Trusts between November 2020 and July 2021. Interviews explored decision-making around how best to reset services, and the impact of decisions on the everyday working practices of health professionals. Additionally, during May and June 2021 we conducted

five focus group discussions (FGD) with patients and their families (n = 26) to explore their involvement in decisions about resetting services, and the impact of changed healthcare delivery practices on their experiences.

## 3.1. Setting description

Our project focused on NHS maternity and paediatric surgery services. Maternity services were chosen as an area of care that could not be suspended, and paediatric services as children were at lower risk of severe effects of COVID-19 infection (Alsohime et al., 2020; Cheng et al., 2020). These were also services where professional and patient organisations were highlighting the adverse impacts of efforts to balance healthcare with measures to respond to COVID-19 (Anonymous, 2020, Association of Paediatric Anaesthetists of Great Britain and Ireland, 2020, First 1001 Days Movement, 2020; McDonald et al., 2020). Our previous rapid review (Frith et al., 2021, Chiumento et al., 2021) drew attention to how the impact of IPC decisions, such as visiting restrictions or virtual care, might have profound effects on everyday experiences of offering and receiving healthcare in maternity and paediatric services where family-oriented, relational care is usually embedded in service structures and models of delivery.

Our data collection spanned periods of regional and national lock-downs, including school closures; changing social mixing as restrictions were eased (e.g. 'rule of 6', 'eat out to help out' scheme); varying mandates for mask wearing and social distancing; and the gradual opening of international travel (Institute For Government, 2022). These events, in conjunction with the development and roll-out of COVID-19

<sup>&</sup>lt;sup>2</sup> Six trusts confirmed capacity to take part in the research, but due to the pressures on workforce at the time of recruitment, participants were ultimately recruited from only five of these.

vaccines, provided contextual touchpoints in our discussions with participants. Importantly, the wider public health narrative of easing restrictions and 'living with' the virus remained incongruous with the lived-experiences of health professionals, patients and their families, who continued to face stringent IPC measures in NHS settings throughout our study period.

## 3.2. Research process

Our qualitative study was conducted at five NHS trusts, spread geographically across England and purposively recruited for offering either maternity and/or paediatric surgery services. Specialist children's (n = 2), women's (n = 1), women and children's (n = 1), and district general hospitals (n = 1) were included. Senior managers were selected according to their job role and recruited via e-mail from a nominated hospital contact who provided a brief description of the project and an invitation to participate. Health professionals (doctors, nurses, midwives, and allied professionals) working in hospital or community-based maternity or paediatric surgery services, and from all levels of seniority, were also recruited by the nominated contact, who disseminated study adverts by email, public notices, and health professionals' social networks (e.g., Facebook or WhatsApp groups). Focus group recruitment involved purposive sampling of members of the public involved with maternity or paediatric surgery services since April 2020 at any trust in England, focussing on trusts where the interviews were conducted. Recruitment was conducted primarily via trust patient partnership organisations (e.g., Maternity Voices Partnership and Public Patient Involvement groups) and social media (public posts via Twitter and adverts posted with permission to closed patient support Facebook groups). Expressions of interest for interviews were made to CR, and for focus groups to CG.3 Both researchers provided study information and consent materials, and scheduled interviews or focus groups with those willing to participate.

Interviews followed semi-structured topic guides piloted with one participant. All participants were informed that ethical values and conflicts were of specific interest and were encouraged to share anonymous examples of challenges or discomforts they had faced to illustrate their experiences. Interviewers remained attentive to emerging lines of enquiry that probed the ethical dimensions of participants' everyday experiences of healthcare. For senior managers, the interviews explored approaches to decision-making and justifications for those decisions, as well as views on ethics support and training. Interviews with health professionals explored changes to everyday working practices to accommodate the pandemic that persisted during the reset phase, the ethical issues those changes presented, and their views on ethics support and training. Public focus groups explored how involved participants had felt, and had wanted to be, in local hospital decision-making, and how this was or could have been facilitated in the context of the pandemic. Perceptions of organisational priorities and values guiding approaches to balancing staff and patient safety in a changing context were also discussed, building on emerging themes from interviews.

Table 1 summarises interview participants' demographic information for senior managers and health professionals (gender, hospital locations, ethnicity, job role).

The FGDs had between 3 and 7 participants in each, involving a total of 26 members of the public (24 female; 2 male). Between them, participants had interacted with 13 NHS Trust locations during the COVID-19 'reset' phase, either attending for paediatric surgery or maternity care (including outpatient), or as members of patient participation groups.

All interviews and focus groups were conducted online via MS Teams

or Zoom and were digitally recorded with participants' consent. Discussions were transcribed verbatim and then checked for accuracy and completeness, and anonymised for analysis. Quotes presented below have undergone minor editing to aid readability.

## 3.3. Reflexivity

This study was conducted by a team of interdisciplinary researchers working in the fields of bioethics/empirical ethics, law, sociology/mental health, and paediatric medicine. All worked remotely from home throughout data collection, with a two-day in-person analysis session at the end of the project. The team members are predominantly female and have primary and secondary family care roles. All had experiences of healthcare during the study period, either directly (accessing treatment), indirectly (through family/friends working in or navigating health services); and some provided clinical ethics/legal support to NHS and social care settings responding to the pandemic. All team members were motivated by a desire to explore the empirical everyday ethical foundations of healthcare during an exceptional time, considering the impact of the tensions between public and clinical ethics frameworks for the future of health services.

## 3.4. Ethics

Ethical oversight and sponsorship was provided by the University of Liverpool (Central University Research Ethics Committees, REC no: 794-8290). Additional Health Research Authority approval was given, and each NHS trust approved participation. All participants provided individual informed consent, either orally, recorded at the start of each interview or FGD in an audio file separate to the main discussion, or by completing and emailing a signed consent form. Reports summarising key findings have been provided to all participating trusts, and individually to participants who requested them.

## 3.5. Analysis

Our analysis adheres to a social-science-of-bioethics approach (Hedgecoe, 2004), where the empirical interview data is drawn upon to inform a critique of normative concepts. To achieve this, we conducted a reflexive thematic analysis (Braun and Clarke, 2022) situated within a broad phenomenological epistemology that attends to participants' descriptions of their lived experiences (Schuetz, 1944, 1945). The theoretical flexibility of reflexive thematic analysis allowed us to pay particular attention to the local moral worlds and lived-through experiences of compassionate care (Kleinman and van der Geest, 2009; Mol et al., 2010), and to the ethical tensions that (continue to) arise in the resetting of health services. Analysis involved data familiarisation and inductive open coding (conducted by CR and AC) on a subset of transcripts to develop an initial coding framework. All team members<sup>5</sup> then applied this framework to two or three transcripts each, leading to iterative refinement through consensus discussion. Subsequent in-depth analysis of all transcripts to the final coding framework was conducted in NVivo by CR, with any new themes discussed at weekly team meetings.

 $<sup>^3</sup>$  [Carol Gray] was employed on the [Anonymised] project to conduct FGDs with the public. Details on her role in the study are provided in the acknowledgements.

<sup>&</sup>lt;sup>4</sup> A primary carer is defined as someone who plays a substantial role in the care for another person, who may or may not have multiple primary carers, describing the level of responsibility to care for another person, rather than being the sole carer. Secondary carer refers to someone who undertakes caring responsibilities, but another person carries out the primary carer role. Adapted from Advanced HE equalities monitoring information, available here: https://www.advance-he.ac.uk/guidance/equality-diversity-and-inclusion/using-d ata-and-evidence/monitoring-questions/caring-responsibilities.

 $<sup>^{5}</sup>$  All team members refers to all co-authors, and [Anymoised] (see acknowledgements).

Our focus on everyday ethical experiences led to the identification and further analysis of the theme of 'compassionate care'. AC and SF revisited interview and focus group transcripts to analyse the occurrence, development, and key features of compassionate care in participant narratives. Initially conducted by participant categories, this analysis was then explored across the dataset to provide a holistic view of perceptions, expectations, and experiences of compassionate care across all participants. Additional iterative movement between the data, wider empirical and theoretical literature and NHS policy and operational documents identified two broad analytic themes relating to compassionate care: (1) health professionals' ability to offer compassionate care to patients, and (2) ensuring that health professionals are compassionately supported (cared for). The essential features of compassionate care across both themes emphasise moral, emotional, and relational components of what it means to offer or receive healthcare.

#### 4. Results

We very quickly within our trust, um took on board ... [IPC] measures ... and that influenced a lot of what we did (...) minimal face-to-face meetings. And we quickly went to two metres, which also changes the dynamics of a team. And so a lot of our work now is done by Zoom, um very two dimensional, changes an awful lot of how people are responding to each other, and understanding what is actually trying to be delivered. I'm a nurse....it's an art, very colourful. But actually on a computer ... wearing a mask ... that has been quite difficult ... the delivery of the service that we give, has also changed, um because ... we feel we're holding back, ...we can't be that nurturer that comforter ... to parents as well. Um, you know, a good old hug is magic medicine isn't it? ... well, we no longer can do that. (B2, HP)

Both themes reported above are echoed in this quote, and we structure our findings around them, with the theme of offering compassionate care to patients considered via two interlinked subthemes: (i) effects of IPC guidelines on meeting individual patients' needs, and (ii) IPC, delivering care virtually, and relational care. Following this, the provision of compassionate support to health professionals, reflecting the NHS Constitution aim of ensuring that staff are 'valued, empowered and supported' (NHS, 2021 - Principle 3), is explored.

# (1) Offering compassionate care to patients

Effects of IPC guidelines on meeting individual patients' needs: All participants noted challenges to meeting individual patient needs due to IPC guidelines, with the extent and nature differing depending on the hospital and/or people or situation involved. For example, a FGD participant suggested that there was: 'no flexibility to ... deal with patients that had had difficult pregnancies ... previously. No acknowledgment of ... why there might be heightened anxiety ... poor I would say ... seemed quite draconian, many of the rules' (FGD4). Contrastingly, some health professionals reported that there was flexibility/discretion in implementing IPC visiting restrictions or holding in-person appointments:

we were also able to (...) look at it from a clinical picture ... to make our decision ... autonomously (...) although it was in the ... guidelines to say telephone ... for the first visit, we were able to ... discuss that that wasn't always the right thing to do. And the management were absolutely happy with that. (B4, HP)

As the reset period progressed and hospital IPC guidelines began to be relaxed, some health professionals found it difficult to regain decision-making autonomy, despite this facilitating the compassionate care they were striving to offer:

even though we launched a policy, we discussed it, we co-produced it, staff would come to the door and say "I've got this woman, and this is the situation, can she have her mother with her?" (...) And I said, "but if you read the policy, it's your call ... make it ... I will support it" ... that ... took a very long time. (B4, SM)

Differences in COVID-19 guidelines across sub-specialities led to FGD participants describing situations where health professionals picked-up the roles of others to ensure continuity of care:

the health visitors were not coming out. (...) [so] my midwives ... were coming ... so I could get continuous care ... they said ... we want to hold on to you and make sure we see you from beginning to end. (FGD 5)

Unsurprisingly, some FGD participants experienced inconsistencies in rules across settings, possibly attributable to rapidly changing guidelines, differences in local interpretation of national guidance, or increasing staff discretion in guideline implementation:

I'd been in isolation at <<host style="list-style-type: square;">host even allowed into the corridor, had to have ... COVID tests every ... couple of days. And when I got to <<host host style="list-style-type: square;">hospital B>>, it was the utter opposite. I was in so much shock that I had anxiety about going into the corridor, and going to Tesco's to get my own lunch ... I could just easily catch COVID from Tesco and bring it back into the heart ward. So I was just flabbergasted at the difference. (FGD4)

These three quotes indicate different perceptions of acceptable risk behaviours across senior managers, health professionals, and patients, which, in turn, affected the compassionate care that could be offered to patients, and their family. Reflecting their position and roles, senior managers took an organisational and system-level view, serving patients through the scaling down and then resetting services, mutual aid, the allocation of bed space, or compliance with national guidelines and directives. Some senior managers did, however, engage with the particular circumstances of patients and their families, which, in some instances, promoted guideline changes that recognised the relationships embedded in healthcare. For example:

a young child that sadly ... was going to pass away (...) What they really wanted was one last time together as a family, mum, dad, and the siblings (...) we ... worked a way of being able to safely ... gather them together. And as a result, we then set up what we call 'Sibling Saturday' ... from listening really (...) our families need ... and want to be together. (A5, SM)

This quote emphasises how attending to the everyday emotional and relational dimensions of compassionate care prompted senior management reconsideration of organisational policy, leading to the introduction of a practice that reinstated opportunities to offer compassionate care to meet patients and families' needs.

(ii) IPC measures, delivering care virtually, and relational care: COVID-19 led to the introduction of IPC measures that created barriers to offering and experiencing compassionate care. A senior nurse captured many health professionals' feelings of frustration at being unable to display compassionate care to families due to social distancing rules:

nothing replaces giving someone a hug does it? D'you know what I mean, if you're really upset, putting your arm around somebody is not

<sup>&</sup>lt;sup>6</sup> Quote identifiers for interviews: HP = healthcare professional; SM = senior manager. The letter and number before the participant group identifies the site, and interview number at that site. Focus groups are identified by FGD and a number for each group.

replaceable. (...) we're at one parent ... that's been hugely difficult. (...) if you're upset yourself, being on your own with a nurse in a mask and gloves and an apron, who's standing a good distance apart from you, isn't the world's most comfort. (C5, HP)

Despite this, treatment still had to be provided, and health professionals and FGD participants acknowledged that this was facilitated by IPC measures to reduce risks for staff, patients, and the public: 'If (...) you've got a COVID positive woman, you would have to provide [treatment] ... it was all about risk assessing' (D3, HP).

However, all participants reflected that the balance between the risk and benefits of providing healthcare did not always give the relational contexts of maternity and paediatric care sufficient weighting. For example, in the maternity context, many FGD participants were clear that 'birth partners ... shouldn't be seen as a visitor. They were ... a fundamental part of the birth and afterwards and it's their baby and you [the mother] need them' (FGD4). These concerns were echoed by paediatric health professionals, reflecting their family-oriented philosophy and approach:

as a neonatal community, we've spent so many years trying to move away from being very medical and paternalistic to enabling families to be very much involved as part of a team. (...) And that was literally taken away overnight (...) in March [2020] ... the fathers ... or the partners of the women were suddenly banned from the hospital. It's completely against our ethos. (B2, HP)

Health professionals acknowledged that pressures on physical space had (unexpected) consequences on families joining and perpetuating informal communities to offer daily acts of care to one another:

Our patients are long term. (...) there's no communal spaces that [family members] can use. There's no play areas open ... the parent's room is open [for] making food etc. But it's one in one out. And so a lot of their support network within the ward has gone both because they can't have family members visit, and because they can't spend time together with each other. So I think that's been a huge impact. (C11, HP).

For some health professionals, restrictions on wider expressions of compassionate care offered to patients and their families, such as attending funerals, were challenging:

what you don't have at the minute is obviously the funeral follow up. (...) And a lot of that is for the parents' benefit for them to know that they weren't just a name on a clinic list. They ... meant things to people. (A7, HP)

Virtual consultations received mixed responses from health professionals and senior managers:

digital and virtual appointments [have] almost embraced all of the family being able to be a part of consultations at home, and more of a relaxed approach, but still very different because it doesn't involve physically examining a child ... dealing with inevitable clinician anxiety about having to work in a different way ... was tremendously difficult. (A4, SM)

While telephone or video consultations can be appropriate in some situations, compassionate care in line with professional expectations was for some *only* possible via in-person interactions: 'I couldn't see how I could be a nurse from home' (C13, HP). Telehealth might be inappropriate where, for example, interpretation was required:

due to COVID ... interpreter use has become more virtual (...) communicating to a person who is ... on the end of the phone, and he or she is talking to another person in front of us, or sometimes even that is virtual, you can imagine how things can go wrong. And you can really feel that what you are doing there is not a complete 100% thing. (B3, HP)

However, for other health professionals' tele-interpreters were vital; for example, in the delivery room where IPC measures meant choosing between a birthing partner or an interpreter being present in person.

Health professionals expressed concern that virtual approaches hindered some aspects of healthcare, including observing patients' body language, or conducting safeguarding and mental health assessments. This was particularly raised in relation to maternity care:

you don't know who's in the room who's behind the computer ... you can't ask certain questions, you don't get the same feel for somebody. (D2, HP)

body language as they're pushing the pram (...) carrying the baby looking at ... her facial expressions ... look at the baby, and straightaway you've got all this information ... that you can't see on a video ... on a telephone conversation (E1, HP)

Conversely, a number of FGD participants identified the positives of virtual care, such as quicker responses and reduction in the time/costs of travelling to, and waiting for, appointments. Health professionals also recognised that technology could improve families' experiences when visiting was not possible:

diaries online that families could actually see ... they could log in from home ... and they could see exactly what had happened that day to their family member. (...) We got lots of feedback from ... [families] that they felt involved. (A6, HP).

#### (2) Ensuring that HPs are compassionately supported

All participants recognised that COVID-19 placed health professionals in extraordinary situations, necessitating additional attention to, and support for, their wellbeing. The cumulative effect of a novel coronavirus leading to rapid changes to the professional and private lives of health professionals was consistently recognised:

we have to think about the people who are delivering the care, our staff are our strongest commodity. And they ... have so many stresses on them. Imagine ... the nurse who has to work on triage ... who may have two children and a partner who's on furlough and having to homeschool<sup>8</sup> ... they've got their own stress that they bring to work and then have other people stress at them. It must be increasingly difficult to deliver compassionate care in these circumstances. (A8, HP)

Senior managers recognised that supporting health professionals' wellbeing was crucial to the compassionate care that they could offer: 'if staff feel valued and treated ... in a compassionate way, they will do the same for the women' (D4, SM). One way of achieving this was disseminating information via online platforms or e-mail newsletters to facilitate transparency in decision-making, ensuring that 'the direct caregivers ... [can] understand the balance of the patients that we're caring for now, and the risk for them and our staff, against the risk of children on the waiting list coming to harm' (C1, SM). Some trusts set up daily lunchtime briefings and Q&A sessions with, for example, the Chief Executive, Medical Director, and Chief Operating Officer, viewed by senior managers as important for ensuring that 'people understood what the plans were and had the opportunity to question' (A4, SM).

Some participants reported that the inability to communicate in person led to a loss of a sense of community. While Zoom or WhatsApp facilitated *functional* discussions, virtual meetings meant that the informalities and reciprocal caring gestures ordinarily offered to

 $<sup>^{\,7}\,</sup>$  This references the prohibition on both parents being at a child's bedside at the same time.

<sup>&</sup>lt;sup>8</sup> Whilst schools remained available for children of health professionals, policies encouraged parents keeping children at home if they could ([Withdrawn] Children of critical workers and vulnerable children who can access schools or educational settings - GOV.UK (www.gov.uk)).

colleagues in-person were missing: 'we've lost that more community feel of a morning ... that more supportive, calmer maybe "let's ... have a coffee, we'll run through this, we'll find out where we can help" (C5, HP). These impacts were recognised by senior managers:

a lot of soft communication has been lost ... from a personal ... and ... nurse's perspective, we used to walk around the organisation a lot more. Now I just sit in front of a screen. (...) so the visibility ... and that soft intelligence that you get when you're walking around (D5, SM).

To provide compassionate support for colleagues, senior managers and health professionals described maximising existing support structures and offering new initiatives, including 'wobble' or 'recharge' rooms (Rimmer, 2020), providing refreshment and lunches, and enabling access to mental health professionals:

a staff liaison service ... which we started up during COVID. (...) you can just ring and talk to people. (...) online yoga and exercise classes, we've sent out care packages to people ... a thank you letter, and just a few things like some nice hand cream and ... box of chocolates (...) it was amazing what a difference it did make to people. (A3, SM)

Health professionals appreciated acknowledgment of what they were doing and being asked to do: 'senior clinicians have ... acknowledged that extra work has been done ... the extra strain, and they have provided extra pay' (B2, HP). Supporting colleagues through personal texts and phone calls were described, as was being adaptable to rapidly changing everyday practices:

recognising that we're all ... trying out new things, and to give that little bit of leeway ... it's that care for each other. (...) people share food ... because we can't go anywhere, this is kind of the family from ... our home family. And ... catching people ... when they fall. (D2, HP)

Some senior managers took comfort from feedback that acknowledged their efforts to support staff: 'our ... staff survey responses (...) are better than ... last year, i.e. some of the things in terms of looking after our staff (C4, SM). However, while some health professionals noted the gratitude (and compassion) of their senior managers, patients and the public ('the clapping for keyworkers was quite encouraging' (D3, HP)), others felt excluded, 'invisible', because acknowledgment and gestures went to hospital-based staff and were not shared with community-based professionals: '[community midwives] are going without lunches ... it is what it is, but it could have (...) made us feel ... more valued' (B4, HP).

FGD participants recognised the difficulties that health professionals faced in adjusting to rapidly changing COVID-19-related guidelines, balancing risk to themselves and offering treatment and, where possible, compassionate care to patients: 'it was really a very tough spot, …because they're trying, but then they weren't getting the help that they also needed … to make these changes. (…) I did really feel for the staff' (FGD5).

# 5. Discussion

We have explored experiences of the everyday moral, emotional and relational components of healthcare in England's NHS settings during a unique period of the COVID-19 pandemic through the lens of compassionate care. Our analysis has made visible the normative dimensions underpinning how patients/families and healthcare professionals ought to be cared for and supported. This builds on a social science tradition of attending to care as an object of concern to render visible the values that underpin its organisation and practices (Mol et al., 2010). Our analysis brings into focus the importance of responding to the care needs of both patients and health professionals, recognising that health professionals need to be compassionately supported in order to offer compassionate care to patients and their families. Notably, we highlight compromises to healthcare brought about by a public-health driven response to the pandemic, and the (ongoing) impact on patients and health professionals of maximising functional treatment using IPC measures as routine services were resumed.

Consequently, our analysis foregrounds compassionate care – health*care* – as an essential dimension of the *normative standards* underpinning the NHS. In this discussion, we consider the complex interrelationships between the moral, emotional, and relational aspects of compassionate care that arise in our data, before outlining some wider implications of these findings for future planning for exceptional circumstances. We are motivated in our attention to the everyday ethical implications of participants' narratives by the recognition that:

if care practices are not carefully attended to, there is a risk that they will be eroded. If they are only talked about in terms that are not appropriate to their specificities, they will be submitted to rules and regulations that are alien to them. This threatens to take the heart out of care – and along with this not just its kindness but also its effectiveness, its tenacity and its strength. (Mol et al., 2010, p.7, p.7)

Our key finding, echoing earlier research from the acute phase of the UK's pandemic response (Dowrick et al., 2021; Faux-Nightingale et al., 2023; Hoernke et al., 2021), is that throughout the reset phase, compassionate care continued to be significantly restricted by IPC measures including social distancing, visiting restrictions, telehealth and online meetings, masks and PPE. These measures were problematic because, as Kleinman has highlighted, care is an *embodied* experience:

caring acts are centered [sic] on physical acts of touching, embracing, steadying, lifting, toileting, and so on ... But they also include the way we look at someone, ...the way we connect (or fail to do so); the quality of our voice, our very presence. (Kleinman, 2015, p.240, p.240)

In these everyday acts of care the moral values inherent to healthcare are enacted and animated (Kleinman and van der Geest, 2009). Our data foregrounds the impact of restrictions to the agency of those receiving care (Mol et al., 2010), and highlights the active attention patients and their families pay to experiences of compassionate care (Jennings, 2018), echoing statements of NHS values (NHS, 2021). The embodied, emotional relationships that emerge, most notably between health professionals, patients and families, are captured in our data. Physical spaces, people, and organisational rules all shape healthcare experiences. Patients and health professionals we spoke to consistently emphasise the importance of non-verbal practices of compassionate care (the hug or empathetic touch; being 'with' patients and families during difficult experiences); and of health professionals being empowered to include family members in offering healthcare, and for families to establish and maintain peer support communities on hospital wards. As Kleinman (2015) highlights: '[t]he quality of care registers for the receiver and caregiver as communication, presence, respect, emotional support, and moral solidarity, as much as it does professional competency, time spent, and services performed' (p.240).

Restoring acts of care and compassion as integral to healthcare as soon as feasible during or after a pandemic reflects the values embodied in the NHS Constitution: retaining 'humanity and kindness' to offer compassionate care to patients, families, and colleagues (NHS, 2021). NHS operational documents also recognise that compassionate care entails embracing relational connections between health professionals, patients, and families: 'The people that we care for, and in many instances their families and carers, are our partners in care and our practice must reflect that.' (Commissioning Board Chief Nursing Officer & Department of Health Chief Nursing Adviser and BOARD, 2012, p.18). The ethical importance of relational values and professional norms were emphasised by senior managers, health professionals, and members of the public.

Foregrounding relationality as a core value in healthcare draws attention to the agency of individuals and collectives. Spaces for interrelated activity and the scope for choice in pursuing particular practices or courses of action (what Jennings (2018) describes as the constitutive context of interdependence) were limited by IPC measures throughout the reset period, to the detriment of healthcare. This finding echoes other

studies examining the interplay between the material spaces and practices of health services, and the enabling or constraining of healthcare during acute phase of the pandemic in the UK (Harrison et al., 2022; Dowrick et al., 2021). Hoernke et al. (2021) document the impact of material and spatial barriers such as masks and PPE on the ability of health professionals to communicate with patients as well as colleagues, compromising emotional and relational connections. What is distinctive about our data is the exploration of the extended impact on healthcare experiences for health professionals, patients and the wider public beyond the acute phase of the pandemic, and into the resumption of routine health services as they were being reset.

Compassionate care is fundamentally understood as 'how care is given through relationships based on empathy, respect and dignity' (Commissioning Board Chief Nursing Officer & Department of Health Chief Nursing Adviser and BOARD, 2012), and is premised on health professionals themselves being compassionately supported to undertake their professional roles. IPC measures recast the reciprocal and symbiotic interdependence between managers, health professionals, and patients and their families in ways that challenged health care providers' foundational professional values, and thus their wellbeing; as well as public expectations of healthcare. Research suggests that health professionals' wellbeing is inadequately supported (Ford, 2022; Collins, 2021; Deng and Naslund, 2020)), despite the recognition that measurable patient outcomes defining 'quality' care (such as improved clinical outcomes and increased patient satisfaction) are intimately linked to supporting health professionals compassionately (West et al., 2020; Strauss et al., 2016). In the light of long-established evidence that a lack of personal control over work roles has a significant impact on staff physical and mental health (Kuper et al., 2002; Marmot, 2006; Marmot et al., 1978), support for health professionals should strive to prioritise role-related autonomy (West et al., 2020). Our study illustrates how the IPC rule-driven culture necessary to control an infectious disease during a pandemic erodes the freedom of health professionals to offer compassionate care in line with their personal and professional values (Ulrich and Grady, 2018).

The centrality of compassionate support to health professionals' wellbeing for patient experiences of healthcare emphasises the urgency of restoring the scope for embodied, relational care as soon as possible. In the event of another pandemic, it is clear from our data that ethics and wellbeing support for health professionals should be increased from the outset. In addition, public-facing messaging to establish expectations for limitations to health professionals' abilities to offer healthcare will be essential, alongside professional training to explain how, why and, ideally, for how long their autonomy and professional identity is likely to be impacted. In the UK context, it remains imperative that the challenges of addressing the treatment backlog caused by the suspension of routine services (Association, 2021; Horsch et al., 2020; Ulrich and Grady, 2018; West et al., 2020) are conducted in ways that minimise the harms that arise when compassionate support for health professionals, and compassionate care of patients, is compromised. In global settings with diverse health systems, it will be important to consider the findings of this study in the light of the global diversity of bioethical frameworks (Ewuoso and Hall, 2019) and core constructs such as compassion (Augustine and Wayne, 2019). It will also be important to account for contextual differences in national and local health systems, as well as attending to structural inequalities which may shape the exposure of different cadre of healthcare workers to particular ethical conflicts and dilemmas (Deng and Naslund, 2020; Erland and Dahl, 2017).

# 5.1. Study strengths and limitations

This study offers important insights into the experiences of NHS managers, health professionals, and members of the public working in, or interacting with, paediatric surgery and maternity services during the reset phases of the pandemic. Our data was collected during a time of collision between pandemic and 'everyday' health practices and ethics,

illuminating the experiences of professionals and, extending previous research, of patients and the public, during an unprecedented period for the NHS. Some important limitations to our data must, however, be recognised. First, we recruited low numbers of participants from black and minority ethnic communities, despite their high representation in frontline NHS staff, suggesting structural barriers to reaching this participant group (West et al., 2020). We also struggled to reach more junior health professionals, and may have missed the views and experiences of those shielding. Finally, our recruitment to FGDs through existing participation or involvement groups resulted in high representation of participants active in hospital governance structures or patient involvement groups, which may have led to an emphasis on particular aspects of participants' experiences due to their pre-existing knowledge and positions.

#### 6. Conclusion

We have explored the interplay between the moral, emotional and relational dimensions of healthcare - the relational practices that embody and signal compassionate care - drawing attention to the everyday ethical considerations entangled with offering it. In foregrounding examples of barriers to health care, we explicitly seek to avoid ascribing blame or a sense of failure, recognising the extraordinary constraints imposed by the pandemic on health services worldwide. Instead, we invite engagement with the complex and often ambivalent questions of what it means to enable healthcare by offering compassionate support to health professionals (Mol et al., 2010). Our theoretical framing, and our exploration of compassion in the context of the NHS Constitution and related policy guidance, demonstrates how the values arising in our data reflect the moral vision for healthcare in the NHS (Redhead et al., 2023). Recognising that there will be future pandemics of novel pathogens (Marani et al., 2021), healthcare services will inevitably need to (re)adopt public health measures aimed at risk-reduction, as has occurred in previous infectious disease outbreaks (see e.g. Deng and Naslund, 2020). To address the tensions between the norms of clinical ethics and public health ethics (Baines et al., 2020), we suggest that approaches that minimise and repair fractures between the functional and compassionate dimensions of healthcare in exceptional circumstances should feature as a key concern in decision-making. It is essential that frontline health professionals and the public actively participate in these discussions, which must also attend to the wide-ranging impacts of such fractures. In this context, our findings provide a foundation for considering how the moral, emotional and relational dimensions of healthcare can be protected and promoted, by seeking opportunities for informing decision-making grounded in compassionate support for health professionals, and compassionate care of patients and their families, both in 'normal' and exceptional circumstances.

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**Patient consent statement:** All participants provided individual informed consent, either orally, recorded at the start of each interview or FGD in an audio file separate to the main discussion, or by completing and emailing a signed consent form.

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applicable.

**Conflict of interest disclosure:** All authors declare they have no competing interests.

## **Author contributions**

This study was originally designed by LF and HD. Securing funding to facilitate the study was led by LF, with HD, AC, SF and Paul Baines as coinvestigators. CR and Carol Gray led the subsequent refinement of research methods, securing of ethical and administrative approvals, and recruitment of NHS trusts and research participants. Data collection and curation was led by CR and Carol Gray, with supervision and support from LF, HD, SF, PB and AC. Initial phases of data analysis were conducted by all team members, with additional analysis and data interpretation for this manuscript led by AC and SF. Preparation of the original draft manuscript was led by AC and SF. All co-authors have reviewed and actively contributed to the final manuscript through editing and revision.

#### Data availability

Data will be made available on request.

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